

LIVING WITH ACHROMATOPSIA



**Members of the
Achromatopsia Network
share experiences and thoughts
on many subjects.**



**Edited by
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Second Edition

**A Publication for
The Achromatopsia Network
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Living with Achromatopsia (Second Edition)
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The Achromatopsia Network is a support network and information network for individuals and families who are affected by congenital, inherited achromatopsia. Information about this network is presented on page 164 of this book. Frances Futterman is editor and reporter for the Achromatopsia Network Journal, facilitator for the network, and author of the book, *Understanding and Coping with Achromatopsia*.

Many thanks to Mark Futterman, who served as production supervisor, editorial assistant, and information resources specialist for this book.

Thanks also to all of the members of the Achromatopsia Network who have shared their thoughts and experiences on the subject of “living with achromatopsia.”

Information about products and services in this book is for your consideration only and does not imply a recommendation.

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Introduction

What is it like to have achromatopsia? What is it like to go through life with very poor visual acuity, the lack of color vision, and the most severe form of light sensitivity that can be experienced by the eyes? To have a vision disorder which causes one to experience varying degrees of visual impairment, depending upon the factors of illumination which vary from one place to another? Readers of this book have the opportunity to gain knowledge and understanding regarding this rare and challenging disorder.

This book consists entirely of comments from persons who know first hand about living with achromatopsia. Adults and teens with achromatopsia and parents of children and teens with achromatopsia share thoughts about how this vision disorder has affected their lifestyles, their relationships, and their approaches to various activities. They tell of their experiences in connection with work, school, recreation and sports activities, and much more. They tell about the problems they have faced and the ways they have dealt with these problems – i.e., the coping strategies, adaptive devices, attitudinal changes, support systems, and special resources that have played important roles in their lives.

The comments that fill the pages of this book have been gathered almost entirely through correspondence I have received from members of the Achromatopsia Network, a support and information network that I started in 1993. Most networker input has come by way of postal mail and e-mail. Some of it has been excerpted from tape recorded letters from networkers, and some from a published paper by network member, Knut Nordby, entitled: “Vision in a complete achromat: a personal account.” Most of these comments have previously appeared in the “Comments from Networkers” sections of the Achromatopsia Network Newsletter (1994-2000) and the Achromatopsia Network Journal (2001-2004).

Having complete achromatopsia, I knew from personal experience how difficult it was to obtain information about it – and even more difficult to connect with anyone else affected by the same vision disorder (it affects 1 in 33,000 in most parts of the world). So I decided to create publications that would present the kinds of information that achromats and their families need.

From the beginning, I have invited network members to share their thoughts, experiences, and suggestions in connection with a wide range of subjects and have assured them that their comments would be treated confidentially. Quotations from networkers are always presented anonymously. In keeping with this policy, there are no names attached to the comments printed in this book, although you will find that many of them are preceded by a brief introductory phrase, such as “From a man with achromatopsia in his 50’s” or “From the mother of a 6-year old girl with achromatopsia.” Most comments do not have introductory phrases. Some of my own comments are scattered throughout the book, and they are presented anonymously, just as all the others are.

You will find a wide range of viewpoints reflected on the pages of this book, and that is as it should be. Although we achromats must struggle

with many of the same kinds of problems and concerns, we are probably as diverse as any other group of people, and it is fitting that this diversity be reflected in a book such as this.

It is important to point out that the views and opinions expressed by individuals whose comments have been included in this book should not be interpreted as reflecting the views and opinions of this writer and editor. As facilitator of the network, I have encouraged the expression of viewpoints related to all of the issues confronting persons affected by achromatopsia; and, as editor, I have sought to make sure that the networker input in this book represents as fairly and as fully as possible all members of our network.

It is also important to point out that there are greater and lesser degrees of vision impairment among persons diagnosed with achromatopsia. Some have greater sensitivity to light than others, some are totally without color vision while others have a limited amount of color vision, and some have better visual acuity than others. These differences are often reflected in networkers' comments pertaining to various subjects. As one example, those with better vision (the incomplete achromats) face fewer limitations in terms of sports participation.

Please take the time to read thoughtfully the content of this book. Be mindful of the fact that never before has there been anything like this in print. Many of these comments are very moving. Some of them are humorous. All of them are useful to those who wish to learn about this extraordinary vision disorder and about how achromats and their families cope.

There is a companion book to *Living with Achromatopsia*. It is entitled *Understanding and Coping with Achromatopsia*, and it includes information about many matters of interest to members of our network – inheritance factors, diagnosis, options in tinted lenses, optical devices, special needs in school, achromatopsia research, and much more. Information about how to obtain this book and other publications of interest to network members or concerned professionals may be found on page 165.

I feel very honored to have been the recipient of the correspondence from which I have selected excerpts for inclusion in this book. Compiling all of these comments to be published in one volume has truly been a “labor of love.” I would like to say “Thank you” to all of the network members who put into writing (or recorded on tape) their thoughts about these various aspects of living with achromatopsia. Thank you for being candid, articulate, and resourceful and for so generously sharing your experiences and your wisdom, so that others may benefit.

Frances Futterman, editor

Living with Extreme Light Sensitivity

From a man with achromatopsia: "As a child, I avoided bright light and direct sunlight as much as possible – I preferred playing indoors with the curtains drawn, in cellars, attics and barns or outdoors when it was overcast, in the evenings, or at night. This, of course, was quite the opposite of what well-meaning adults considered to be right for children. My whole childhood was, in fact, a continuous struggle against the prevailing views about what is proper for children; i.e., being out in the sunshine as much as possible, not playing outdoors after dark, not drawing the curtains during the day, and not playing in cellars and other dark places."

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From a networker in his 40's: "Usually I manage fine in day-to-day coping with my vision condition, making sure I bring all my glasses with me when I go places. Most of the time that's OK with me. But there are times when I just want to 'hang it up' and stay home until the sun goes down."

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From a woman with achromatopsia: "I am thoroughly enjoying my favorite season, Autumn. The reduced daylight hours and the reduced brightness of the sun lift a visual burden from me and leave me feeling somewhat liberated. Also, I find that I am becoming increasingly attuned to the different shades of foliage that are visible to my eyes, even though I am colorblind."

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From another networker, writing in December: "This is my favorite time of year because of the light festivals, etc. In one of the areas downtown there must be a million tiny lights. I suppose the colors of the lights are breathtaking (to those who can see them). A friend of mine was quite awestruck by the addition of yellow lights this year. Personally, I just appreciate the effect of the lights against the darkness. I think I get as much out of it as anyone else – which is rare when it comes to enjoying scenery. Interestingly, however, I have to be careful not to get depressed at this time of year. I think that extended dark periods bring on a sense of isolation. I certainly experienced this once when we lived farther north, where we had very few hours of daylight in the winter."

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And from another: "I have always enjoyed the greater visibility I have during the winter months, due not only to the fact that there are so many more waking hours when it is dark outside but also to the fact that twilight comes so much earlier in the evening than it does at other times of the year. During periods of my life when I had regular 9-to-5 working hours, this sometimes meant that, during both the time that I was en route to work in the morning and the time that I was returning home after work, I could manage outdoors without any dark glasses at all or with just my light tinted ones. However, while I have always enjoyed the greater freedom that these seasonal changes brought, I can't honestly say I've been happiest at this time of year. The truth is that I feel better, psychologically and otherwise, during spring and summer, when there is lots of sunshine. Experiencing reduced visual functioning outdoors during the sunny months is actually not nearly as important to me as the many positive effects I experience from sunlight."

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"Despite his eye condition, our 5-year old son rides bikes (four wheelers). He plays out in bright sunlight with the rest of the children but always has his two shades of tinted lenses close at hand, one for bright places indoors and one for outdoors, and he wears a baseball cap to block the sun."

“Some of my friends have told me I have beautiful eyes and scolded me for ‘hiding’ them by wearing my sunglasses. It’s so hard for people to understand.”

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“When our son watches TV (usually videos), sometimes he lies back on his bean bag chair and almost completely closes his eyes. Thinking he is asleep, I go to turn off the TV, and he says, ‘Hey, Mom! I’m watching that!’ After I read in the newsletter about how some achromats can see (momentarily) with their eyes closed, I asked him if he can see with his eyes closed, and he said, ‘Sure. You try it, Mom. Just close your eyes and you’ll see.’ He demonstrated this, describing to me what he saw with his eyes closed. I was amazed. He never told us this before. He had assumed everyone could do it. Of course, I knew that he squinted and blinked a lot, but I didn’t completely understand how doing this helped him see. I told him he is special, because he can see with his eyes closed. He might as well have some positive feedback about his vision.”

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From a woman in her 50’s: “I have complete achromatopsia. For the first 17 years of my life, I had no sunglasses. During most of those years, I lived in a small Texas town where there was lots of sunlight, very little shade anywhere, and assorted obstacles and hazards to watch out for in roads and pathways. Needless to say, navigating outdoors in the daytime was extremely difficult. I had to develop many survival skills and strategies. In order to see outdoors in the daytime, I had to blink rapidly and continuously. When I would open my eyes even briefly, I could not see the world around me, because I was blinded by light. It was like having strong floodlights aimed at my eyes. The squinting and blinking allowed me to obtain just enough visual information to move about in reasonably safe surroundings. For walking around town or crossing the highway on my way to and from school, I needed someone to walk with me. What my blinking made possible is rather amazing. Each time my lids opened a little, I saw only the blinding light, but each time they closed, I got a fleeting glimpse of my surroundings. Thus, with my eyes closed, I could ‘see’ what it was not possible for me to see with my eyes open. I now understand that the light entering my pupils was saturating my rods and that, within a split second after closing my eyelids, the light level diminished sufficiently to allow my retinas – which were rich in rods but lacking cones – to experience a brief after-image. So, during all those years, I made my way around outdoors by using these after-images. My vision in full sunlight consisted mainly of seeing with my eyes closed!”

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From another networker: “If I don’t have on my sunglasses in bright light, I can just close my eyes and see an image of whatever is before me. As a child I went around outdoors with my eyes closed most of the time. People were always asking me why I didn’t open my eyes so I could see. I used to get so mad. I always hated not being able to read in bright light outdoors, because I love to read. As a child I read a lot, holding the books almost against my nose. I used to read under the covers at night, with a small flashlight facing away from me.”

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“I find that the most debilitating and distressing consequence of having achromatopsia is the hypersensitivity to light. The practical problems of being dazzled, the narrowing of the visual fields, and the social problems connected with light aversion and feeling clumsy in intense light constitute more of a hindrance than not being able to experience colors or to discern minute detail.”

From an achromat: "The fact that I don't see well confronts me at all times, even in my dreams. I have lots of dreams about being blinded by bright lights. A recurring 'big stress' dream for me is about losing my tinted contact lenses."

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"When I was in high school in the early 70's, they stationed adults in the bathrooms to make sure no one smoked, or worse. The one in the girls' restroom scrutinized me carefully every time I went in. She often asked if I was okay. I dreaded going in there. Naturally, I knew what she was assuming. Because of my photophobia, I must have looked 'stoned.' But I could not bring myself to tell her that she could stop worrying about me. (Why the reluctance to inform people? I remember being very angry with people for never giving me the benefit of the doubt.) One day she said she was going to escort me to see the nurse, so I finally decided to explain my 'problem' to her. Another time I was very ill and went to see the school nurse, who accused me of having taken an illegal substance. I was writhing in pain, and she kept asking me what I was 'on.'"

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"It is a pleasant fantasy for me to imagine an ideal room for me, as plans are being made to build a house. I think I would ask for northern exposure windows – and lots of them, because I love windows and views of the outdoors, and I get claustrophobic rather easily. And I would ask for shade trees and other foliage outside those windows, to help diffuse the light, although the northern exposure would keep the windows from ever being flooded with sunlight. Inside the room there would be shades, drapes, or curtains to further diffuse the light (as needed), and I would pull curtains or drapes to the side whenever the light was dim outside, so that my view would be as unobstructed as possible."

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"Although my visual system is well adapted for vision under low light conditions, my vision will not function at all in very bright light (e.g., out-of-doors in full daylight) unless I adopt specialized visual behavior and strategies (such as squinting, blinking, turning away from the light, etc.). I am easily dazzled and, in effect, blinded if exposed to bright light. If I open my eyes fully for more than one or two seconds under such conditions, the scene I am gazing at is quickly washed out. It turns into a bright haze and all structured vision is lost. It can be very distressing to have to perform demanding visual tasks in very bright light. This hypersensitivity to light is often referred to as photophobia, but it has nothing to do with the irrational psychodynamic 'phobias.' In fact, I really enjoy being out in the warm sun, provided I don't have to perform exacting visual tasks. I do not like to read or write in the sun, but digging in the garden or mowing the lawn is no problem for me even in bright sunlight."

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"I have developed special visual strategies for restricting the amount of light entering my eyes. The most obvious strategy is, of course, simply to avoid direct strong light. Staying indoors or in the shade is one way of achieving this, if there is no special reason for being in intense sunshine. Indoors, whenever possible, I try to place myself with my back towards bright windows and strong light sources and avoid having direct sunlight falling on my workplace. Shading my eyes from direct, intense light with my hand or a visor may be necessary, and ordinarily I also wear sunglasses outdoors in the daytime."



“The squinting and blinking is a strain socially. People notice that something is wrong with my eyes and show this by their reactions. As a child I was often approached by total strangers, demanding to know what was wrong with me. Wearing dark glasses can alleviate this social burden to some extent.”

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“Many achromats would appreciate the long winter nights we have here in Canada. Sunset is at 4:30 P.M. this time of year. And the Northern Lights are breathtaking. If achromats happen to be going through Saskatchewan in the middle of the night in December (it should be around 35 degrees below zero about that time), they can appreciate the spectacle as much as anyone else – perhaps more so.”

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“When I was 10 years old, my parents took me to an eye doctor who created some very dark sunglasses for me. He said they were made from glass used in telescopes for photographing the sun. My mother said I discovered all sorts of things on the trip back home using these sunglasses, such as telephone poles that I had never seen before.”

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From a woman with achromatopsia: “I was almost 30 before I started wearing hats or visors. Previously, I did understand about how such items could help to shield my eyes from sunlight, but there were so many reasons not to wear them. Most of my life I lived in very windy territory. It was hard to keep hats from blowing away, and so most people didn’t wear them, except for fashion hats (usually without brims), which were worn only to church or on other formal occasions. I knew that people who worked outdoors wore hats or caps and that baseball players wore caps. But the idea never appealed to me as I was growing up. For one thing, hats had to be color coordinated with your clothing and shoes! Also, hats can press down and mess up your hair. Since I started wearing hats, I have especially enjoyed shopping in stores that specialize in hats for both men and women, because of the variety of styles to try. I have found my most useful hats in shops that sell camping and sports supplies or safari clothing. My favorite hats have brims that aren’t too wide but which have a good slant, cutting out the most light. For travel, I prefer a hat that can be folded and kept in my bag when I prefer not to wear a hat – which is still most of the time.”

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“After years of managing with various sunglasses that gave limited degrees of help with my photophobia, I found an optometrist who earnestly wanted to come up with a system that would give me the best possible vision outdoors in the daytime. He prepared tinted lenses darker than any I had ever seen and then fitted the frames with side shields and an attachable top shield. The result was remarkable. I was able to see more outside than I had ever been able to see before, except at twilight. At first this was very exciting; but, before long, I began to notice that some lighting conditions under which I was usually comfortable were no longer comfortable for me. For instance, I could no longer take off my sunglasses upon entering my moderately lighted apartment and feel comfortable. I found that I was keeping dark glasses on more of the time and even resorting to light tinted lenses in places where I had previously been able to enjoy the freedom of not having to wear tinted lenses. I also began to feel depressed. I think that, on a very deep level, I missed the sunshine. I decided to return to wearing my old, not-so-dark sunglasses and to set aside the new ones for times of greatest need. It wasn’t

long before I was able to feel as comfortable in moderately lighted places as I had been before, and the depression lifted.”

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“Our 5-year old refuses to wear a visor. Hats are appreciated strictly for their ‘dress up’ qualities. He wears his dark glasses outdoors almost all the time in the daytime, unless he is deliberately challenging himself. He does not use tinted lenses at twilight or indoors with incandescent and/or indirect natural light.”

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“My 11-year old daughter will not wear her red-lensed swim mask in the water anymore, because ‘it looks too weird and nobody else wears them.’ In the water she will only wear her Corning red lens glasses (which is risky, because she could lose them, and the leather side shields get funky). She still wears her dark glasses during the day, but she gets tired of people asking, ‘Are you a pilot?’ or ‘Are you a movie star?’ These people are well meaning but just don’t know that she has a visual handicap. If she is not wearing her glasses, she frequently gets asked if she is sleepy, because of her squinting. She gets very tan around her glasses, and she gets called a ‘raccoon’ because of the tan-lines around her eyes. Sometimes she just doesn’t reply to these remarks.”

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“Especially as a child, it can be so frustrating to feel helpless, disoriented, awkward, or frightened in certain situations (under bright illumination), when you know it is not at all natural for you to be this way when lighting is favorable.”

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From a man in his 50’s: “I want to see light; and so I only wear very dark lenses when absolutely necessary. For some reason, I feel that I want to experience the intense light, if I can do so without jeopardizing my safety or the work tasks I am performing. In some situations in bright outdoor settings, even if I say that I am OK, others will – out of kindness and ‘in my best interest’ – offer me ‘better eye protection.’ It seems as if, once people have grasped the idea of relieving the heightened light sensitivity by using dark filters, they sometimes pursue this idea too far. I am quite capable of knowing myself in what situations I really do need the best light protection. So, when I wear low level protection voluntarily, it is because I feel I don’t need high level protection just then.”

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From a woman with achromatopsia: “As a kid, did you ever endure the discomfort of forcing your eyes open, in order to try to look normal? I did, and I also used to pretend that I could read from a distance, when other people were watching me. But it’s hard to ‘cover up’ when you get older. And it’s totally not worth it. People have to find out sooner or later. Recently I had an appointment in a brightly lit office, and right away I asked if I could close the curtains in the office – and, naturally, this was okay with everybody concerned. I would not have done that five years ago.”

.....
From a woman in her 50’s: “I do a lot of walking, and one of my favorite things is observing trees as I walk. In the summertime, because the trees have so much fullness, they are so much more beautiful, and the shade is so much ‘shadier.’ I have felt an intense love for trees for as long as I can remember. As a child I didn’t even realize that my love of trees was connected with my vision impairment. I just remember that trees always gave me a special sense of



security. Some trees offered me considerably more shade than others, and these were my favorite ones to go and visit.”

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From a woman with achromatopsia: “Maybe this eye condition should be called ‘the Cinderella Syndrome,’ since we achromats all ‘lose our glass slippers,’ so to speak, when the dawn comes.”

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“I grew up on the coast and people there thought I was weird, because I thought the beach was a boring place to be (except when I got to go there at night). I avoid beaches. Whenever I do have to be in such surroundings, I take along one of my children for protection. One of my daughters is especially sensitive to my needs. She actually worries that I might get lost.”

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From a networker in her 20’s: “I have no problem falling asleep at any time I lie down during the day; but, when night rolls around, no matter how tired I am, I cannot get to sleep easily. Often I wish for a world with all achromats, so that everything would be open all night long. Being wide awake at night, especially when I have given in to sleeping some during the day, can get rather boring.”

.....
From a networker in her 30’s: “I find that I get tired after extended visual tasks, like reading, computer work, or trying to watch a speaker, especially in bright lighting. I have heard that the act of trying hard to see is actually quite taxing physically and causes an increase in blood flow to the brain. Most of these times, I do not get headaches, except when I’m under fluorescent lights for too long. Instead I just get fatigued. But, even when I’ve had to experience this during the day, I feel better, once night comes along.”

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From a woman in New Zealand: “I have just read *The Island of the Colorblind* by Oliver Sacks and realize that at last I can put a label on my affliction. I am nearly 80 years old. I am one of a family of 7. I had 3 brothers and 1 sister with perfect eyesight, but I also had 2 sisters with the same vision problems as mine – complete colorblindness, being very nearsighted, and the horrible aversion to daylight. In order to see outdoors, I have to wear specially made dark spectacles – until dusk or until I can be indoors with artificial light (Oh, rapture, rapture!). It has always been a morale booster whenever I can be someplace where I can keep my eyes open without having to wear dark glasses. On the street outdoors in the daytime, if people speak to me first, I am able to greet them. Otherwise I just smile and try to look pleasant, in case I might be in sight of someone I know. I really do deserve an Oscar for my acting ability. As for color, more pretending! I ‘see’ everything in degrees of light and dark. Association plays a big part in how I relate to color. Somehow I have muddled through. Having no color vision has always taken a back seat to the more serious sight problems I have. After all, one can always ask other people about the colors of things.”

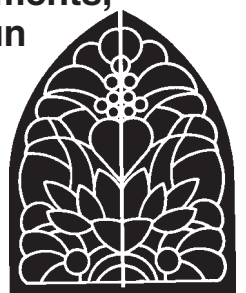
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“I wonder if other achromats have had problems with headaches due to photophobia. I’ve learned that there is a connection between the kind of light I am in – and the amount of time I am in it – and my headaches. Sometimes I have to ‘un-focus’ or rest my eyes after only about 30 minutes of a vision-related task, depending on the quality of light I have to work in. My husband has developed into a good masseur, so we can sometimes manage the tension pretty well. I find that it’s hard to know when to quit, when it comes to activities that strain my eyes.”

From a mom: “Our son (age 7) seems to see better and to be more comfortable outdoors in the fall of the year. During the summer he prefers to be indoors, because it is so hard for him to see outdoors, even with his tinted lenses on. Indoors we have only had to make a few adjustments, such as closing the shades or curtains during the middle of the day and into the late afternoon.”

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“Nowadays I feel quite differently about summertime than I did when I was younger. Back then I very much dreaded the onset of summer. I liked the part about being out of school but not the part about being expected to spend more time out of doors. We lived near the beach, which was, of course, considered by most people as ‘the place to be.’ I tended to be a loner, spending most of my time in the neighboring forest, where I was more comfortable. Once I grew up and was out on my own, however, I really began to enjoy summertime. I love being in the sun on my own terms, and I can get pretty depressed in the winter.”

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“Recently a friend in the network phoned in to share his excitement about having just purchased a house. For the first time in his life, he was going to make choices about paint, flooring, window treatments, etc. He wants his house to be a place which will meet his visual needs and which will also be enjoyed by the friends and colleagues he plans to invite over. He wanted to brainstorm about this subject with another achromat. As we discussed interior decorating, it became clear (not surprisingly) that our preferences are affected as much by the many factors that make us unique individuals as they are by our having achromatopsia. For example, I told him about how much I love bamboo shades because of the way they create pleasantly filtered natural light, but my friend did not particularly go for this idea. But we did agree about loving windows and not wanting to have natural light shut out. I mentioned that I like the look of wood paneling and cork-board. We agreed that, while we don’t like white walls or ceilings, we do not want walls to be dark.”

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From a woman in her 40’s: “Recently there was a Confirmation ceremony for some children, including my niece. I am her godmother, so I had a special part to play in this ceremony. I have to say that I was truly dreading this day, because the light inside the church can vary so much, depending on the weather. It had been quite overcast until the morning of the Confirmation ceremony. Then, as if for spite, the sun shone brilliantly for most of that day. There is a large stained glass window behind the main altar and one at each of the side altars. There are also several smaller windows around the altars. Depending on the time of day, the altar can be almost completely bathed in sunlight. I had my very dark glasses with me but didn’t want to be wearing them indoors for this occasion, and lighter tinted glasses would have been of no use. At one point in the ceremony, when the bishop was delivering his sermon, I saw his head disappear. I could see his vestments, since they were of a dark color, but I could not see his head, as the sun shone so brilliantly on that region of his anatomy. I find that some of the visual experiences which occur when one has achromatopsia are quite ridiculous, and the aforementioned is a good example of this. When I am in a good mood, I can laugh at such things, but this isn’t always the case. *(Editor’s note: achromats are well acquainted with phenomenal visual experiences such as this.)* Since the altar was so



brightly illuminated by sunlight, I was worried that I might make some mistake while walking up the steps to the altar or might miss seeing that my niece's time had come to go up to the altar. The children were in one aisle and the sponsors were in the opposite aisle. But everything worked out well. Before the ceremony I had told a lady next to me why I was nervous, and together we worked out a strategy."

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"About searching for that elusive 'perfect pair of sunglasses:' I have experienced mostly frustration, because very few people in the field of optical services know anything about this special need we achromats have. Sometimes they just give me a blank look when I try to explain. So often they will say, 'That's all we have,' or they may show me pictures in a catalog showing some kind of frames they have never ordered before. Over the years only two of these people have ever offered to investigate possibilities for me. But 30 years of efforts on my part have bolstered my courage to persevere and strengthened my belief that I am an important consumer. I should not have to feel uncomfortable about asking for assistance when I'm in the market for a particular product or service. That's what they're there for – to be knowledgeable about their field and to provide customers with the best products for their individual needs."

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From a woman in her 30's: "My advice to other achromats having tinted lenses made for them is not to be afraid to ask the optometrist or optician for permission to go directly to the lab where the work will be performed. This can work very well when experimenting with the different types of lenses and tint options available these days. The people in the labs that I've dealt with have been very courteous to me. They've allowed me to take the lenses they have prepared for me outside the building, so that I can conduct practical application experiments in the sunshine. This has made such a difference in my level of satisfaction and in the quality of vision I have with glasses that were made for me. In recent years I have learned that there are many new innovations in lenses that can be considered – various tints, coatings, etc. However, many opticians are not really educated about these options. Don't be afraid to make them stretch their minds. Also don't let them assume that they know what's best for you! I've wasted so much money over the years on sunglasses that were only mediocre, because I believed that the 'specialists' knew everything. I have never had a single optician offer to absorb the cost of a pair of sunglasses that turned out to be a 'bummer.'"

.....
From a woman with complete achromatopsia: "Whenever I have experimented with sunglasses that were made really dark – so dark that I would not have to squint or blink outdoors – I would often feel very uneasy when I found myself in shadowy places, like under trees or awnings or in shaded walkways. As I walked in and out of indoor and outdoor spaces that had varying levels of illumination, I would find myself frequently wanting to take off the glasses in order to see better. I was repeatedly having to switch very quickly to a pair of glasses that were not so dark or having to take off my super-dark glasses and manage momentarily without any tinted lenses (sometimes this was OK, but sometimes it wasn't) or else keeping the super-dark glasses on and just accepting the experience of having my vision dimmed in these indoor or shadowy places. I finally decided that I



would rather save the super-dark glasses for certain times when I have to be in bright outdoor light for extended periods of time and I would wear my sunglasses that weren't tinted quite so dark for every day use outdoors. With these 'less dark' glasses on, I feel sure that, if optometrists were to test me, they would probably find that I do not have quite as good visual acuity outdoors as I would have when wearing the super-dark lenses. But the increased adaptability I have by using these 'less dark' sunglasses is wonderful. I am able to just breeze along from place to place, going in and out of buildings and moving from shady places to sunny places. I never have those sudden feelings of frustration at being 'blinded by the darkness' that used to happen so much back when I tried to go around with those extremely dark glasses on."

.....
From a man in his 40's: "I use 5 different pairs of tinted glasses, each one best suited for a specific lighting condition. Like others in the network, I have found that I do not really benefit from having more light protection than I actually need. Over-use of extra tint seems to create a dependency on the tinted lenses and lead to increased intolerance of light. So I've found, through much trial and error, how to use tinting most carefully. Having to strain a bit to see can be a good thing. But, on occasion, I indulge myself, because I find that there are times when having extra tint can be more comfortable and even soothing."

.....
From a woman with achromatopsia in her 30's: "The onset of dusk always feels like a sublimely liberating moment for me!"

.....
From a woman in her 40's: "I am concerned about how some optometrists think achromats should wear lenses that keep their vision at twilight level, so we won't squint. Over-reliance on dark tinted lenses can hinder the one thing that we achromats really have going for us – which is our good 'indoor vision.'"

.....
From a man with achromatopsia in his 50's: "I believe that living in a constant 'twilight' (as a result of routinely wearing very dark lenses) would be most depressing and impractical. And, if it leads to dependency on dark lenses and increased intolerance for light, then, instead of just being disabled by bright light, we would also become visually disabled at low light intensities, i.e., under the light conditions in which we achromats would normally excel."

.....
From a man with incomplete achromatopsia: "My wife and I recently made a trip to Australia. This trip offered me a long-awaited opportunity to shop for a hat. I've always liked wearing hats, but I've had a hard time finding hats that fit me well, because I have a large head. The Stetson I bought in Texas 17 years ago no longer does the job, and the best I can do in the way of a sun shading brim is a generic ball cap. I knew I would be able to find what I wanted in Australia. For about \$60, I bought myself an Akubra, which is the traditional Australian stockman's hat. It keeps the sun off your neck and the rain out of your face. I love it, in particular because it drastically cuts down on the reflections and light leakage that diminish the effectiveness of my sunglasses. Sure, I might look odd striding around anywhere but Australia wearing this hat and my large dark glasses, but this hat is stylish, and it has drawn many admiring comments. Whenever there is a strong wind, I have to tie it down to prevent it from being blown away. As broad-brimmed

hats go, you can't do much better than an Akubra. I suppose a Mexican sombrero would be the extreme."

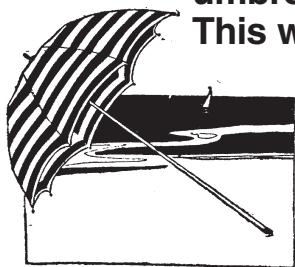
.....
From a woman with achromatopsia: "There's not a lot that I can do about my work environment, except turning my back to the window. So I find that I need to take breaks – even if it means just going into the bathroom, sitting down, and closing my eyes for 5 minutes. I try to relax as much as possible in transit to and from work. I'm a firm believer in taking 'power naps,' when possible."

.....
"Summer twilight times and summer nights offer wonderful opportunities for me to enjoy using my good night vision outdoors. As a child, one of my favorite things to do on summer nights was to chase the lightning bugs that would appear in our yard (some people call them fireflies or glow worms). I did not actually want to catch them and collect them in jars the way some other kids did – I was just enchanted by the way their little 'lights' went on and off. It was magical!"

.....
"Our son (age 7) wears his dark Rx lenses all of the time to reduce glare, improve his visual acuity, and reduce his need to blink and squint, and he also almost always wears a cap, which he tends to tilt over his dominant eye. I do worry about his staying excessively dark adapted as a result of this, possibly causing a state of oversensitivity to light and thus actually worsening his photophobia. He wears this one pair of glasses all the time in all illumination, only removing the cap when the lighting is very favorable."

.....
From a man in his 40's: "I love to be in the sunshine, as long as I don't have to do something that requires good visual acuity. As soon as lighting conditions permit, I tend to take off my sunglasses, even if this means I'll have to do some squinting. I do this whenever I feel that, for overall visual functioning, I do not really require 'heavy' shading. As a result, I think I have developed much adaptability to changing light conditions and changing visibility. In 'intermediate' lighting situations, I prefer to be able to choose whether to use sunglasses or whether to squint as much as I need to. Being visually and psychologically dependent on sunglasses can be like an impairment in itself, and I have found that sunglasses make my vision worse in some of the shaded or darkened areas. I find that there are some extreme situations in which this adaptability I have developed helps me a lot. For example, when I go to the seaside and leave my beach umbrella to take a swim, I cannot wear my sunglasses into the water (I don't yet have tinted swim goggles), so my rods are almost totally bleached out, and my squinting is maximized. Yet I can very carefully make my way into the water and then return to my beach umbrella by relying on the 'after-images' which I get when blinking and also on my overall orientation and knowledge of where I am. I look for and memorize conspicuous structures that can be seen in relation to the position of my beach-umbrella and memorize the exact row and position of my beach-umbrella.

This way I can confidently return there. Of course, I prefer to have someone accompany me when I go to the seaside, but it has bolstered my self-confidence to know that I can manage by myself if I have to, even in such extreme situations as this. I don't know how it would affect me psychologically if I were to continuously wear sunglasses, but I believe that it is a natural self-preserving



instinct that urges me to take my sunglasses off wherever I can and just as soon as I can.”

.....
From a woman with achromatopsia: “What works best for me is to have on hand a variety of sunglasses for different lighting situations – and to minimize my use of tinted lenses in general, so that I may enjoy making the best use of my ‘indoor vision.’ I dearly love natural light and love being without glasses whenever possible. I love being in the sunshine and am happiest in Spring and Summer and in locations which offer lots of sunshine. When the situation requires that I see my best, I resort to using my darkest sunglasses and usually a hat or visor too. But, when there are no such visual demands, I use lenses that aren’t so dark. I like to sunbathe, closing my eyes or turning my face away from the sun. I often find a comfortable, shady spot in my backyard or in some safe and pleasant natural setting like a park and just relax, enjoying the sunshine and accepting my unique view of the world. I blink a lot and squint if I need to (most optometrists would be horrified at this, I know). When I am with other people, I will keep my sunglasses on, because other people need to be made more comfortable about my vision. When I am alone, however, it matters much less, because I’ve become more comfortable with who I am. When it’s time to go places or do things that require my being able to see better, I gladly reach for the dark glasses that can raise the level of my visual functioning in bright light.”

.....
From a network mom: “Our 5-year old daughter will do anything in order to stay up late. She’ll be up until 11:00 at night playing outdoors, if she can con us into it. She’ll play in her sandbox, on her bouncer, anything – just to be outdoors at the times when she feels so free.”

.....
And from another parent: “Our son, age 3 and a half, is not really a ‘day kid.’ He will play outside in the daytime sometimes, but he’s basically a ‘night owl.’ After the sun goes down, he loves to run around and play, and he does this even in the dark. We still find this so bizarre!”

.....
“I wonder if other achromats loved Halloween as much as I did when I was growing up. To me it was one of the most exciting things to happen all year. There weren’t many occasions when it was considered okay for kids to be out on the street at night. But on Halloween I could run with my friends from block to block trick-or-treating in familiar neighborhoods. I could move about as easily and confidently as the other kids – and sometimes more so. Later in life, as a parent, I gave myself permission to frolic under night skies on Halloween night, ostensibly supervising my son and his friends as they went trick-or-treating – but secretly I knew that I was re-living the fun of Halloween. I have also thoroughly enjoyed dark tunnel rides and ‘haunted houses’ at carnivals or theme parks, etc. My son has outgrown trick-or-treating, so now I must find other excuses to wander outside on Halloween, joining the goblins making their way through dark, shadowy places. As a child I did not understand that my love of Halloween was connected with my eye condition. To be able to run around outdoors so freely and to see so clearly was not possible in the daytime for me, and opportunities to do so at night were very limited. So I would always make the most of every Halloween.”



From a woman in her 40's: "I wonder, did those of us who had such visual deprivation as children (having to manage without sunglasses) gain any benefits from the experience? I believe that most things in life that have a disadvantage also have some advantage somewhere along the way. For instance, I gladly leave off my sunglasses most of the time when I am indoors (though sometimes I will use them when watching TV) and I find this quite comfortable to do. I really don't want to have to wear any tinted lenses unless I really have to. I had the chance to talk with a younger member of the network who told me that she puts in her tinted contacts first thing in the morning and wears them until bedtime. I think that, if I were to do that – to have to be looking through tinted lenses all of my waking hours – I would feel as if I had an eye disease like retinitis pigmentosa. I do so love natural twilight outdoors and the natural daylight when I am indoors."

.....
"My son (age 12) wears regular sunglasses that we buy off the shelf at the store. We go on a sunny day and let him try on lots of different sunglasses, and then he picks several pairs to buy. From the time he was 2, he was fitted with sunglasses with side shields. He wore them for 10 years, and then he discovered that he could wear the kinds of sunglasses that other people wore (less attention getting) and that, instead of the side shields, he could enjoy using wraparound sunglasses that allow him full vision at the sides. He was very pleased with the chance to wear different styles and to give up his old glasses that had the side shields. He would have nothing more to do with them. And, after he started reading the newsletters, he finally became convinced to start wearing a hat – which his vision resource teacher and I had been trying to get him to do for years. Now he readily admits that he can see so much better outdoors with a hat on."

.....
From a networker in the U.K.: "I wore contact lenses for 20 years, but then I started having problems. At the eye hospital they said that I had 'insufficient tears' (dry eyes) and that I should stop wearing contacts. I was quite happy to stop wearing the contacts at the time, but now I would like to have the choice again. I am thinking of going to a contact lens specialist to see if he can help me understand this better and find a solution to the problem. Perhaps I'll be able to wear soft contacts. The continual swapping of light tinted spectacle lenses to dark tinted sunglasses while going in and out of places gets to be tiresome. I don't find bright sunshine so much of a problem, especially since I found some very dark (nearly opaque) sunglasses, with which I have even been able to participate in outdoor ballgames for the first time, which has been very exciting for me. But we have lots of overcast weather here in the U.K., which creates much more diffuse light and which can be very bright. And also in the winter it can be embarrassing to be seen wearing sunglasses; although, since they have become so trendy – and as I get older – I care hardly at all about this anymore. Tinted contacts were great, because of less wear and tear on my face, ears, etc. and because of having just one pair of sunglasses to take on and off – and being able to look 'cool.' I did worry, however, that wearing red contacts might make me look so odd to other people. I didn't want to look like a freak, and, since I am colorblind and couldn't see my 'red eyes' in the mirror, I couldn't tell whether I did or not."



“I love to be outdoors right after sunset. My vision is best then, and I don’t have to wear tinted lenses. I can see so much better to pick flowers, vegetables, or fruit. I like to go for walks at that time of day. I feel so much more relaxed and animated. Because I don’t have to blink a lot or squint in this kind of light, people can’t tell that I have a vision problem (it only comes up if I have to read something or identify a color).”

.....
Several years ago, on a Sunday morning in November, a young man with achromatopsia in our network was surprised to hear the minister of his church read to the congregation a poem written for that season of the year. The minister, Rev. Mark Belletini of the Starr King Unitarian Church in Hayward, California, did not know that this young man in his church had achromatopsia and that this poem would have special meaning for him.

INVOCATION

Less light. A time of rest for eyes weary of bright lights all competing for our attention

Less light. A time to focus carefully on things that the spotlight has missed

Less light. No need to squint. Eyes wide and alive

**Less light. No need to look frantically for what we might be missing.
Eyes closed and breath steady**

Less light. Ample time to see the slant sun of dawn kindling dewy webs between bare wet branches

Less light. Ample time to see the setting sun turn rainclouds into formations of flamingos

Less light. A blessing to all who never quite find time to sit in the dark silence during the noisy summer

Less light. A reminder to all those who need help remembering that few paths in this life are clearly lit

Less light. A time to notice shapes and textures as well as color

Less light. A gift of the tilting earth

Less light. A gift, a blessing, a reminder, and a time of opportunity

Blessed are you, light that wanes.



To persons with achromatopsia, the subject of “Living with Extreme Light Sensitivity” is of the greatest importance. Experimentation with different kinds of tinted lenses has played a major role in their history of seeking ways to cope with this challenging vision disorder. Therefore, a substantial amount of information about the various options in tinted lenses and considerable input from network members regarding this subject are presented in the book, *Understanding and Coping with Achromatopsia*. Included is information about different kinds of frames, lenses, readymade sunglasses, and much more. Also, there is a special issue of the “Achromatopsia Network Journal” which focuses specifically on “Options in Tinted Lenses.” For information about ordering either of these publications, write to any of the addresses given on p. 164.

Living with Colorblindness

From a woman with achromatopsia in her 20's: "When it comes to shopping for clothes, I find it helpful to shop with a trusted friend or family member who knows my tastes and knows what I look good in. My husband has had to get used to questions like, 'Does this color look good on me?' and 'Is this a pretty shade of green or is it one of the icky shades?' I insist on being color coordinated. I try to have lots of 'basics' on hand (jeans, black tops and black pants, etc.), so, if I'm in a hurry, I don't have to worry much about matching. I try never to buy any item in 2 colors that look very similar to me. For example, I would never buy 2 identical T-shirts, 1 in black and 1 in navy. Whenever I do have different colored shirts or blouses that look similar to me, I write the color on the inside label. I ask someone which items go well together, and then I usually rely on my memory. I have been blessed with a great memory. With the system I have described, I can usually match my clothes without any help. There are times, though, when I'll forget the color of something or I'll try to create a new combination. Then I just ask my husband to help. Also our 5-year old son loves helping me with colors."

.....

From a man in his 50's: "For purely practical reasons, I have often wished that I could perceive red and its protagonist green, since they are used nearly universally as danger signals and 'go-ahead' signals. It is quite puzzling that this has come about, since such a large percentage of males are known to have a deficiency in the ability to differentiate between red and green. I have never had any notion of a 'favorite' color, but I have been told that I seem to prefer to wear beige, light blue, gray, or khaki-colored clothing. It has been rather puzzling to me when people have raved about a beautiful sunset, a beautiful blue heaven, or a beautiful fall day with leaves in all the colors of the rainbow, etc. I have always been good at guessing the colors of objects, especially if I have had some prior knowledge as to which colors to expect or a general knowledge about the most likely colors of objects (i.e., oranges are orange, fire engines are red, and apples may be red, yellow, or green, etc.). Many people have been surprised when I have correctly used color names or have identified various objects by color. But at times I have also made some horrible mistakes."

.....

From a networker whose vocation is writing: "Lack of color vision is probably my greatest challenge as a writer. I love descriptive scenes, especially as they relate to character development; but, of course, I personally could go on and on in writing descriptive scenes without ever alluding to the colors of things. What comes naturally to me is detailing the warmth of a handshake or the richness of woodgrain and that type of thing. But I realize that virtually all of my readers would experience a void if I left out color description, which constitutes such an important part of their visual imaginings. It's an ongoing challenge. At this point, my color vocabulary is very dictionary-oriented."

.....

"Some people have asked me what colors I would most like to see, if I had the chance. First of all, I want to say that I have not gone through life wishing I could see color, though I have certainly wished that I didn't have to deal with the inconveniences and limitations that result from my inability to see color. As for color preferences, I feel a special fondness for what green represents. To be able to see

green grass or green leaves would be a pleasure, I think. My choices in colors for clothing and household items tend to be the colors which I am told are ‘earth colors.’ I enjoy selecting browns and nice shades of green and blue.”

.....
From a woman with achromatopsia: “When I was growing up, my normally sighted older sister was very critical of my appearance and she held high standards about how everything had to look ‘just right.’ Makeup, hats, clothing, shoes, stockings, accessories – everything had to be the ‘right’ color and well coordinated. This had a powerful, lifelong effect on me. I have always tended to be cautious and conservative about color choices and have needed lots of reassurance from the ‘significant others’ in my life that neither my home decor nor my wardrobe was offensive or mismatched. I have dealt with this concern by limiting the number of clothing items that have to be coordinated, not even bothering with makeup at all, and keeping my clothing accessories to a minimum.”

.....
“I wear Corning red-orange lenses, and I have noticed that, when I have them on, blue things turn much darker than they appear to me when I don’t have these lenses on, yellow things turn lighter than they appear to me when I don’t have these lenses on, and many orange and red things look nearly white. So, if I compare the way things look with these lenses on and without them on, I can pretty accurately guess certain colors. Also, if I want to be able to see something clearly that is printed in red against a black background (or vice-versa), I just put these sunglasses on. I’ll bet someone could come up with a system of using colored lenses to give us achromats a kind of ‘color perception.’”

.....
From a man in his 50’s: “A colleague of mine asked me recently if an operation that would give me color vision suddenly became available, would I take it and at what price – a million dollars? \$100,000? \$10,000? \$1,000? I replied that, if I had been given this choice as a teenager, I would probably have accepted such an operation at any price. But today I would not consider such an operation at any price, not even for \$10. I believe that, if color information were suddenly to become available to my eyes, it would so bewilder me that I would probably have great difficulties adjusting to it. However, I would like very much to have better visual acuity and to be less bothered by strong light, but these problems can at least be helped by using various optical aids.”

.....
From a woman in her 40’s: “I do not desire to see color, because I have lived without color perception all my life. However, I would love to be able to recognize a friend walking down the street on a sunny day, and I’d love to be able to drive a car and to see birds flying in the sky. I guess at the colors of things. I memorize what goes together. I wear red sunglasses, and they change the appearance of red, yellow, orange, green, and some blues. The first time I put them on, I was so thrilled. I ran home admiring all the fall foliage and looking at things more like a color-sighted person does. With these lenses on, I can distinguish between red and black. Previously I had always thought of red as a dark color, but now I know it is a bright color, not dark in the way that dark brown or black is.”

.....
“Have other networkers found, as I have, that people have trouble understanding that glasses can’t correct everything – and that they sometimes ask you to try on

their glasses to see if their glasses will help? And many people think that, if they hold something under a nice bright light, I'll surely be able to see the color. Personally, I don't care about not seeing colors. I guess it's like someone who's eaten turnips all her life and has never had lasagna – and so doesn't really care about lasagna, since she doesn't know what she's been missing.”

.....
From a woman in her 40's: “I think of colors simply in terms of ‘light’ and ‘dark.’ When people describe color to me, I just listen and try to be agreeable. People where I live go to the mountains in the fall to see the colors. Well, I have always been puzzled about what exactly was so thrilling about the leaves in the Fall, with some shades barely lighter than others. I have often thought that everything would be so much simpler without this color thing. People have tried to tell me that red is a hot color and blue is a cool color, etc. But, these descriptive terms just do not work for me. At Christmas I love to go out at night to see the Christmas lights, and it doesn't matter to me whether the lights are colored or not.”

.....
From a woman with achromatopsia: “Color is just not really a part of my life, except that I want my clothes to match and I want my kids' clothes to match. I want to be socially acceptable color-wise. All my children have good color vision, and they have each related differently to my colorblindness. My 6-year old daughter and I have come to loggerheads over color. She doesn't really care which shirts she puts over which pants. I arrange her clothes in her drawer with ensembles folded together, having committed the colors of her clothes to memory. But she doesn't like being so organized and doesn't want to always wear the same shirt with the same pants. She would rather mix and match. This is threatening to me, because then I feel helpless. When she mixes and matches, I'm chasing everyone in the family around to try to find out if her clothes match. My older daughter was never like this, and she is totally intrigued by my colorblindness. Her class at school is currently studying a unit on disabilities, and I learned that she practically leaped out of her seat to ask if her mother could come to class and speak about being colorblind. She told them all about how she helps me match socks and also helps me dress her younger sister. She asks me questions to the point of annoyance. But she is unusually sensitive and probably wants to ‘figure me out.’ I did speak to her class, and they were very interested and attentive. I didn't talk just about my vision but also about ways they can deal with their natural curiosity about people who have other kinds of disabilities – dealing with their curiosity in a healthy way and not staring or making rude comments.”

.....
“I often revel in the humorous side of being colorblind. I have shined my husband's burgundy shoes with brown polish (the polish was labeled, the shoes weren't), worn pink pantyhose with a red dress (I hear that's an unusual combination), tried to explain to the doctor why I can't say what color my baby's stool is, applied makeup with no help (always good for a laugh), and once found myself consulting my 3-year old about whether my scarf matched my sweater.”

.....
“To other achromats: Do you remember when you first found out that they paint curbs different colors? Or that, in playing cards, hearts and diamonds are red? Do you get frustrated, as I do, wishing you could read instructions printed in black on red packaging?”

“I wonder if others in the network choose to dress ‘as if they’re colorblind.’ My sister (also an achromat) does, and she’s proud of it. Not me. I’m a conformist, so I want to make a good impression. If that means my clothes have to match, then so be it. I have a friend who has a name for every single hue of every color God created, so I like to take her along when I go shopping. She picks out coordinates so that I can’t go wrong. The result has been so good that, when people find out I have no color vision, they sometimes ask who ‘dresses’ me.”

.....

From a woman with complete achromatopsia: “One night soon after we got a new color TV, I was watching the news, and the anchorwoman’s scarf almost jumped out and hit me! It seemed 3-dimensional against the rest of the picture. I asked my husband what color it was, and he said it was red. This happened again as I was watching ice skaters on TV (both red and yellow skaters’ outfits caught my attention – they seemed to have a sort of warmth, I guess) and again when a news anchor was wearing a red blouse. If seeing in color is anything like the way that woman’s red scarf struck me, then I don’t see how people with color vision can concentrate!”

.....

From a network parent: “Last year, in fifth grade, my daughter refused to do any assignments involving color at school and shed many tears over both homework and getting dressed in the morning. She seemed to be more self-conscious about her vision impairment than she had ever been before. This year, by some grace, she is more relaxed, is extremely social, and is keeping up with assignments. She likes to wear blue jeans or blue denim shorts, because she knows they go with everything. She doesn’t always trust me to select matching colors for her.”

.....

From a network parent: “As a child, I had no information whatever about my eye condition. I only knew what it was like to experience it. Whenever I had to tell others that I couldn’t see colors, a common response would be ‘Oh, then you see everything in black and white’ or ‘So you must see everything in shades of gray.’ Both statements disturbed me. Neither statement was true. For one thing, the only two ‘colors’ I could ever identify with certainty (without help) were black and white, and I took great pride in my ability to do this. I knew that relatively few things in the world were black or white. For everything else, I saw an amazing variety of ‘shades’ ranging from very dark (almost black) to very light (almost white). And I was able to distinguish fine differences in things that were different shades of the same color – I could see differences that other people seemed to have a hard time seeing. I did not understand at the time that people used the term ‘black and white’ simply to mean ‘not in color,’ as in ‘black and white movies,’ etc. To me ‘black and white’ sounded like a hideous way for the world to look, and so the application of this term to my way of seeing made it sound garish and far more restricted than it actually was. Therefore, I would adamantly declare that I did not see in black and white! I found it equally disturbing to be expected to agree with the assumption so many people made that I saw everything in shades of gray. Early on in my life I began to develop meaningful concepts of various colors. I had a sense of what ‘red-ness’ and ‘green-ness’ meant, for example. I even had favorite colors, based on what they seemed to represent. But gray? I really could not get a sense of what gray was – and, to this day, I still find gray the hardest

‘color’ to comprehend. No one was going to convince me that everything in the world I knew to be so richly varied in shades of light and dark was all supposed to be called ‘gray’! To me, it seemed ridiculous to imagine that, for instance, a dark tree and a light colored flower would both be identified as ‘gray.’ If I could see – or if I had ever been able to see – any colors, then I might perceive the absence of color as gray. But my visual experience has never included seeing color – and so gray, for me, has always been just one more ‘color name’ to have to memorize and learn how to use (as in describing cloudy skies, hair color, etc.). To those persons who are genuinely trying to understand total colorblindness and who ask me if I see grays, I usually respond with something like this: I suspect that, if it were possible for you to see through my eyes, you might find that you were seeing in shades of gray. But, since this can’t happen, we’ll never know for sure. I see many different shades of light and dark. I see things as ‘darker than’ or ‘lighter than’ other things. It is important to me that I describe my visual experience honestly and in terms that have real meaning for me, and so I have to say that I do not see gray. Perhaps someday those of us with achromatopsia will have a special vocabulary that can adequately describe the way we see.”

.....
“When my sister, also an achromat, had her house painted, she chose orange for her kitchen, because she spends a lot of time there, and orange looks kind of dark to us. People thought she was crazy to do this, but she found it relaxing.”

.....
“I think it would be very interesting to perceive color. I just don’t really miss color, because shapes, faces, etc., are all visually interesting to me. I wonder what would happen if I had the opportunity to see in color. I am a little scared that, because of the way I am accustomed to seeing, color would be grotesque.”

.....
“When I was a kid, I got to go to a summer camp for visually impaired kids. It was great. We played sports that were challenging but possible for me to do. Psychologically it was good for me, because none of the kids there saw well. Only a few could see better than me. Most couldn’t see as well as I could or couldn’t see at all. I found ways I could help some of these kids and enjoyed doing so. It was interesting for some of the nearly blind kids to find out that they could see colors and I couldn’t. They seemed thrilled to be able to help me in this way.”

.....
“At buffets or smorgasbords, I can’t tell tuna casserole from scalloped potatoes or chocolate chip muffins from blueberry muffins. Once I took something I thought was potato salad and it turned out to be some kind of marshmallow jello.”

.....
From a network mom: “Our preschool son loves acting, singing, and dancing. He memorizes lines and songs from videos, and he dresses to match the part he chooses to act out. He is obsessed with using the right color in drawing and coloring. We have to pick out the colors for him, and we have to swear that what we’ve chosen is exactly right for what he is coloring. If it is a shade too dark or too light, he complains. I wonder if this obsession is common. I’ve heard that



some children with achromatopsia happily color things any color they wish to and don’t want to be corrected. I almost wish he were like that. We try to make color a non-issue, but he always brings it up himself. He is also very particular

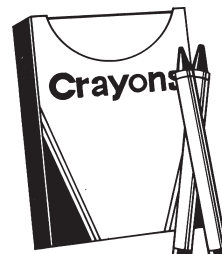
about details. His costumes have to be just the right size, style, color, etc. When he colors in a picture, he very rarely strays outside the lines. He is only 4, and he colors in pictures better than I do!”

.....
“When I was about 14, I discovered, quite by accident, the use of colored filters for identifying certain colors. We had a large salad bowl made of transparent red plastic. One day, while holding the bowl before my eyes, I noticed that the red checks of the tablecloth turned nearly white when looked at through the bowl. By moving the bowl back and forth, I could make anything red change from dark to light and then back to dark. I was intrigued by this discovery.”

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From a woman with achromatopsia: “I want to share an anecdote about how my teenage son is ‘on’ to my colorblindness. He is always trying out new things with his appearance, and his hair is a frequent topic of debate. Recently, when his friend Nat was over, he asked, ‘Mom, can I have my hair just like Nat’s?’ Nat’s hair was parted on the side and cropped above the ears. It looked tidy, so I said, ‘Sure, go ahead.’ He clapped his hands and cried, ‘Yes!’ I couldn’t understand why he was so overjoyed – until he revealed that Nat’s hair was dyed purple.”

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“Our daughter, who has turned out to be very artistic, has always wanted to use conventional color choices, even when she was a preschooler. We would take our cues from her. If she wanted information about color, we gave it matter-of-factly. She was interested in learning what colors various things usually were, and she memorized this information. Since color is a major identifying feature in our culture, it was understandable that she would want to be well informed about this. Learning colors is a major focus in preschool, so it was natural for her to want to participate and be included in whatever way she could. When she was in 1st grade, at her request, we labeled a set of markers for school and a set for home – R for red, BK for black, G for green, etc. Now in high school, she still uses labeled markers for making posters, etc. She asks us about which colors look good together and which colors clash, and we are happy to talk about it. When she does creative art work, she generally prefers to work in black and white, using pencil, pen and ink, or printmaking. We often talk about how things look to her and compare our visual experiences with hers. We view her way of seeing as just as valid as ours. She even teases us sometimes about how we color-visioned people get distracted from the essence of things by the superficiality of color.”

.....
“When I was a kid, I wanted to color everything ‘right.’ I recall once coloring an automobile and choosing something light like yellow for the tires. I looked at it afterward with dissatisfaction, because I knew that tires should be dark. Learning the colors of things was important to me, and I would commit to memory whatever someone would tell me about the color of an object. I was the only kid in 1st grade who didn’t peel the paper off my crayons – because that was where the name of the color was given. One of my teachers came up with a wonderful system to help me select the right colored pencils or felt pens quickly. She organized the ‘basic 8’ in this order, from left to right: red, blue, green, yellow, orange, purple, brown, black. I still use that system to this day. So, instead of reading all the labels, I reach for the 3rd from the left, and it’s green! I drew pictures incessantly as a child and might



have gone into commercial art, if I hadn't had this major problem with color perception. I mainly drew with pen or pencil, but I always loved those big boxes of 64 crayons. I was very careful in selecting the colors for my pen-drawn outlines. I didn't have a clue about what some of those color names meant (magenta, mauve, fuchsia, periwinkle, etc.), but some were self-explanatory (forest green, carnation pink, etc.). My favorites were gold, silver, and copper, because they were shiny. Actually, I used color quite a lot in my art work, though I'm not sure why. Perhaps I thought it lent authenticity."

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From a woman with achromatopsia: "My young daughter is just finding out that I can't see colors. She has started learning her colors, and she asks me all the time what color things are. For me, it's almost like being back in grade school, when kids were always asking me to guess what colors things were."

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"In my early childhood, when I used coloring pencils or crayons, I always broke all the 'rules' about the correct colors to use. I would happily color the sky green, the grass orange, the sun white, and so on. I was always corrected in these choices by those who knew better, and so eventually I gave up painting and coloring."

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"Trying to explain to someone with color vision what it's like to be totally colorblind is a bit like trying to explain to a normally hearing person what it's like to be completely tone deaf. However, my task is somewhat simpler than that, because everyone has some experience with achromatic (colorless or 'black and white') or monochrome pictures, and everyone has experienced the gradual disappearance of colors, as darkness sets in. I compare my color-less world to the visual experiences normally sighted people have when viewing black and white movies or good black and white photographs (sharply focused, high contrast with a long gray scale, such as one finds in crisp, high quality technical prints)."

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"When painting or redecorating, my wife normally selects the colors. If there is enough contrast between the old color and the new color, in tones I am able to see, I have no problem doing the painting. When buying clothes on my own, I only take advice from a salesperson in whom I have great confidence. Otherwise, I ask for 'safe' or neutral colors – white shirts, gray trousers, black socks and shoes, etc. For important color choices I rely on my wife or close friends who know my preferences. I often mark my socks in some way, so I won't mismatch them."

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"A continually recurring harassment throughout my childhood (and later on too) was being called on to try to identify the colors of scarves, ties, and all kinds of multi-colored pieces of clothing for people who found my inability to do so rather amusing. As a child I could not escape these situations."

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"I have acquired a knowledge of the physics of colors and the physiology of the eye's color receptor mechanisms; and, from the study of art and other studies, I have learned about the various meanings attributed to colors. But none of this has helped me understand the essential nature and character of colors. When I know the color of an object, I often use its color name when referring to it. Communication is made easier. This, in turn, leads others to use color terms when speaking with me, even those who know about my colorblindness. Sometimes this is helpful – e. g., when they refer to a red book that is among light colored

books. But referring to a red book among dark colored books is not helpful to me, since red looks dark to me. Looking at paintings, I can appreciate form, composition, and technique, although I cannot appreciate the color aspects. I can, however, appreciate monochrome prints, graphic art, sculpture, and architecture in the same ways that persons with normal color vision do.”

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“Colors are often used to code or highlight information. For me this usually makes matters worse, because what constitutes good color contrast for the normally sighted very often does not transform into good contrast for me. Sometimes the contrast that is visible to me is so low that the information is almost lost. Black print on red price tags, yellow print on a light blue background, and dark green on a bright red background are all extremely difficult for me to perceive.”

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From a 14-year old girl: “When I was 3, my mother didn’t understand about achromatopsia, and she tried to teach me colors. She got very frustrated when I didn’t catch on. In kindergarten I had to learn the color words. Throughout my school years, I usually asked what colors were correct to use. This year I am a freshman in high school. My art teacher told me she wanted me to be free to paint my pictures the way I see things. She didn’t want me to have to try to paint the way everyone else sees colors. So I painted a picture without the help of my friends. I didn’t want it to look too silly, so I decided to mix up only one of the colors and paint the rest of the picture with colors that were already mixed. I thought I had mixed brown and so I used it to paint my bunny. Later I found out I had made a purple bunny! It looked brown to me! (By the way, I got an A on the picture.)”

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“When I was a teenager, I had a friend who was also visually impaired but with a different eye condition, albinism. We had some similar problems, because she also was very sensitive to light. However, unlike me, she had her color vision to help in spotting things. For instance, she could at least see where a street sign was, because she could see a shock of blue or red or whatever color it was.”

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From a 15-year old boy: “I’ve got a couple of tricks I use to compensate for my colorblindness. To help with matching clothes, I keep all my clothes in a certain order. For instance, I keep all my black clothes in one part of my closet and I keep other colors separated. Since I wear a lot of black, I don’t have much trouble matching colors. I am very good at drawing pictures, but, when I try to color in my drawings, that’s a different story. I’ve found that colored pencils with the names of the colors already printed on the side work best for me.”

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From a woman in her 30’s: “I’ve been irked by a situation which does not happen frequently but which has occurred a few times lately. My roommate’s niece (age 10) said, as I was making a silly grin at her, ‘Your teeth look yellow!’ Well, I didn’t know whether to be embarrassed or not. I don’t know how yellow the average person’s teeth are in the middle of the day. Are mine abnormally yellow? Was it because I had just had coffee? Should I run somewhere and brush? Should I not show my teeth in public? In such situations I have no base to stand on. Like how much gray is in my hair these days, and how much is considered too much when one has long hair? My hair color is relatively light, so I can’t tell the



parts that are turning gray. I wish I could be the judge of whether and when to color my hair and whether I like the color. It's like being in a boat with no anchor, tossed about at the whim of whomever I must turn to for the answers."

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"Regarding the problem of mismatched socks. In our home we deal with that problem this way – I bought a box of large safety pins: and, when my husband takes his socks off, he pins the socks together. Whatever goes into the washer and dryer as a matched pair comes out the same way. (*Editor's note: Whenever safety pins are used on clothes to be washed, they should be the non-rustable type.*)

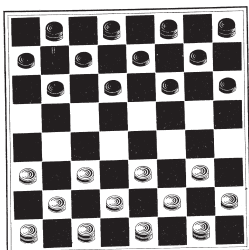
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"My father told me that, during my childhood, he had noticed that, when I was sorting my colored blocks in daylight, I usually put the red blocks and the black blocks together in one pile. Indoors, in artificial lighting, however, I would usually separated the red blocks and the black blocks into different piles."

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"A friend of the family actually believed that my inability to name colors was due to my parents' not having taken the trouble to teach me the color names. This person often tried (but in vain) to train me in naming colors."

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From a woman with achromatopsia: "My kids know full well that I'm colorblind, but they can't seem to stop referring to things in terms of color. 'Mom, have you seen my blue notebook?' 'Did you wash my red shirt?' My 12-year old daughter is really into fashion, and she loves to describe to me in rich detail the colors of clothes she saw at the mall. I don't want to douse her enthusiasm with cold water by saying, 'I don't care what color it was,' because it's very important to her and, hey, at least she still talks to me! The other day my 6-year old daughter was wearing a pair of mismatched socks, sorted by me. Even when her older sister pointed this out to her, she would not change them. She said, 'They match! See?' Then she proceeded to show how each sock matched some part of the multicolored print shirt she was wearing. Such a sensible child!"

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"I don't think of myself as seeing 'gray.' So many people in my life have assumed that I did see in grays that I had begun to accept that idea myself. However, now that I am becoming more assertive, I usually will answer, 'Well, for all I know, I might be seeing everything in shades of blue!'"

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From a 14-year old girl with achromatopsia: "There are many things we can do to compensate for our colorblindness. Picking out clothes that match is something that is learned over time. Neutral clothes which will go with almost anything – such as blacks, whites, tans, and blue jeans – are perfect for us. We can learn to color pictures by memorizing the colors of everyday things – cherries are red, grass is green, etc. Whatever we use to apply color needs to have the color's name on it. Many games are built around colors. Games such as cards, checkers, and Candyland become tedious tasks if we don't use compensation techniques. Since many card games require the player to know the red cards from the black cards, achromats must find a way to know which is which. So we learn the symbols instead; the red cards are hearts and diamonds, and the black cards are spades and clubs. Red checkers and black checkers look much the same to achromats, so we must find a way to tell our own checkers from our opponent's.



Marking all the checkers of one color with small pieces of white tape and leaving the others as they are is one way of doing this.”

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From a professional friend of the network: “Perhaps these tips will be useful to your networkers: (1) As an alternative to safety pins to keep mated socks from going astray in the laundry, one can use plastic ‘sock locks’ that are available through several specialty catalogs which are popular with people who have low vision. (2) A special checker set made up of round pieces and square pieces (designed for visually impaired people) would solve the color problem for those who cannot distinguish between red and black checkers. (*Editor’s note: Readers who would like to have a list of specialty catalogs for people with low vision can contact: Vision Community Services, 23A Elm St., Watertown, MA 02472.*)

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From a complete achromat: “I completely agree with the networkers who say that they don’t think of themselves as seeing gray. I’ve never seen gray either. I don’t know what this ‘gray’ thing is that people talk about. I’m told that gray is the absence of color, but the world as I see it certainly doesn’t look ‘gray.’”

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“At times in my life I have had some funny reactions with respect to the colors of things. Whenever someone tells me that an object I had always thought to be one color is actually a quite different color, my feelings toward that object will sometimes take a shift of some sort. For example, I once had a favorite wall hanging (fortunately, as it turned out, it was hung on a neutral wall) which I’d always thought was in shades of blue – and so I thought it was very restful for people to look at. However, after someone pointed out to me that it was actually in shades of purple and red, I could never look at it afterward without thinking about how ‘busy’ and ‘active’ it must be – and so I finally gave it away.”

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From a woman with achromatopsia: “In one of the newsletters someone commented on the ‘guess the color’ game (which Knut Nordby was being subjected to in the film, *Island of the Colorblind*). Personally, I abhor the color guessing game, but I’ve learned that being willing to play this game sometimes with my children has helped them to understand what ‘colorblind’ really means. They know, after seeing me guess wrong nearly every time, that I really am totally clueless. My older children are careful not to use colors when referring to things (‘Mom, please hand me the video in the brown . . . er, I mean, in the dark colored case’). I found out last week that one of my daughters has for years been under the impression that I could see red. We traced this to the fact that, when we play board games, I always ask to have the red pieces. My choice has been based on the fact that the red pieces look very dark to me, and so I can easily distinguish them from the blue, green, or yellow pieces – but she has thought all along that it was because the only color I could see was red.”

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From a woman with achromatopsia: “I recently read Oliver Sacks’ book *The Island of the Colorblind*. I very much enjoyed reading his sympathetic response to Knut Nordby, although it also made me feel sad in a way. I have to say that I do not experience the visual world as richly textured as Dr. Sacks conjectures that achromats do, but I do think that I enjoy it from a different, albeit less detailed, perspective. We live in a culture that is very visually oriented, but human beings have other senses with which to experience the world.”

Using Adaptive Methods and Adaptive Devices

“I was raised in the Roman Catholic Church, and I just recently realized that one reason I had not been able to pass religion class as a child was that I hadn’t been able to see what the priest was holding or what was on the altar. There were a bunch of items in the front part of the church which, in catechism or parochial school, the children were supposed to be able to identify. It was not permissible in those days to walk up close to these objects. But a lot has changed since then, and perhaps nowadays the items can even be taken off the altar and shown to a visually impaired child, as their symbolism or use is being explained. In fact, this could be done with other kinds of public exhibits too.”

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From a man in his 40’s: “I can manage well enough with most (but not all) sizes of print, but I rely on having reasonable contrast for reading. Either I am getting older and wiser or more practical, but I now prefer to carry a magnifier with me at all times. I only started this practice a few years ago, when I met another achromat who wondered why I didn’t use one. Using a magnifier and having several different pairs of tinted lenses available just makes good sense. For Christmas last year my wife bought me a special bag for carrying these items.”

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From a woman with achromatopsia in her late 30’s: “I used to be able to read anything that I could bring close to my eyes, but now I just can’t read small print as easily or for very long. Partly for this reason, I have really enjoyed listening to Talking Books. I think that, at this time in my life, I would even appreciate those large print books that I didn’t like having to use back in school.”

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From a parent in Texas who has 2 young sons with achromatopsia: “Our family loves going to the lake, Sea World, and the ‘Six Flags Over Texas’ theme park at night time. Our 8-year old is doing well in regular classes. Adaptations he uses include using a monocular and a portable computer dictionary and moving around the classroom in order to get close to whatever he needs to see.”

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“My son (age 7) plays piano. All of his music gets enlarged, but he also needs to have it brought close to his eyes, not just resting on the piano. Currently I hold the music for him when he plays. I am looking into the possibility of a music stand or other device that would allow the music to be closer to him.”

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“I wonder if anyone in the network has experimented with different colors of paper for writing. Recently I discovered that, when print is on blue paper, it is easier for me to read because of the absence of the glare given off by white paper. So I am now experimenting with different colors of writing paper.”

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From a woman in her 60’s: “I always carry a 5X magnifier in my pocket or purse, so I always have it handy. I use a CCTV for working crossword puzzles and other word games, paying bills, and doing needlework. I’m a mystery story buff, and I like to listen to them on Talking Books.”

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“About CCTVs: at first I did not like them, because the light from the monitor bothered me. I have experimented with changing the background and have remedied that problem. Still I cannot use a CCTV or a computer for long periods of time. I have migraines, and a lot of exposure to light will trigger one.”

From a man in his 20's: "I carry a monocular with me wherever I go. I use it not only for seeing signs and traffic signals but also for checking out the women."

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"Early on in my university studies, I was employed as a part-time lecturer, which meant I could have my own study, where I had full control of the light level. I would draw the curtains during the day, if needed. When attending lectures and seminars, I would arrive early – not out of courtesy to the lecturer but to be able to get a good seat (if possible, with my back to the windows and close to the blackboard or projection screen). For reading printed material, I have tried many kinds of magnifying aids but have found that they are usually either too large, too obtrusive, too weak, or too powerful for my needs. The best magnifier for me is one I can easily carry in my shirt pocket, small and easy to use but with sufficient power for reading small print, such as the print in telephone directories. I have tried CCTVs, but they are too large and heavy to be portable, they are complicated to use, or they are too powerful, giving a very small field of view and thus making it hard for me to read continuous text."

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From a man in his 40's: "For certain tasks such as reading newspaper want ads, I use a closed circuit TV. I feel that it could also be useful when working on circuit boards or when making repairs of something composed of small parts. I prefer to use a 4X magnifier to 'spot read' telephone books or maps."

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From a man in his 50's: "I use a small, folding pocket magnifier for reading most materials, even when the print is large enough to read with my glasses alone. This way I can read large amounts of text without undue visual strain. When reading, I usually hold the magnifier in my right hand and the book in my left, and I always read with my dominant left eye. Together with my spectacles, this magnifier is the most important tool I have, and I always carry it with me."

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"When traveling in unknown surroundings, I always carry a small 8 power monocular, which I can conceal in my hand and which I use for reading street names, destination signs, and other information I cannot get close to."

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This section about adaptive methods and devices would not be complete without some input about tinted lenses, since they are probably the most significant type of adaptive device used by achromats. Many more comments from networkers about tinted lenses are included in the first section of this book, "Living with Extreme Light Sensitivity." The following comments are from a man in his 30's:

"I did not have tinted lenses as a child, because the eye specialists I saw thought that wearing them would increase my light sensitivity. I now realize that they didn't understand how severe my light sensitivity was, so they couldn't comprehend how important tinted lenses would be for me. Until age 11, I basically had to make do with untinted prescription lenses that the doctors said I should wear. But these lenses really served no useful purpose for me. Wearing them was like looking through clear glass. I eventually gave up the prescription glasses altogether. After years of walking around outdoors with my eyes shut and in a lot of discomfort, I decided (at age 18) to go to an optician and try to get some dark lenses made for me. The optician, like the eye doctors I went to see as a child, was reluctant to make a really dark tint for me, and so I had to accept some gray

photochromatic lenses (again, with a prescription added which did not help me see any better) to which he added just a bit of extra tinting. Cosmetically, these lenses were an improvement (covering up my squinting and blinking, etc.), but they served very little purpose in terms of my vision. I eventually gave them up in favor of some inexpensive over-the-counter sunglasses of a wraparound style. These shut out more light than the spectacle frames I had been wearing which were fitted with the tinted prescription lenses, and so I could see better. Since discovering the network and obtaining the network books and newsletters, I have learned so much about what my options are in terms of frames, lenses, tints, etc. I feel that this information has saved me years of trial and error. I have been able to learn about the advantages and the drawbacks of various options, and I now feel I can make informed choices and can also inform the professionals. I made an appointment at the ophthalmology department at a teaching hospital in my city and also went to the optical lab where they send patients for having custom tinted lenses made. At both places I was able to discuss knowledgeably my special needs in tinted lenses. With their help, I am getting to try out several options. I have also purchased some ski goggles with leather side shields. I find that the side shields restrict my peripheral vision too much. I walk around the central part of the city a lot and must cross busy intersections. The side shields do shut out light, but I also sense that they shut out the rest of the world. Because they so completely shut out peripheral light, I have the distinct feeling of being behind a barrier. I think that these are not a good everyday solution for me but that they will be good for certain outdoor pursuits in which having my full peripheral vision is not so crucial. I find that I do not have bad experiences with eye doctors, opticians, etc., when I go to see them knowing what my requirements are and why.”

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“Low visual acuity has not been an insurmountable obstacle. My sister (also an achromat) has done all kinds of needlework, producing tatting, bobbin lace, and embroideries to very high standards. To keep her hands free, she uses a clip-on jeweler’s loupe on her working glasses. The loupe provides high magnification but a very small field of view, so it is not very suitable for reading.”

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From a network mom: “Both our children have glasses that have telescopes mounted on the inside. They wear these to all events such as concerts, sporting events, etc. They say that it is great to be able to applaud and watch the event at the same time. With their hand held scopes, they could not do this.”

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“I went to a zoo once when I was a kid and couldn’t see some of the small animals within a fenced area, so my mom got them to let me go inside the area. I got to pet some of the animals. My sister told me later that there were a lot of jealous eyes watching when that happened.”

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From a woman with achromatopsia: “When you take a vision impaired child to a symphony, you can talk to an attendant beforehand to get permission to walk backstage for a closer look at the instruments. You may have to tell someone important that your child is ‘legally blind.’ The instruments are really quite beautiful, and even a ‘scope’ can’t capture that beauty like viewing the instruments up close does. I’m told it’s best to go backstage after a performance, instead of beforehand, because the musicians are more relaxed then.”

“I constantly have neck aches. I know this is due to the way I stretch downward to read something on my desk or lean toward the computer screen to read. It seems that my neck, poor thing, is always in a strained position to allow me to get up close to see things. The CCTV’s are a frustration to me. I cannot look at their light for any long period. I like what they do, but I just cannot tolerate their light directly in my eyes.”

“My pre-teen daughter has the problem of ‘hunching’ over to read, do homework, eat, draw, view the computer screen, etc. So far, she doesn’t complain about neck aches, but I would think this would get to her after a while. Luckily, she loves to stretch and exercise, so she does not get stiff.”

“A friend of mine who is a chiropractor recommends a ‘mirror image exercise’ to compensate for neck aches due to leaning forward to get close to desk work, etc. This involves performing an action that is the opposite of the one which caused the strain. He demonstrated by sitting very erect and pulling his chin back into his neck. He also suggests getting what he describes as a ‘spring-loaded pivoting platform’ for your computer monitor. This makes it possible to pull the monitor horizontally toward your face. It works like those goose-neck lamps.”

“I don’t like to sing in choirs anymore, because sometimes I have to share the music; and, even when I don’t, during performances they turn the spotlights up so high that I can’t see the music anyway. The logical solution is to memorize everything, which I used to do years ago. But I no longer have the time or motivation for that. Also, I’ve seen pictures of myself holding music close to my face during choir performances, and I’m uncomfortable about how I look in those pictures.”

From a woman in her 30’s: “To others in our network who are singers, I recommend an organization called the Sweet Adelines. This is a barbershop style chorus for women. There are chapters all over the country. I joined partly because they don’t use sheet music. Everyone in the group has to memorize the music. I have seen pictures of myself singing with my church choir and also with our local oratorio society. I stick out in these pictures like a sore thumb, because it looks as if I have the music book shoved up my nose. There I was, thinking at the time that I looked so cool holding the music farther out than I would normally hold it, because I was somewhat familiar with what was on the page. With the Sweet Adelines, I’ll get to wear my favorite color when I perform. My favorite color is ‘sparkly.’ I love sequins and rhinestones!”

“I was 30 years old when I got my first miniscope, and what a wonderful aid it was! I took it to a park to look at things that were too far away for me to see without it. Being able to see a bird or to watch a squirrel scamper up a tree was a thrill for me. At home I reached for my miniscope to find out what that was on the ceiling – and it turned out to be a magnificent looking spider! Around town I was able to read distant clocks, wall menus, and signs at bus stops. In my college classes, I used it to see whatever was written on the chalkboard and classroom demonstrations. If only I had had this wonderful device when I was growing up! (In 6th grade I once brought an inexpensive telescope to school, hoping it would help me see the chalkboard. It



did indeed, but it was soon taken away from me by my teacher, who considered it ‘disruptive,’ because all the kids in class wanted to use it.) I now own a miniscope which allows me not only to see far off but also to scrutinize objects that are close to me and to see information that is just outside my reading range, such as information high on bulletin boards and the titles of books on high shelves. When I first took a miniscope to church, I was eager to be able to see the faces of people in the choir, but I was shocked to see that many of the faces showed signs of distraction, boredom, or fatigue. I realized that I preferred my old way of enjoying the songs of the choir, complete with the illusion that a choir would look as good as it sounds. I also learned that I prefer to listen to speakers mostly, rather than to keep focusing on their faces with my ‘scope.’”

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From a woman in her 30’s: “I recently bought a 50-inch projection TV. Now I can finally quit sitting on the floor in front of the TV set and can instead watch it while sitting comfortably on the couch.”

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“Our daughter has been playing piano for 4 years. For awhile her dad would make enlarged copies of her sheet music, but it just got too awkward. So he made her a holder for regular size sheet music. She sets up this holder on the partially pulled out dust cover for the piano keys. So far, this is working for her.”

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“My husband and I often sing duets in church. He lets me hold the music, or sometimes I hold an enlarged copy of the music or index cards on which I have written the words to a song, using a felt tip pen. By the time we have sung a particular song together on several occasions, I’ve got it memorized, and it becomes a part of our repertoire.”

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“I was asked to lead Christmas carols and to accompany on my guitar for a meeting of a women’s religious group in which I am active. I agreed to do this. I obtained overheads to project onto the wall and borrowed a book that had guitar chords for the carols. Since the book wasn’t mine, I did not ‘over-write’ the chords with black felt marker, which I’ve done with my own music at times. Using pencil, I simply wrote the chords in large notation, which I could erase later. When I practiced these songs at home, I had no trouble. But at the meeting, even though the room was darkened to facilitate the projections, I really had to struggle to read the chords and couldn’t see the words in the songbook at all, while I was playing the guitar and trying to lead the singing. In retrospect, I realize I should have used a couple of phonebooks on the podium to bring the music closer to my eyes (I stood behind the podium). People were obviously noticing that I was struggling (this is what I hate more than anything), and one person came up to ask if I needed her to hold the music closer. That was thoughtful, but by then the really hard to read songs were already over and botched. Another person brought a lamp over, thinking that would help me (Egads!). I had to tactfully refuse the lamp in front of everybody. People were very kind, but they clearly felt my misery and embarrassment.

 After it was over and I was back home, I thought about all the positive beliefs I have expressed about accepting my achromatopsia. At that moment I was cursing my eye condition, while at the same time struggling to ‘make friends’ with it again. I tried to imagine what it would be like to stand upright and effortlessly read sheet music from 2 feet away, to be able to concentrate on my guitar playing instead of on struggling

to see, to not have to feel guilty because I hadn't found the time to memorize the chords and to type the words to all 6 songs (3 verses each) ahead of time in a large font, so that I could more easily see them. I find that my frustration over this experience is like a fresh wound, and I'm feeling rather insecure, just like 'old times' (i.e., all the embarrassing and frustrating experiences from earlier in my life). I think that my vision disorder and I need to find a way to live harmoniously with each other again, moving forward together. For me this does not mean that this recent embarrassment didn't happen, but perhaps it means putting it to some good use. Perhaps in the future I won't be as likely to overestimate my abilities. Sharing this with others in the network means so much to me, because I think that many of them have 'been there, done that.'"

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From a woman in her 20's: "As a child I took piano and hated having to struggle to see the music. I found it much easier to memorize everything. In 4th grade the school music teacher wouldn't let me learn to play an instrument with the other kids, because I wouldn't be able to read the sheet music while playing. That's when my parents started me on piano lessons. I have studied voice for many years and I love to sing. I rely on my memory to learn all of my songs. Now I feel that I may have done myself a disservice because of not having disciplined myself to learn to read music. I am hoping to invest in a keyboard and re-teach myself piano. This time I will have the music enlarged or will rig up something to bring the music close to my face."

.....
From the mother of a preschooler: "Our daughter's accommodative skills have become more finely tuned. Looking out the window, she will sometimes switch to a darker pair of sunglasses if she can't see what she is trying to see well enough. She doesn't refer to colors, only to 'light' and 'dark.' Yet she can identify all the colors of the parachute they use at 'Gymboree' (a preschool gym activity). She can locate red as the darkest of the colors in the parachute and yellow as the lightest color, and she memorizes the location of the blue and the green. She was the first in her 'Gymboree' group to identify different shapes. She notes patterns and textures as well as shapes. She often points out details such as these to me that I would otherwise not notice, distracted as I am in my world of color."

.....
From a man with partial achromatopsia: "My most valuable tool now for distance vision is an optical device, which I obtained at a low vision center a few years ago. It's a 4X telescope/ periscope system mounted horizontally above a pair of prescription glasses. While not exactly inconspicuous, it is quite discreet and it has made a vast difference in my life. It is especially useful for computer work, watching videos or theater, etc." *(Editor's note: These devices may be more useful to those who have better visual acuity to begin with, such as incomplete achromats, and they are very expensive. Low vision specialists can be consulted by persons who want to try using these and other distance vision aids.)*

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"I remember people generally being very helpful to me as I was growing up. I was always in regular classrooms. It never occurred to me or to my parents that I should be anywhere else. In 2nd grade I was given large print books and large print handouts. I didn't really like them, though. They made me stand out, and the books never had the great pictures that regular books had (especially the book

covers). I think I went back to regular print in 3rd grade. In 4th grade a vision teacher was assigned to me. She was one of the greatest people who ever came into my life. She alerted the other teachers about my special circumstances, supported me when I wanted to learn to play the saxophone, and gave needed encouragement whenever I had doubt about what I could achieve. I was especially inspired by her, because she had less vision than I had, and yet she was carrying on this important job (with the aid of a driver/assistant). For most reading I don't use a magnifier, because it slows me down; but, for reading all the journals with small print that I must peruse for my university courses, I have recently obtained a magnifier that clips onto my glasses. Several years ago I received my first monocular, and it changed my life so much! I can read the chalkboard, signs, menus at fast food places – and I can see so many things I wasn't able to see before. I love my monocular so much – I 'never leave home without it.' Another godsend to me has been an enlargement program on my computer. I no longer have to strain so much to see the type on the screen."

.....
"I find myself wondering how much easier it might be for me to see written material on a page, if it were white print on a black background, as it is on my computer screen. I think it would certainly cut down on glare. But there is no inexpensive way that I know of to reproduce printed materials in the 'negative.' In this sense, being an achromat is like being a left-handed person in a right-handed world. Society cannot easily accommodate this particular visual need of mine, because the rest of the world just doesn't need it that way – Thoreau's 'different drummer' principle." *(Editor's note: Opportunities to read white print against a black background have been appreciated by many achromats, whether in the form of something written in white chalk on a blackboard, white-on-black text viewed on a computer screen or CCTV screen, or printed material produced with white text on a black background. Some people have arranged for pages with white-on-black print to come through a laser or ink-jet printer, but using a printer this way on a regular basis can quickly deplete the toner or ink supply. However, network members vary in their preferences in connection with this – some prefer viewing white print on a black background and others prefer black print against a white background, with the screen brightness adjusted.)*

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"I got a great monocular through my eye doctor. I haven't had a monocular since fifth grade, when I was too afraid of looking weird to actually enjoy using one. This new one is better than the one I had back then. I bring it to the grocery store sometimes and use it to read the aisle markers, which is much nicer than walking up and down each aisle until I find what I need. We recently took a trip along the coast, and I used it to look at sea otters (a first time experience for me). Of course, binoculars are better for things like that, but the monocular fits in my purse, so it's always with me."



.....
"When my son and his family stayed with us at Christmas time, my little granddaughter, who has achromatopsia, enjoyed the wax candles which were used to decorate our Christmas tree. The lighting in the room that was provided by the candles was very much the way she likes it. She and her brother, who is normally

sighted, were both very careful with the candles. We obtained a music stand for her to use in reading. It stands on a table; and, when a book is placed on it, she can get very close to the book without having to bend her neck down."

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On the network membership form, one woman gave this answer to the question about what resources she uses for coping with achromatopsia: "I use very dark glasses, I have a vivid imagination, and I have great acting ability."

.....
"Our choir director loves the fact that I memorize my music. I am in a choir group that leads the singing every other week. On those Sundays he enlarges the song sheets for me. One Sunday our group was asked also to read scripture verses aloud, and I found that he had enlarged that for me as well. I find that some people care and find ways to be helpful, even without my asking for help."

.....
From a woman in her 40's: "I have no problem at all with wearing mirrored lenses or any other kind of lenses, for that matter. I think whatever vanity I had went out the window years ago. I'll wear whatever helps me see most comfortably and allows me to have a more interesting and varied lifestyle."

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From a man in the U.K.: "I learned about the network while using the Internet. I am employed as a paybill modeler for the National Savings Agency, and I also design custom software applications for use in human resource management projects. I use various tinted lenses, 2 different monoculars (one with close focus), a pair of zoom binoculars, jeweler's eyeglasses with 2 different powers, a 6X hand held magnifier and a 3.5X folding magnifier. I make extensive use of computers at work and at home. At work I use a 20" monitor and the largest fonts available on both my PC's. All of these low vision aids are very useful, but by far the most important resource I have is the support of my wife. The help and encouragement she has given me has completely changed my outlook, and I now look upon my vision disorder not as a disability but as a challenge. I think I am very lucky!"

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"Just before school started, our 10-year old son's Vision Teacher pushed us into obtaining a Talking Book machine from our state library for the blind. They sent him some books on tape; and, after trying this system of reading books, he absolutely hates it! I wonder how other kids in the network feel about this." *(From the editor: this reaction to Talking Books is very common among kids with achromatopsia, although Talking Books are highly valued among those with more disabling visual impairments. However, books on tape are often viewed quite differently by adult achromats and sometimes by older teens, who often enjoy "listening to a book" while working at some manual task or while exercising or traveling. Many adults relish the experience of "being read to" while resting their bodies and their eyes. Adults usually are not so concerned about the stigma attached to using a device associated with the blind. Few of us would have accepted Talking Books as kids; but, by the time "middle age vision" comes along in our 40's, making reading somewhat more troublesome and tiring, we tend to look more favorably at this option. However, students whose only vision disorder is achromatopsia should never have to rely on Talking Books to meet their reading needs, as is so often the case with many other visually impaired students.)*



Social and Psychological Aspects

From a man in his 40's: "When I'm with people with whom I'm just getting acquainted, I'm careful not to disclose my vision impairment until I feel it's the right time to do so. But, when I'm out in public around total strangers, I'll just go ahead and hold reading material as close as I need to. At such times I find myself thinking, 'I don't know these people anyway. Let *them* deal with the sight of someone who has a vision disability.' Then I feel guilty because I feel that I'm inflicting a 'freakish' sight upon them. And every now and then, while I'm reading closely in public, I'll even feel a flash of hostility toward those around me, because I imagine that some of them are judging me as 'uncouth' for reading like this in public. I'm not comfortable with the fact that allowing my disability to be so visible puts me in the same league with other kinds of stigmatized people in our society. In fact, I try to avoid the thought of having a 'stigma.' I'm conscious of telling myself repeatedly that I'm not like those other people in our society who stand out because there is clearly something wrong with them. One might think that I should be especially compassionate to people who have other kinds of disabilities or who are stigmatized for other reasons, but I have to say that my experiences have not produced more compassion in me. I probably have the average amount of compassion for other people, but no more."

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"Regarding the question of whether to read in front of other people and thus draw attention to my vision impairment: sometimes, I'll be reading and I'll look out of the corner of my eye, wondering if anyone is noticing how I'm reading. Often there appears to be what I would call 'civil inattention' – i.e., people are trying to keep me from knowing that I am being observed. Sometimes, when I'm reading on the bus, I'll hear people laugh, and I'll wonder if they are laughing at me. So I've always listened to what they would say after they had laughed – and almost never has it turned out that they were laughing at me."

.....
"Often I fail to recognize people I know, with embarrassing consequences. Sometimes even the people who know about my visual handicap are offended by what seems to them to be my disinterest or my neglect of them. The reason may be that my visual behavior is so often rather normal, leading them to believe that what appears to be my disregard for them is intentional rather than simply a result of my not being able to recognize their faces from a distance."

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"I had a very close knit family growing up and didn't grasp the full scope of my disability, partly due to the protective nature of my family and partly due to a general lack of maturity. I hated the notion of being seen as blind or being called blind. At one point in my life, I experienced a wave of depression as I began to perceive myself as being ignorant about many things and significantly behind my peers in many ways. Eventually I began, reluctantly, to accept my vision disability for what it was, mostly because I had no other choice. I took steps to get some optical aids, which have made an incredible improvement in my life, both academically and in other ways. I know that I am more fortunate than some people, and I feel that I should always keep this in mind. I think that the insecurity I live with is simply one of nature's harsh realities that I will have to learn to deal with."

From a man in his 20's: "I think that, in some ways, those of us with achromatopsia have it worse than a lot of other vision impaired people, because we're 'in the middle.' People don't know we have a serious vision impairment, and so they make assumptions about us. And often I find that, even after I have explained my vision impairment, they forget it, because it's not 'in their face' all the time."

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"The anonymity of a large urban setting has allowed me to read close to the page with a devil-may-care, almost rebellious attitude at times. But I realize it's also as if I'm living a double life; because, when I'm first dating someone new, I try to imagine their shock and state of discomfort if I were to begin reading in front of them the way I read when I am surrounded by strangers. Because of this potential for shock, I always try to avoid this kind of exposure when in the presence of someone new in my life. I even feel that I owe it to other people, as much as possible, to blend in and not inflict the sight of my strange near-sighted reading upon them. I am aware that some of my attitudes on this subject create tension in me."

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"Sometimes I find myself wondering, 'Should I force my eyes open in a bright place when someone is talking to me? Should I pretend that I can see what someone is pointing at when I really can't?' Well, just as there is such a thing as 'civil inattention,' maybe there is also such a thing as 'civil homogeneity' or 'civil blending in' – the 'civil chameleon' aspect. Perhaps, in a way, it is sometimes actually good manners to appear to be like others, even when we're not. It does help to maintain rapport. Visually impaired persons who are always pointing out how they are different and how their needs are different, etc., may actually be pushing people away by doing this. I would rather err on the side of having people 'under-serve' my needs. I realize, however, that some of my difficulties in life have happened because I hid the facts about my vision impairment even from myself and, consequently, remained almost perpetually inconvenienced."

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From a woman in her 50's: "I am almost as inhibited about holding reading material up close to my face in front of strangers as I am about doing this in front of people I know only casually. Actually I am only really comfortable about doing this in front of people who know me well. I realize that it is usually better to do whatever one needs to do in order to visually access information, whether it means reading up close or making use of an optical aid, and this gets easier for me to do as time goes by. But I think my resistance has to do mostly with the fact that I value my privacy so much and really prefer being inconspicuous and 'anonymous' in public, rather than calling attention to myself. When I used to read a lot while commuting by train, I would sometimes get a judgmental remark from a passing stranger, such as 'You ought to get some glasses!'"

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"Upon first meeting someone, I do not say, 'Hello, my name is _____, and I'm an achromat.' I don't want people to feel awkward around me before they get a chance to know me; and, after all, it's not as if I'm in a support group for people with addictions and am expected to identify myself this way. Being colorblind can sometimes have hilarious results, and I use such moments to remind my friends about my vision impairment ('Sorry about my socks. I just found out they don't match'). My friends get used to me and they forget. Often they remember that I can't see well at a distance, but I think that colors constitute such a salient feature

in their world that they can't comprehend the thoroughness of my colorblindness. I do tell store clerks that I am colorblind and ask them, for example, if they would help me find black socks, because making the right color choices is important. It's easier for me to admit my colorblindness to clerks than it is to admit to a cashier at a fast food place that I'm visually impaired and can't read the wall menu. I think this is because being colorblind just doesn't bother me as much – it isn't the reason that I feel fettered. But I'm past the stage where I have the emotional energy to 'fake it.' I think I bring a great deal more to the world by expressing who I really am – and achromatopsia is a big part of who I am – than by striving to be someone that my retinas won't allow me to be. Also, I feel guilty when I've pulled off a ruse. No matter how ingenious I've been, it's still deception."

.....
"My self-perception and my perception of how I look to others has changed over the years. When I was a kid, I couldn't figure out how people could so easily guess that I had an eye problem. Now, when I look at old pictures of myself, even those taken in good lighting, I look 'odd' somehow. My eyes look sort of out of whack. Self-consciousness has been, for me, a constant companion."

.....
"I hate the thought that others are seeing me blink so much. I wish I had a quarter for every time someone thought I was 'stoned' because of the way my eyes looked. I'm especially self-conscious around children, because I think my eye movements (the nystagmus) might be scary to them."

.....
"About compassion: I don't hang out with the lady at my church who's in a wheelchair. I like her fine, and we chat sometimes, but I don't necessarily relate to her. I believe having achromatopsia has made me more compassionate insofar as it has made me sensitive to what other people go through when they are different or stigmatized. But I don't think I show more compassion because of it."

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From a man in his 40's: "I don't think that just having a disability and being different confers upon me an innate ability to accept and relate to differences among people. While my vision impairment has taught me to appreciate the world in a different way, it has also limited my ability to learn about the world. I have to be mindful of the fact that I am not always seeing a complete picture with regard to things that are happening around me, and I need to solicit feedback from others. I need verbal information from someone (often my wife) about people's reactions in more complex interactions, particularly in group situations."

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"We achromats lead lives of paradox. We need to become independent, and yet we need someone to get us from here to there, to help us match clothing, etc. It's important for us to learn to accept help graciously, without feeling bad about it. We should remember that we also have special gifts which we can give others in return. If someone has gone out of their way to help me, I'll bake something for them or help them out in some way. The bottom line is: everyone needs help."

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"It's too much for anyone to expect that life should be fair. It never has been and never will be. So, since we can't change the external world to our satisfaction, we may as well work on what we can change – ourselves. I'm a big believer in building bridges, and I think that sharing about our vision problem can be a good way to do this. The other day I met a guy who was waiting for a lung transplant he needed because of cystic fibrosis, and did he ever bless me with his perspective

on life! He's just glad to be alive! But I found out later that he wouldn't have opened up to me and talked about it if he hadn't learned that I also understand what it's like to have no choices about something (in my case, having to be content with shades of gray or whatever it is that we achromats see instead of seeing colors)."

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From a woman with achromatopsia in her 40's: "Most of my life I could – and did – 'pass' as being normally sighted, at least in situations in which I was involved with people indoors (or in the evening) on a superficial level."

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"We achromats can 'fake it' so well in the sighted world that we feel a great deal of pressure to conform. When we can't 'fake it' (like when we have to make use of the same kinds of adaptations that blind people use), it's disillusioning to us. Having so much vision (at least when the lighting is right for us), we have a pretty good idea of what we're missing and it's 'no fair!' For me, the issue of conforming was settled in nursery school. There was no way I could really be or act just like the other kids, although I tried hard. But, if you can't fit in, you make some kinds of adjustments, so that you can stay psychologically healthy."

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"Another partially sighted person I know deals with her insecurities by telling people everywhere she goes, even before they can get a word out, that she can't see well. It takes the pressure off her, but it sure can leave other people feeling awkward. She tells waitresses, people behind the counter at drugstores – lots of folks who really don't need to know. It's alienating and it annoys even me. But that's her way of coping. I cope by being an introvert, except when I'm with people I know. I don't even like to ask for directions at the mall. The question of disclosure is an individual decision. But, if there's any possibility that someone is going to be left feeling uncomfortable because of not having known about my vision problem, then I want to let that person know about this from the start. If curiosity leads someone to question me further about my vision, which is often the case, then it's easy for me to explain the details. At times I've even drawn a picture on a napkin, showing an eyeball with a retina that had rods but no cones."

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From a man in his 40's: "Several people have told me that, as they have gotten to know me better, they have become less conscious of my limited vision. Sometimes people are not even aware that I have limited vision until they observe me struggling to see something. I do feel self-conscious sometimes, but I don't think it is abnormal for someone like myself who squints, wears tinted lenses, and looks closely at things to feel self-conscious. I believe that we need to do what we can to build our self-confidence and that others will regard us according to how we conduct ourselves."

.....
"In bright light people immediately notice that something is wrong with my eyes, and they show this by their reactions. As a child I was often approached by total strangers who would demand to know what was wrong with my eyes. Wearing tinted lenses can alleviate this social burden to some extent."

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From a man in his 50's: "I often avoid showing my visual handicap and sometimes simulate normal sightedness. If I expose my visual disability before people get a chance to know me, I often encounter negative attitudes or am treated in a patronizing way. If, however, I wait to expose my visual handicap until people get a chance to know me, I get fewer such reactions."

“One of the problems of having this ‘hidden disability’ is that, after awhile, I start believing that I don’t have a disability. Then, when I have troubles resulting from it, I assume that it’s some kind of character weakness. Having the chance to express these things through the network is an important outlet for me.”

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“Something I’d like to shed is my feeling that the first thing people think of when they look at me is that I have an eye problem. Is this a weird paranoia? I sometimes feel more self-conscious walking around someplace where everyone knows me (my kids’ school, my church, etc.) than places where I am a stranger. I know a lady in a wheelchair and a guy with a hearing impairment, and I am acutely aware of their particulars when I am with them. It’s right there in the back of my mind (open the door for her, speak very distinctly to him, etc.), even though it doesn’t cloud my appreciation of them as human beings. I wonder if that’s how others are thinking when they are with me.”

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From a man in his 20’s: “I’ve spent most of my life trying to downplay the significance of my vision impairment. I had pushed it way back and had even become skittish whenever I had to talk about it with anyone. To me it had always been just a liability that had brought pain and punishment in my school years and had made me conspicuous as an adult. Now (having discovered the network) I feel as if I have stumbled upon a room full of people who understand my experience, as I do theirs. This fills me with a great sense of peace. Before this I had never even thought it would be possible to meet another person like myself.”

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“Although our vision impairment is a very important part of our identity, there are so many other aspects of who we are as individuals. Unless we have the chance to be known among our peers for our other qualities, then our vision impairment can easily become the main impression people have of us. I think that most of us would like for people to get to know us mainly in terms of our skills, interests, ideas, or whatever qualities we may have which we prefer to project. It is a basic human instinct to want this. And yet postponing disclosure about our vision impairment for very long can create problems. I don’t think there are any easy answers to this dilemma. Disclosure was especially hard for me in my teens. As adults, we tend to develop self-knowledge and self-acceptance and to look beyond outward appearances in other people. And, as adults, we are more likely to find acceptance from our peers. This has certainly been true in my life.”

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From a woman in her 30’s: “I just finished reading *The Planet of the Blind*, an autobiography by Stephen Kuusisto, who grew up with a serious vision impairment (something other than achromatopsia). The main conflict of his life was accepting his vision disability. For several decades he tried, with severely limited vision, to ‘pass’ as normally sighted. Personally, I am all too familiar with this kind of excruciating self-consciousness and unwillingness to accept limitations – which is, at best, a self-transcendent ideal and, at worst, a self-defeating strategy. I think *Planet of the Blind* is a courageous book.”

.....
From a man in his 40’s: “I never feel fully confident about always having to be seen wearing sunglasses outdoors in the daytime. People in my running club always see me with sunglasses on, even on very cloudy days, and some of them have teased me about this. But I have never told them why I do this, and I don’t

believe it is necessary to do so. The flurry of questions which would inevitably follow revelations about my visual condition would probably not be to my benefit. There are times, I think, when people's curiosity just has to go unaddressed."

.....
From a woman in her 30's: "I think that one of the great difficulties in coming to terms with achromatopsia is that, during any given day, there are times when I experience much better vision, and at these times I feel much more capable and more at ease. At other times during any given day, the opposite is true – i.e., times when I experience my worst vision. I find that acknowledging that considerably less capable side of myself – acknowledging it both to myself and to others – is the hardest part of living with achromatopsia."

.....
From a man in his 40's: "About the social and psychological aspects of having achromatopsia: On the positive side, I believe my vision disability has contributed to my being a thoughtful, caring, and polite person. Friends, co-workers, waiters, clerks, and cashiers (most of whom are unaware of the seriousness of my visual limitations) think that I am a special person. However, on the negative side, I feel that my vision has caused me to be more shy than I might have been inclined to be if I'd had normal vision. Many people have concluded that I am conceited or unfriendly because I have not acknowledged their smile or a wave from across a crowded room, across a wide hallway, or on the street. I find myself in the predicament of not wanting to advertise my vision disability to the world; but, by not doing so, I sometimes find myself unjustly labeled as 'stuck up.' I think that the day-to-day stress of trying to function in life, aware that I must be prepared to make accommodations 'on the fly' whenever I encounter small print, bright light, or color-related situations which I had not anticipated, takes its toll on me. I know that I am always just one misstep away from either making a fool of myself or having an accident – even though such things do not happen very often."

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From a woman in her 30's: "I have always tended to be a loner, though I'm not sure how much of this is my 'nature' and how much has to do with 'nurture' (i.e., influences from my childhood). Mine was not an overly nurtured childhood, to put it mildly. But having achromatopsia has definitely contributed to my tendency to be a loner. I don't feel that I 'fit in' with normal society. I don't pal around with my co-workers outside of work. And, as for the people I do associate with on a regular basis, it's mostly on a surface level. I have one very close friend. Not being able to see across a room and perceive people's subtle reactions, expressions, etc., definitely hampers interpersonal relations. I miss out on a lot."

.....
"Because of achromatopsia, I feel that I am always 'on the fence' between being normal and being handicapped. The trouble is that I am glued to that fence. I can't seem to move over to the 'normal' side because of the continual reminders of how abnormal I am, and I simply won't move over to the other side."

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"It's been tough growing up with this vision disorder, and I believe the challenges and adversities I have faced have had profound effects on the development of my personality, in both positive and negative ways. Having to overcome many of my fears has helped to shape me into a person who is strong-willed, outgoing, and sometimes exceedingly stubborn (yet also very introverted at times). I believe some of these traits were needed to help cover up my overly sensitive feelings. In

childhood I was always an outcast and ‘picked on’ by other kids. I had to build up a tough exterior to mask the fact that most of their barbs hit home. I also learned early on that I had to stand up for myself by being smarter, since physical combat wasn’t really an option with vision as poor as mine. My vision disorder is such a hindrance/nuisance in terms of accomplishing my many goals that I often become very frustrated. Then I strive even harder to get around the obstacles. Occasionally I simply have to ‘cage my lion’ and just accept the fact that there are times when I won’t be successful. Learning to accept one’s limitations gracefully is difficult for lots of people, even those who aren’t physically challenged. Most of the time I manage to do this, but there are times when it seems that the whole world is hostile and that no one out there understands what I’m going through.”

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“It took me many years to accept the fact that I would have to wear dark glasses outdoors in the daytime the rest of my life and so would always look so ‘different’ because of this. This is especially difficult living in a small town instead of a city, where one can enjoy more anonymity when traveling about. I suppose one of the benefits of getting older is that one becomes more pragmatic about things. Here in Ireland we have a saying: ‘What can’t be cured must be endured.’”

.....
From a network mom: “I am grateful to all of the networkers who have spoken out about their bouts with depression. I believe that their comments gave our son the confidence to open up to us recently about this subject and helped him to understand that he’s not the only one with these feelings. He’s not alone. What a breakthrough this has been! Whether by talking about it or writing about it – just to ‘get it out.’ I think our son struggles daily with the feeling of being ‘different’ from others and, therefore, somehow ‘less’ than others.”

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From a woman in her 40’s: “I went through hell growing up with this eye condition, and I don’t want to diminish what that was like or negate its lasting effects on my psyche, but I believe that the injuries are not permanent. The wounds do heal. Achromatopsia is ‘handicapping’ enough, so to speak, without continuing to ‘cart around’ the emotional baggage too. Being ‘the only one with it’ has probably been the worst thing about this condition.”

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From a woman in her 20’s: “I remember one time in junior high when we had a substitute teacher who told me to take off my ‘sunglasses.’ I politely told her they were tinted lenses that had been prescribed for me. She didn’t believe me, but the rest of the class stood behind me to convince her that this was true. That was a great feeling for me when they came to my defense. Once, also in junior high, a girl told me she hated seeing my glasses. I wanted to tell her that I hated seeing her face, but I wasn’t going to stoop to her level. I just ignored her. If people make comments about my glasses out of curiosity, I explain my eye condition, and they are usually fascinated. Kids can be cruel, but your true friends will stick up for you.”

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From a woman in her 60’s: “I remember well my deep depression in my teenage years. I didn’t even have a name for this eye condition or an explanation for it. There were so many things I couldn’t do that others could do. I felt like some kind of freak. No one was offering me any kind of guidance, counseling, or hope regarding what I might do or be after I made it through high school. But I had a strong survival instinct, strong religious faith, and a healthy interest in many

things, so I think these forces kept me from dwelling too long in a seriously negative state of mind. If there had been this network back then – or if there had been even one other person who understood about achromatopsia – it would have made my teenage years so much easier.”

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From a young man with achromatopsia in college: “I had to endure a lot of mean teasing all through school, and it really got to me. A couple of times I made plans to off myself. Thankfully there was always someone around to help me get through the situation, or circumstances kept me from doing anything like that. But I learned through all those troubled teen years that a lot of people are just very ignorant. A hearing impaired friend of mine told me that no one can really understand what it’s like to be physically impaired except those of us who are. Thinking about my own life, I know that even the most well-meaning people who aren’t impaired themselves can’t really understand. That’s why we need to stick together. We can help each other, because we do understand. I’ve found ways to deal with the negative energy which comes from some people and which arouses negative energy in me. For one thing, I have found that playing guitar seems to help me, and listening to certain kinds of music helps. And, if people treat me in a negative way, I say they’re too ignorant for me to have to deal with. I find other people to associate with. I have found that, if those around me don’t produce happiness in me, I’ll make some happiness for myself, from somewhere within myself. This past summer I was a cabin counselor at a Lions Club camp where I went to camp as a kid. I got to work with lots of kids who have different kinds of disabilities – hearing impaired, cognitively disabled, visually impaired, and others. I also was at camp for a week with visually impaired adults. These experiences gave me new ways of looking at my own impairment. I learned that all of these people have lived through the same kinds of experiences I have lived through. And I also came to realize that the ignorance which causes so many people to treat persons with impairments in negative ways is an impairment in itself.”

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From a woman in her 30’s: “I have experienced deep emotional battles during my life and have had to cope with depression at times. However, I don’t think my periods of depression were exclusively connected with my vision problems. There were other issues I was having to deal with as well. I have come to accept the fact that I am fundamentally melancholic in temperament. I tend to be either extremely ‘up’ or extremely ‘down.’ I struggled with self-esteem issues when I was growing up. Kids can be so mean! I grew up thinking that others saw me as ‘flawed.’ I was ‘that girl who can’t see well.’ I wanted people to see me as so much more than that, because I was so much more than that. I have been very blessed to have a supportive family.”

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From a woman in her 40’s: “I experienced a lot of teasing when I was a kid. Being teased is hard for anybody, but I suspect that some people take it harder than others, and some just aren’t able to ‘repair the damage’ without help. I’ve wondered why some people seem to overcome these problems and others go into a serious depression or carry their emotional wounds for many years. I suspect that these differences may have to do with differences in an individual’s emotional durability and also the differences in people’s external support structures (family, friends, teachers, etc.). I have found that, among the people I have known who have

vision disabilities and also those with other kinds of disabilities, some persons struggle profoundly with the social and psychological problems related to their disability – sometimes to the point of chronic depression. I wonder – would depression be the response of these individuals to life’s other kinds of challenges, even if they didn’t have a disability? From my own experience in knowing disabled people, I would venture to say that, in general, persons with disabilities actually tend to develop stronger coping mechanisms than the non-disabled do.”

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“Our son, age 12, is a Black Belt in the United Fighting Arts Federation and in American Martial Arts. This has done wonders for him. When he tested for his black belt and wrote his essay on ‘Why I want to be a Black Belt,’ he explained that, as a young child, he thought he was not as good as everyone else because of his vision disability and that, through the martial arts, he has proved that he can do anything he wants to and that he is as good as everyone else, though his eyes don’t work the same as other people’s eyes. He believes this is his ‘gift,’ not his ‘disability.’”

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From a woman in Brazil: “Reading *Understanding and Coping with Achromatopsia* caused me to remember so much about growing up with this eye condition – so many things I thought and felt but never told to anyone. I am lucky to have a sister with the same eye condition. We have always shared our feelings with each other, and sometimes this has meant sharing our sadness. We had many psychological problems during childhood and adolescence because of our vision. We had to go to therapists. School was difficult, but we did our best. But socially – and especially in relationships with boyfriends – we suffered a lot. Now we accept and are proud to be who we are. Our family and friends admire us. We have good jobs and are independent. Our parents were great with us. They were not overly protective, and I think that’s why we became so independent. I can tell you truthfully that I am proud to be an achromat. Does this seem strange? Maybe. But this is how I feel. I feel that I am a winner in my life and before God. I also feel that I have a mission – to help other people with impaired vision.”

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From a woman in her 20’s: “Kids can be so mean! In my memories I can still hear the voices of boys and girls calling me ‘cross-eyed’ and ‘squinty.’ Unfortunately, it got even worse in junior high. (Face it; everything gets worse in junior high!) Back then a group of boys told me that I blinked in Morse code, and they followed me around, calling me ‘Morse code’ and making beeping sounds. But, by the time I was in high school, the teasing had mostly stopped. I put up with the occasional ‘Are you a movie star?’ (referring to my dark glasses). When I started answering, ‘Yes,’ that seemed to stop as well. But in high school I found my fellow students to be more inclined toward being helpful and interested in me than inclined toward teasing me. As an adult, I have never been teased. Occasionally someone will see me reading and will ask if I’ve forgotten my glasses. A clerk once thought that I was blind and asked if I wanted my dollar bills folded any particular way, but that’s no big deal. I would like to reassure the children in the network that the teasing does go away as your peers grow up. Those comments hurt, but don’t let them tear you down and make you feel as if you are defective. How we feel about ourselves affects what we project to others. Let those around you see the beautiful, strong, and capable person that God has created you to be, and that will shine brighter than any of your limitations.”

From a man with achromatopsia in his 40's: "I am not sure that depression is necessarily in the future for young people with achromatopsia. There is, however, a lot of grief that can result from 'not being able.' Not being able to compete for certain jobs, not being able to recognize people at a distance, etc. Beginning in my teens, I tried not to appear visually impaired. Unfortunately, this has at times led to misunderstandings about what my limitations really are. Some people seem to feel that I do not appear to be 'needy' enough to be worthy of special accommodations. What has helped me cope has been the network – i.e., being able to compare and share experiences with other people who are most similar to myself."

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From a mom: "Coping with the limited vision and the need for various adaptations are the easy parts of dealing with achromatopsia. What has been much harder to deal with is the way our son has been treated by other kids, from an early age, for being 'different.' Teasing has been and continues to be the most difficult and painful part of this treatment. It has been especially rough during his junior high school years. Fortunately, his 8th grade counselor directed him to a special class in communication skills. The students in this class learned various social skills through a step-by-step process. They worked through units with titles like 'Starting a Friendship' (what is a true friend?), 'Dealing with Teasing and Joking' (what is the difference between friendly teasing and mean teasing?), 'Handling Peer Pressure,' 'Coping with Bullies,' 'Anger Reduction,' etc. The class was not a cure-all, but it helped him to be more in charge of his feelings, improved his self-image, and helped him to define himself by his many abilities instead of by his vision disability. My son is one terrific, positive kid – and he has a great sense of humor too! What a lucky parent I am!"

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"Our daughter, age 16, is having to deal with the issue of not being able to drive a car. Fortunately, she is weathering the storm. Our son, age 13, also has achromatopsia. Being 'different' is hard on anyone, but there are so many 'macho' activities that are out of reach for boys with this vision impairment."

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From a woman in her 50's: "I was very shy as a child and had a hard time establishing friendships. During recess and after school I could not participate in the physically active outdoor games and sports that the other kids were doing. This greatly affected my chances to get to know – and be known by – my classmates. So, for the most part, I was a 'loner,' and the few friendships I did form were with kids who were also 'loners' or who just were not athletically inclined."

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From the mother of two girls with achromatopsia: "It is interesting to observe our two daughters with this vision disorder. They have very different temperaments and personalities. It would have been so easy for me to attribute certain characteristics – for example, shyness in one of my daughters – to the fact that she has achromatopsia, if we had not had the chance to see the very opposite in her sister."

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From a man in his 40's: "When I first went away to college, I became so bewildered by the lack of emotional support such as I had always had in school and at home and which I had always taken for granted – support that had been supplied by teachers and my parents in their concern for me. In the new and relatively 'cold' realities of the college groups, I didn't get that same kind of support. I was a

‘loner’ in college and I sort of ‘floundered’ socially, experiencing a lot of loneliness and lack of full engagement with school activities. I don’t want to overdramatize the impact of my visual impairment on my college experience, but neither do I want to present it as being trivial. I suspect that there are other vision impaired persons who, like myself, did all right in a sheltered school environment but then afterward found that they had to face a whole different set of realities.”

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From a woman in her 70’s: “I can remember that, as a young person, I felt so disfigured in the daytime, especially in front of the boys, and I couldn’t even talk about it with anyone without feeling humiliated. I was an emotional mess.”

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“I am my own worst critic. I am especially hard on myself, and I think this trait somehow has to do with having this vision disorder.”

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“Concerns about mobility have prevented me from doing lots of things I was capable of doing but not brave enough to do – or didn’t want to expend the extra energy for. I wonder if other achromats tend to be relatively reclusive – even those who are by nature very sociable, like myself. This can happen because of the photophobia and because getting around is challenging and sometimes scary.”

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I have always preferred to be inconspicuous in public, but having to wear dark glasses outdoors in the daytime year-round and indoors when the lighting is bright has made it difficult for me to be inconspicuous. I’ve had to either ignore or else respond to a variety of remarks from people. ‘Hey – a movie star!’ is a common remark. More annoying ones are, ‘The sun’s not out! You don’t need those on!’ and ‘Why don’t you take those off, so you can see where you’re going?’ I have been perceived as being anti-social (‘Why are you hiding behind those sunglasses?’), trying to look ‘cool,’ being ‘a suspicious looking character,’ attempting to travel incognito, or hiding bloodshot eyes due to a hangover (or worse, being on drugs). Sometimes strangers have assumed I was blind because of the dark glasses and have been patronizing toward me or have attempted to guide me or help me in some other way.”

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From the mother of 2 children with achromatopsia: “There are times when it is very hard to witness the problems our children have to deal with because of their vision. For me, sadness and tears surface again and again. While their courage amazes us, their moments of anguish are hard for us to bear. What helps most is being able to say these very things – often and to empathic listeners, who can validate such feelings and experiences (the network). I would urge achromats in the network to write even more about the ‘feelings’ part of this vision disability.”

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From a woman in her 40’s: “I’m concerned whenever I jog in our neighborhood that the neighbors will think I’m ‘stuck up,’ because, when cars drive past, I can’t tell if they’re neighbors or just people driving by – and, of course, I can’t tell if anyone is waving to me. So I just ignore the cars. Today I didn’t see a man getting his newspaper until I was almost past him. I should have just waved, but I’ve always had trouble with doing that. There’s so much ‘mental gymnastics’ involved in making the decision ‘to wave or not to wave’ that, by the time I notice a person, I don’t have the time it takes to talk myself into waving. Pretty pitiful, I know, but there have been times when I’ve found myself giving a friendly nod to trash cans.”

Relationships – Dating and Mating

From a man in his 40's: "When I meet women that I might want to date, I am conscious of the ongoing struggles and concerns I have about my vision. I don't know if I want to subject them to these struggles, so I tend to be reticent. I don't think that the best way to deal with this is just to tell them about my vision when I first meet them. This is partly because I don't think most people would know what to make of it. How could they possibly know whether my being visually impaired would or would not affect them? Giving them a 'warning,' so to speak, by telling them all about my vision right off the bat might scare them off. Or they might think, 'This guy is obviously worried about it, so I should be worried about it too.' Yet, if I don't talk about it early on – during the period when I'm trying to get to know someone well enough before the subject of my vision has to come up – then this leads to certain 'camouflages.' For example, recently I went out with someone new. I was wearing tinted contacts and probably appeared to be just fine, but at the restaurant, I found I couldn't read the menu without putting on reading glasses and holding the menu close. I was too self-conscious to do this, so I just ordered something I knew the restaurant served. Sometimes I just ask, 'What's the most popular thing at this restaurant?' Besides the reading problem, the disclosure that I don't drive could scare someone away. I want first to be seen as a worthwhile person with something to give before a physical liability is mentioned. But this creates stress in me, and I know it's only a matter of time before everything will come out. I am willing for this to happen ultimately, but I want to 'cushion' it. If I describe everything right away, I feel that I will be avoided. I don't want to be like so many people I've met who, within minutes after meeting you, disclose all about their problems. I don't want to hear about other people's problems right away. I'd like to feel a little charm about the person I am getting to know and I'd like to feel a level of friendship and interest before dealing with such subjects."

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And from another networker: "Regarding dating and mating: let's not pretend that this isn't a real challenge for anyone with a disability. Not only are there the problems of not being able to drive, recognize faces across a room, or read a menu without looking as if you're trying to sniff the food descriptions – there's also the fact that we all want to be recognized (liked, even loved) for our personality, intellect, looks, without our disability distorting the picture which our potential friends or partners see. It does help if we can get to know people without the disability having to 'intrude' into the relationship too quickly. We've heard from many people in the network regarding their coping mechanisms (and avoidance mechanisms) for accomplishing that. However, sooner or later, the problems of our unique condition come up. It's best to deal with them openly, honestly, and in as matter-of-fact a way as possible. Anyone who balks at the idea of continuing a relationship with you because they find out you can't do certain things as well as normally sighted persons – well, hey, maybe you don't need a relationship with someone like that. I haven't had a huge number of relationships over the years, but I can say that no one ever rejected me or even 'slowed down' because they found out I had only partial vision. I have found that most people are open, interested, and caring, especially if they already know and like you as a person, and their views are not clouded about your condition. I met my wife at work. We started out

as colleagues and friends with common interests. Even though back then I was nowhere near as open about my eye condition as I am now, she learned early on about it. My handicap was never an issue for her. She wanted to understand it and to try to help where appropriate. When we started thinking about marriage, we talked openly about the problems we might face due to my limitations. I was much more concerned than she was. I was worried about supporting a wife and children while encumbered with (as I saw it then) numerous practical challenges that ranged from the mundane to the ridiculous, from the inconvenient to the life threatening (e.g., ‘I can’t drive you to the maternity hospital; you might have to give birth in the living room.’ With the first baby, we took a taxi and, with the second one, an ambulance. It was close, but we made it!) Other worries included ‘What if I can’t tell that the baby’s skin is turning a funny color’ and ‘What if I can’t tell that the hamburger meat is cooked all the way through and we all die of food poisoning?’ What if, what if? But, in 15 years of marriage, it’s never been a point of difficulty between us. Sure, it’s inconvenient that I can’t pick the kids up from school without having to hike half an hour from work and then march them home, another half hour. And, no doubt, my wife gets tired of telling me which tie to wear with which shirt. But love and mutual respect hold it all together. In any relationship there are differences in abilities, skills, attitudes, and preferences. In our home, for example, I’m the more enthusiastic and experienced cook. It may not totally compensate for my not driving, but it does take a load off my spouse. You learn to compensate for differences like that – or just enjoy the variety of the mix. You look for balance. You cope: ‘for richer or poorer, in sickness and in health.’ Love is about mutual support and making up for differences in ability. Love is more important than being able to drive a car or distinguish red from brown or even making sure a hamburger is cooked properly.”

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And from another networker: “Having achromatopsia has had an impact on me in all of my identities – being male, being a professional, being a dad, being a husband. We achromats have a unique life experience – one in which we rarely feel understood and rarely are understood by others. We are more likely to be on our own to work out whatever accommodations we need. I think that not being able to drive is more difficult for a man when it comes to relationships. I think that one way for a man to offset this limitation is to be more attentive to a woman’s need to be understood and nurtured (being understanding and nurturing has been more typically the role of women in relationships). My suggestion to others is to ascertain early in a relationship what value someone places on whether or not you can drive. Not on the first date, mind you – maybe not even on the second. One must use judgement, but this problem has to be dealt with.”

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From a woman in her 30’s: “Regarding reluctance to talk about one’s vision impairment early in a relationship: It has taken time for me to work through my own self-rejection, and it’s a process that can’t be rushed. To purposefully hide the facts about our vision from others to the point where we are inconvenienced is like lying to ourselves. However, I realize that, since I married at a very young age, I haven’t been through what many other networkers have been through in the search for companionship. However, I can recall with acute discomfort the self-consciousness and fear of rejection which I had back when I was dating.”

Only one achromat in our network has reported having married someone who was also visually impaired. The following is from a woman in her 40's: "My husband has retinitis pigmentosa and I have achromatopsia, so we are total opposites in terms of vision. We laugh about it and tell people that he goes around turning lights on and I go around turning them off." *(Editor's note: Unlike achromats, persons with retinitis pigmentosa have good central visual acuity but poor peripheral vision. Also unlike achromats, they see better in bright light and worse in dim light. In these ways RP indeed can be thought of as the opposite of achromatopsia.)*

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"The first impression my husband ever had of me was that I was 'stoned.' We both sang in the choir, and the choir room was brightly lit. He decided that he wanted to get to know me, because he couldn't believe that someone who went to the same church he did would take drugs. We cleared that matter up in short order when he found out that my 'look' had to do with my eye condition."

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From a networker in her 30's: "My husband and I were fine until we started our family. Being the only driver is sometimes exhausting for him. My heart goes out to him, and I try to minimize my own needs for him to drive me places. But he is always willing. He actually prefers doing the grocery shopping himself. He accepts me for who I am and treats me as he would treat anyone else. If I miss a pile of dust while vacuuming, he isn't hesitant to point it out. He's mildly annoyed when I mismatch his socks. (Some say I should just have him do that, but he's usually driving the kids somewhere when I'm dealing with the laundry.) He sometimes is impatient with my colorblindness, but this is because he happens to be very color-oriented. When he goes on business trips, he (very wisely) does his own packing. But he's a white knight when we're out in an unfamiliar setting, making sure I get a chair that doesn't face a window, seeing to it that lighting is low enough for me, seeing that I get a seat in the front row, etc. And he, more than anyone else, has seen the funny side of my vision problems and has really helped me to loosen up and laugh about some of these things. All in all, he really 'shares' my achromatopsia and all of its related concerns."

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From a woman with achromatopsia: "As an unmarried person, I'd like to say that, when you have this vision disorder which prevents you from seeing people very far away, you don't really have the selection that other people have in terms of exploring new relationships. Usually the people you do get to know are the ones who have seen you and who take the initiative to contact you, but these people may not necessarily be the ones that you yourself would like to get to know."

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From a man with achromatopsia: "I suspect that sexual selection and mating (as a biological function) really are affected by being visually impaired. What would ordinarily be aggressiveness in sexual selection must surely become 'muted' because of our vision impairment. There have been times when I've said to myself, 'Well, other guys will get the cherries. You'll have to settle for what's left – the ones that you are able to catch.' Sometimes I've thought that dating through newspaper ads, the Internet, or dating services could be a way around this problem. But, in my experience, there is a high concentration of people who use these services who have other kinds of impairments, some of which are much more significant socially than my vision impairment. I think vision impaired guys

have to be maximally creative to get the most out of the sexual selection game, because obviously the usual ways don't work as well for us. I'm referring to the primary mechanism used by many young males, which goes something like this: 'You look at her, and if you like her, then grab her – and, if she likes you, then that's it!' Well, that doesn't work so well for vision impaired guys. Of course, individual personality plays a role in all this too, so there may well be some vision impaired males who are very aggressive and who can just go after the person they want. But that hasn't been my experience, or else I would have been married by now."

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From a woman with achromatopsia: "To the guy commenting about how sexual selection is affected by having achromatopsia, I would like to say that all women are 'cherries.' Some 'cherries' are juicier than others, and some have bigger pits, but you won't know until you have gently picked one. Single adults need safe places to go to meet other single adults. I suggest finding a church or a civic group, community theater, choir, charity or volunteer group, political action committee, or health club. Also, I feel that getting counseling is an excellent idea for dealing with the kinds of problems we face."

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From a man in his 40's: "Several years ago I had an emotionally traumatizing experience with a normally sighted woman who, after a year and a half of going out with me, firmly rejected me. She did not want to consider marriage with me, and she said this was because she had finally realized that the burden of my vision impairment was too much for her. She told me she had not realized at the beginning of our relationship that my eyesight was as bad as it is. She said she was simply terrified of the possibility that we might have children who would not be normally sighted and also afraid of the possibility that I might one day become blind. Such fears are, of course, not rational in light of the facts regarding my eye condition, but no amount of reassuring genetic counseling could allay her fears. This was a very difficult experience for me to endure. But it was an important turning point for me. I managed to give up my 'pride' and admitted to myself that some psychological support could help me find my way. I began seeing a good professional counselor who specializes in Transactional Analysis. This is proving to be a very positive experience and is supporting me in making very gradual but essential changes. Finding the Achromatopsia Network was another turning point in my life. I now know people who can understand life as I have experienced it."

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From a woman in her 20's: "I am so blessed. My husband is willing to be my chauffeur and sometimes a color coordinator. He describes sunsets to me, naming every color he sees. (I have no idea what orange or red actually look like, but it's the thought that counts.) Occasionally he forgets I have a vision problem and asks me if his shirt and pants look right together, or he will silently 'mouth' something to me from across a room, expecting me to read his lips. I laugh when these things happen, and I feel pleased that he is not always thinking of me in terms of my vision impairment. I do sense frustration in him when we are shopping for clothes and I am continually asking him questions like, 'Is this a pretty shade of green or a nasty shade?' I insist on having things match perfectly, which nearly drives him crazy. I take some of the transportation pressures off him by arranging for rides with friends, family, and people who are going to the same place I'm going. Our 6-year old son is always eager to help me with colors."

From another networker: “Regarding relationships: My husband has become the quiet narrating voice in my ear, helping me with everything from bright, hard-to-see scenes in movies to the identities of faces in a crowded room. He takes all these things in stride. He knows almost better than I do what situations I’m likely to have trouble with. I want to encourage others in the network by saying that, yes, there really are empathetic spirits out there. I told my husband almost from the beginning of our relationship that I had problems due to my vision, but I didn’t dwell on the problems. I have always wanted people to first get to know my personality; and then, as some aspect of my vision impairment would become obvious or significant, I would explain it at the time. I think that this way people become adjusted more gradually – and, if you’ve already hit it off together as ‘just plain people’ and you both want to continue the relationship, allowances will be made. I have found that the people who can’t adjust are usually not the kind of friends I would want anyway. The ‘lightweights’ have dropped away, but I have discovered that I don’t miss these people. The good friends are still here.”

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From a man with achromatopsia who is single: “I have not succeeded yet in finding a special person to share my life with. I want such a relationship very much, and I would prefer for it to happen naturally, yet I also feel that I should be open-minded about using the services that are available these days for meeting other singles. So I tried using an agency set up for this purpose. Of course, I had to decide whether to tell them about my vision condition. I did so and gave a careful explanation about what achromatopsia is and about what limitations it does and does not impose. My hope was that I would be helped to meet someone to whom my other qualities would matter more than my vision impairment. But now, six months later, the results have been disappointing. When I inquired, I learned that my not being able to drive a car constituted a significant barrier with the women who make use of these services. ‘Disclosure’ is turning out to be more of a critical issue than I had imagined. I agree with the networker who commented in a recent newsletter: ‘I want other people, first of all, to see who I am as a person before learning about my vision problems.’ However, I fear that I might go deeply into a relationship, keeping the facts about my vision in the background, only to postpone the time when I will be rejected. I think that the wisest approach lies somewhere between completely deceiving people and having to thoroughly ‘outline’ this eye condition for them. There are probably no ‘rules’ that can be defined in terms of this issue. I suspect it’s something we must discover in the context of personal experience with the individuals who enter our lives.”

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From a woman with achromatopsia: “I would like to say this to guys in the network who have run into some barriers to developing relationships with women because of their inability to drive: Being a woman, I was not expected to pick up my date during the years I was dating. However, I know that this can be a problem for male achromats, (in spite of ‘women’s lib’). If I were in your position, I would move to New York, where mass transit is so extensive that many New Yorkers do not even know how to drive. The freedom you would have in this setting could overshadow any hesitations you may have regarding the move, a new job, or city life. I lived in the Chicago area for a few years and enjoyed the transportation system there, but I believe New York’s transportation system is even better. This

particular barrier to dating would disappear. There is also the added benefit of all those tall buildings blocking the sun. This may seem like a radical solution, but it could be a real adventure for you and is worth considering.”

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From a woman with achromatopsia: “When I was in high school, I did not get asked out for dates. Just about everybody in school knew about my vision impairment. After I graduated, my family moved to a nearby city, where I soon became active in the young adults department of a large church. There were many evening activities at this church and also lots of dating among these young adults in the evenings when nothing was going on at the church. I found myself drawn into a very enjoyable lifestyle in which I was going out night after night and could actually choose whether or not to disclose my vision disability. I became very popular with the guys at the church. Going out on dates at night and being with people in indoor places for social and religious activities placed very few demands on my vision. For the most part, I chose to ‘pass’ as normally sighted during that period of my life, and I relished the kind of attention and status that I had not received in my ‘previous life.’ ‘Passing’ as normally sighted resulted in a certain amount of tension and insecurity, so I am not really recommending it to others. But I have to admit that I had a lot of fun during that period. It was great to be able to experience a social identity that focused on my attributes and which was without the stigma of being ‘disabled.’”

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From a single man with achromatopsia: “Meeting someone special is something I haven’t given up on. But, after quite a few negative experiences, I have decided that I will no longer actively ‘look for’ a woman to have a relationship with. Instead, I have decided to follow my interests and my instincts. I will go to new places and do the things that I like to do. If ever a meeting is to happen, it can happen while I am active doing things I am interested in doing. For example, I have recently bought a trekking bicycle and have joined a group of bike-trekking enthusiasts who travel together on weekends in rural areas, along rivers and over hills. I need fresh air and I find that riding a bike in the midst of a group is pleasant. And there is very little risk involved.”

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From a woman with achromatopsia in her 40’s: “In a recent newsletter a guy asked about how to meet Ms. Right. In terms of developing relationships, my advice is to wait to disclose all about your vision impairment until someone has had a chance to get to know you. However, you should be honest and open from the beginning about disclosing your personality. People may not be able to anticipate what meaning someone’s vision impairment may have in their lives, but they can easily understand what various personal characteristics mean to them. Honest disclosure of personality characteristics can save a lot of time. If you are arranging a meeting by phone (as with dating services), you can arrange to meet on the inside of a building, rather than outdoors, or to meet somewhere in the evening. I prefer to slip in the subject of my vision conversationally, rather than to stop everything and focus on the subject of vision impairment, colors, driving, etc. These subjects usually come up pretty soon. For example, ‘Sorry I can’t offer you a ride home – I don’t drive.’ You can get quite a lot out of how a person responds to that. Does the person seem to want to know why I don’t drive? If so, then that’s when I make an effort to tell about this in an objective way (which I still find

difficult to do). If they ask what this is like for me, I find that to be an encouraging sign and I explain. Often people will notice that there is something wrong with my eyes and ask about it before I have a chance to work up to it. But I think that disclosing one's vision problems is not a good idea before actually meeting someone. It can sound as if you are someone who is asking for help, rather than seeking a partner. It can even seem as if you might have a whole string of special needs. We achromats know that we do have some special needs, but we tend to forget that many normally sighted people also have unusual foibles and their own kinds of special needs. If you and the other person don't turn out to be compatible, then you shouldn't have to trouble yourself with telling about anything that may be uncomfortable to you, whether with regard to your vision or anything else. I know three happy couples who met through agencies. I also know people who have been on dates arranged through such agencies which have been disastrous. Another bit of advice I would like to give is that it really is better to have loved and lost than never to have loved at all – although losing can be very hard. You should give people a chance to gradually get to know you and your eyesight at the same time, neither trying to completely hide it nor telling all about the eyesight problem before having the chance to be known for your other attributes. Not everyone will be put off. You, however, may be put off by other people. While things are harder for us, don't forget that there are plenty of people who are much more severely disabled who nevertheless meet and marry wonderful partners. Remember also that there are many lovely people with no particular physical flaws who go through life alone. And, finally, try not to judge yourself on the basis of whether or not you are part of a couple."

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From another woman with achromatopsia: "I believe that disclosure has to be on our terms. Sometimes we feel like talking about it, and sometimes we don't. However, if we want others to respect us by waiting until we are ready to disclose the facts about our vision, then we should respect them by being honest about it early on in a developing relationship rather than much later. I would say that, if you like someone well enough to regularly spend time over an expensive meal, then that person deserves to know about this rare and fascinating aspect of your persona. I once met a lady with retinitis pigmentosa who told me how she used to deal with her 'night blindness.' If she was with friends in a dark restaurant and she had to go to the restroom, she would pretend that she was drunk, so that the groping she had to do in order to make her way to the restroom could be explained. She would rather have been perceived as drunk than vision impaired!"

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From a man with achromatopsia: "My wife and I have always had full time positions. Since she does the driving, we have organized the chores so that I clean house while she does the shopping. It has taken years for us to work out arrangements that feel comfortable. I do the house cleaning now, not because I want to but because it is better for us as a couple. It offers a way for me to offset the accommodations she has to make for my inability to drive, etc. She really appreciates the cleaning I do. It seems that one sure way to make a woman happy is to have the house clean for her. Something important that our children get to learn as a result of this arrangement is that roles can be assigned according to what is in the interest of a committed marriage."

“My husband’s hobby is astrophotography (taking pictures of the night sky), and my favorite thing is being out on a night when there’s a full moon. We’re planning a trip this summer to the mountains of Colorado, where we can get a look at what my husband calls a ‘real’ night sky. Also we are looking forward to going on some sunset trail rides together.”

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From a woman with achromatopsia who recently got married: “I want to understand what my husband is experiencing in connection with my vision disorder. He has told me that, once in a while, he finds it hard to be the only driver in our family. He said he wishes I could come and visit him at work sometimes or pick up something at the store for him. He told me this in a very gentle manner so as not to hurt my feelings. I felt that this opened a door for communication for us. After we talked about it awhile, I think we both felt much better.”

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From a married man with achromatopsia: “This message is intended to encourage the guys in the network who are looking for love. Partial vision and the limitations that go along with it can be painful, especially when it comes to dating. There really isn’t any way to get around this issue, unfortunately. Most people meet their soulmates in the places they inhabit in their everyday lives: school, workplace, church, neighborhood, places where people with mutual interests encounter one another. My advice to them would be to (1) try and be at ease with your visual limitation and (2) be yourself. Initially a woman may be attracted to appearances, but in the end she will love you for who you are as a person. I have been married for quite a few years now, but I remember that, back when I was looking for a mate, I found that it did not take women very long to decide whether the vision thing was an issue or not. But, even in those cases when it turned out that my vision was not perceived as a big issue, there were other things about me as an individual that the woman either did or did not accept.”

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From a man with achromatopsia in his late 20’s: “I moved to the city where I live now over 2 years ago to do my graduate studies. The worst part about living here is that I can’t drive and public transportation is extremely limited. This entire region was planned on the assumption that the car is the primary means of getting around. Some streets don’t even have sidewalks. For this reason and because of the peculiar demographics of the campus, my department at the university, and the surrounding city, I have found it impossible to find romantic relationships. In desperation I have begun to study with one of the leading experts on the subject of how men can attract women. Many of his teachings are fairly easy to implement: get in shape, get a well paying job and a clean apartment, project a sense of self-confidence, get a nice hairstyle and contact lenses, and become involved in hobbies and community activities. But a number of his teachings are very difficult for me, as a man with achromatopsia, to follow. For instance, he emphasizes the ability to observe body language cues from a distance, the need to have a car, and the importance of having a nicely color-coordinated wardrobe. In addition, I have a nagging sense of inferiority connected with my feeling that I always have to cover up my disability or else face rejection from women. When you cannot recognize with certainty the lady you are interested in unless she is just a few feet away (‘I waved to you yesterday near the student center, but you walked right by’), this immediately projects the image of a guy who has something odd about

him. Life would be so much more fulfilling with companionship. I am seriously considering dropping out of my PhD program here and getting a job in Boston, a city that has a decent public transit system and where I understand there are more accepting womenfolk.”

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From another man with achromatopsia: “If it were easy for me to make visual contact with women, I would probably break up with my current girlfriend and seek someone new. She is lovely but self-centered and often inconsiderate. However, it is nicer to have her in my life than not having a girlfriend. I think that what would be required to goad me into action toward finding someone new is just too difficult. This causes me to place more value on the relationship I have with this person, even with its problems.”

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From a woman with achromatopsia in her 20’s: “Every boyfriend I’ve had reacted differently to my vision. For the most part, it hasn’t been a big problem, except in getting past the initial awkward stage of the relationship. One was aware of my vision from the beginning, so there wasn’t the tension of having to pick the right time and place to talk about it. One potential mother-in-law wanted the details of the genetics of my vision disorder – something that my boyfriend at the time had not even thought about. Once I was dating a guy with the kind of ‘colorblindness’ fairly common among men, and my family would joke about the color schemes we would have in our home if we were to marry.”

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From a man in his 40’s: “Recently I signed up for a Club Med vacation for singles. I hired a wardrobe consultant to help me select some resort outfits that would be color coordinated and help me feel good about my appearance. Indeed, while I was at Club Med, I was approached by several ladies at various times who wanted to get to know me, and I think the clothes helped. In group discussions and activities (which all took place outdoors), I tended to hang back, not feeling able to be as animated as the others, because my limited vision kept me from perceiving all the facial nuances, etc. While my sunglasses kept me from being truly blinded by the light, I did feel as though I was relating to everyone across some sort of indescribable gap. Interestingly, a very attractive lady in the group perceived this as ‘diffidence’ on my part, and she began making efforts to get to know me. She told me she liked men who did not make a big fuss over her and was annoyed by men who fawned over her. I didn’t mind that, to her, my hanging back had appeared to be a quality she preferred in a man. I was careful not to make a fuss over her good looks and other attributes, and our friendship grew.”

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“I didn’t get married until I was 34 years old. My husband and I met through a mutual friend. I hadn’t intended to start talking about my vision on our first date, but we happened to go to a botanical garden for this occasion, and there were some very sunny areas and steeply sloping paths, so the subject inevitably came up. We entered into a warm and fulfilling relationship right away because of having many mutual interests and because of the wonderful mystery of falling in love (some call it ‘chemistry’). We have been together 28 years, and my vision impairment has not been an obstacle in our marriage as I had feared it would be back when I was growing up. My husband has always been wonderfully accepting, understanding, and helpful – more than I could ever have dreamed possible.”

Parenting with Achromatopsia

From a man in his 40's: "As for the ways achromatopsia can affect parenting: In my experience, there have definitely been limitations resulting from my vision impairment. Some of these are serious, and some are not. When my wife was expecting, it was clear that she would have to drive herself to the hospital. This was not an issue for her. She managed with no difficulty. When our sons were very small, I had real concerns about supervising them whenever we would go to the beach. Whether they were in the sand or in the water, it was difficult for me to keep track of them. Watching them every second was the only way I could be sure. It was not as hard for me to 'track' them in the snow. Another problem was (and still is) trying to find them when they are not in our yard. When they are beyond those boundaries, it is hard to distinguish them from other children. My effort to take pleasure in their skating lessons or soccer practice presents a similar but less serious problem. I have difficulty tracking their movement on field or ice. Using telescopic lenses has helped. I am glad they can participate in activities I could not participate in when I was growing up. There is, for me, a vicarious excitement about their participation in this sport. They tend to forget that I can't see very far. They are more apt to be mindful of my colorblindness."

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From a woman with achromatopsia: "My teenage son is competing in gymnastics, and I hope he keeps it up, because he has the potential to go far. But, if he should decide that it's not worth the long hours of weekly practice, I hope I can let him make his decision without interfering. I am conscious of feeling that there's so much riding on him, because he's doing stuff I always wanted to do when I was a kid. I was very active physically and wished with all my heart that I could run after a football or catch a baseball."

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From a man in his 40's: "The fact that I don't drive has always been a problem for our family. We have not been able to participate in as many activities as families in which both parents are drivers. However, we have recently moved to a small town, where I can now bike anywhere with my sons. So I have been able to spend more time going places with them without my wife having to be present, and we have been able to relate in special ways."

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From a woman with achromatopsia in Canada: "Today I accompanied my daughter and her classmate on a field trip to a snow park. There were crowds of people there, and I guess I had no business thinking I could actually keep track of two 5-year olds under those sun-on-snow conditions. But my daughter longs for me to do these things with her, and I don't want her to think that my vision makes me a 'party pooper.' So I told the two girls, 'You must hold my hand when we're walking around. If you see an activity you want to participate in, tell me and we'll go there together.' When it was time for us to go back to our bus, I asked them to find someone from their class for us to follow. I knew that, on my own, I'd never find where the bus was parked, but they were quite capable of finding some familiar faces in that crowd. Amazing what 20/20 vision can do!"

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"My four children have all been very accepting of my poor vision. They are capable of helping me read a recipe, match socks, help keep track of a younger sibling, or get a younger sibling dressed in clothes that match."

“One of my daughters has begun to take a special interest in people who are disadvantaged or disabled. For instance, she was very eager to study the unit they did in school on Helen Keller. I wonder if she has this kind of interest because of me and my vision impairment. Once in a while it hits me that my children do not really understand about my vision. Even when I don’t feel like talking about it with them, there are times when I have to, because I want them to understand as much as they can and to be assured that I’m not embarrassed to talk about it (even though, admittedly, sometimes I am). But I don’t want them to pity me or see me as feeling sorry for myself.”

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“Some of my worst mobility nightmares are picnics and playgrounds. But these are among a kid’s best loved activities, so how can I, as a mother, avoid picnics and playgrounds? Today a friend and I took our family out for a picnic in a park full of kids. My youngest child wore her Mickey Mouse T-shirt, which is black. I discovered that this makes it easier for me to keep track of her. It’s easier for me to see dark colors in daylight. Another good idea for keeping track of toddlers – which I didn’t think of until my kids were older – is to hang a little bell around their wrist or on their shoelaces or pin it to the back of their shirt (but never tie anything around a toddler’s neck). It can be reassuring to hear the bell tinkle and know that your child is somewhere nearby, even if you can’t see exactly where.”

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“Recently, just ‘out of the blue,’ my daughter asked if all my vision problems are related to . . . ‘What is the name of that condition you have, Mom?’ She listed my problems accurately – can’t see far, can’t see colors, sensitive to light. She had spent the day with a friend, and I suspect that her friend had asked about my vision, because my kids themselves don’t seem to give it a second thought. She also wanted to know if her kids would have it, and I told her that it’s so rare that her chances of marrying another carrier are next to nothing. I think it’s neat that she can openly come out and discuss her concerns with me; I didn’t have such freedom when I was growing up. My mom didn’t like to talk about it. I was led to believe, by nearly everyone around me, that it was better to pretend that I was ‘normal.’ My eye problem didn’t even have a name other than ‘colorblind,’ until I went off to college and read the evaluation my doctor had given me to take along. My kids don’t think of me as being abnormal or stigmatized, and they’re not embarrassed to talk about my vision impairment with their friends. My son, age 15, is the only one who is shy about discussing it, but there’s no indication that he’s troubled about it. And I know that he’s looking forward to being our family’s second driver.”

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From a woman with achromatopsia: “I know there are some network parents who are home schooling children with achromatopsia, but have any achromats in the network home schooled their own children? I’ve tried being ‘teacher’ to my children and found it frustrating. Whenever they would have a question about their homework, I would have to get close to their work or their reading material, and they seemed to hate having my head practically in their faces. There was no way that both I and the child could look at the same book or piece of paper at the same time. And comfortable lighting for them is too bright for me. Also, there are problems (for me) like tiny answer codes in math books and color-coded maps in geography. And I’d really like to find someone who’s managed to home school

without being able to drive a car. You just cannot expect your kids to be cooped up in the house with you all day; but, where I live, winters are severe and taking walks is not always feasible. Field trips are an important part of the curriculum when you're home schooling, but you've got to be able to go places with your kids, and using public transit can be expensive and time consuming. Walks can be great times of discovery for home schooled kids. They observe nature and talk about the flora and fauna with Mom. But my kids have so often had to teach me about these things, because I couldn't see the insects, worms, or little purple flowers they would point to. Our kids attend private school now. Often people we know will comment on how much cheaper it would be if I home schooled them instead. But I believe my children deserve (or require) more than I am able to give them. Having to face my limitations makes me angry, but I am realizing that it's important for me to give myself permission not to have to be Superwoman."

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"I have a 6-year old daughter and am expecting another baby. My daughter is becoming more aware of my visual limitations and is sensitive to my needs. When she was a toddler, I had tremendous fears that she would wander off and I wouldn't be able to find her. We had a fenced back yard then, so the back yard wasn't a problem. But in the front yard, which wasn't fenced, I would never let her play unattended. Where we live now, there is a larger yard that is unfenced. When our new baby gets to be a toddler, I plan to buy inexpensive little bells that can be attached to shoelaces to help me keep track of her movements outdoors. Of course, I'll be in the yard too, but I think the bells will help. Little kids think bells are neat. I think they should be on a child's shoes and definitely not on a cord hung around the child's neck, as that could be dangerous. Also, I keep a pair of lightweight binoculars handy. They have made it easier for me to keep an eye on my daughter at stores and playgrounds, as well as in our yard."

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And from another networker: "When my son (now a healthy and well developed adult) was growing up, I had many fears about his safety, especially in connection with my visual limitations in bright outdoor spaces, such as playgrounds and parks. Fortunately, my husband, being self-employed, could adapt his schedule so that he could regularly take our son (and sometimes our son's friends too) on outings. Also, a friend of mine worked as a day care provider, and we had an arrangement in which my son participated in outdoor activities for kids that she supervised, and I provided day care at certain times of the week for her daughter in our home for activities indoors or in our small fenced back yard. Whenever I took my son to a playground, he would do something quite remarkable. He would call out to me from time to time to tell me what he was up to – e.g., 'Mom, I'm at the top of the slide' or 'Now I'm going over to the swings.' I never asked him to give me a running account of his movements, but I think he sensed that I would feel better if he called out frequent reports to me. When he was little, I made sure that he wore dark clothing whenever I had to keep track of him outdoors. When it came time for him to go to pre-school, I selected one with a well equipped and spacious playground, because I was very concerned (maybe overly so) that he should get lots of play time outdoors. I wanted to be sure that my vision problems would not restrict him in any significant way. Back when I decided to have a child, I could not know in advance all the coping strategies I would need as my son was growing up. But I can look back now and say that all the ideas, insights, and

coping techniques that got me through the difficult times seemed to emerge as I needed them. My husband was a wonderful helper during all those years. He did so many of the things that were hard for me to do – everything from clipping baby fingernails to being chauffeur for our son’s social events and field trips.”

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From a woman in her 40’s: “I force myself to deal with more light than is comfortable for me at home, so that my four children do not have to stay so dark adapted and thus likely to be more sensitive to light. I don’t want to mess up their vision in any way. I have been homeschooling them for eleven years.”

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From a network mom: “Just before my daughter was to start first grade at the end of last summer, I asked her if she had any concerns about entering school. To my surprise, her question was: ‘Who will drive my children to school if my husband has to leave for work early, like Daddy does?’ That question reinforced my impression that she has already begun to develop concerns about her future with this eye condition, even at such an early age. I explained to her that she could send her children to school on a school bus. Also, she could ‘trade off’ with a neighbor who drove her own children to school. For example, she could offer help with homework, after-school snacks, or babysitting in exchange for transportation for her children to and from school. I told her that another option could be to live close to the school, within walking distance. Talking about these options seemed to relieve her concerns a bit. I try to emphasize the need to stay open-minded and creative about ways to deal with life’s challenges.”

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From a woman with achromatopsia: “Yesterday my 13-year old daughter revealed that, because of my vision, she is always nervous for me whenever I go anywhere alone. Ever since she was small, she has felt a responsibility to watch out for me. She is the only one of my four kids who has shown an inclination to be ‘nurturing.’ My 18-year old son’s girlfriend has been trying to understand about my vision and, in the process, my son is also learning about it. (He has never shown much curiosity about my vision; he just always seemed to accept it without reflection.) She asks me questions about what color I think things are, but I recognize this as a sincere effort on her part to grasp what my vision is like.”

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From a woman with achromatopsia: “I’ve discovered a company which makes a ‘Bear Bell’ for children to wear while hiking in the woods. It is meant to dissuade black bears from coming near, since they are known to be shy and will likely run from the noise. It consists of a sturdy bracelet that can be attached with velcro around a child’s wrist, and it holds a large, noisy jingle bell. My own children are too old for this, but I think this would be great for visually impaired parents who have young children to use with them when they need to keep track of them outdoors. It can be ordered from Silverfoot, Box 2090, Squamish, BC, V0N 3G0, Canada or online at <<http://www.silverfoot.com/catalogue/bearbells.html>>.”

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From a woman with achromatopsia: “My children find it hard to be left out of certain special events and peer activities because of the fact that I cannot drive them to these events. They are helpful to me in many situations, such as reading ‘walk’ signs, identifying colors, etc., but they wish I could drive, and sometimes they get angry about this. Then I end up feeling really guilty, and I begin to feel self-pity. But that does no good at all, and I know it’s not the way I want to be.”

“My kids know that I’m colorblind, but they can’t seem to stop describing things to me in terms of color. ‘Mom, have you seen my blue notebook?’ ‘Did you wash my red shirt?’ My 12-year old daughter is really into fashion and loves to describe to me in rich detail the colors of clothes she saw at the mall. I don’t want to douse her enthusiasm with cold water by saying, ‘I don’t care what color it was.’ It’s too important to her and, hey, at least she still talks to me! The other day my 6-year old daughter was wearing a pair of mismatched socks, sorted by me. Even when her older sister pointed this out to her, she would not change them. She said, ‘They match! See?’ Then she proceeded to show how each sock matched some part of the multi-colored print shirt she was wearing. Such a sensible child!”

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From a woman with rod monochromacy: “I know some people feel we should not pass on our ‘bad genes.’ Well, my husband (who is normally sighted) has lots of moles, which he has to monitor, lest they become pre-cancerous. Our daughter has inherited his ‘spotty body.’ Her chances of getting melanoma are much greater than her chances of ever seeing achromatopsia again in our family tree. Also virtually every male relative who has died on my husband’s side of the family and my side of the family died of heart disease – and we have a son. So what should I have done? I just think that, if someone with achromatopsia is inclined to take so seriously the possibility of passing on this rare gene, they should first worry about the much riskier (and more common) inherited conditions.” *(Editor’s note: See the book, Understanding and Coping with Achromatopsia, pp. 8-11, for information regarding the genetics of rod monochromacy.)*

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From a man with rod monochromacy who lives in Norway: “Although the chance of an achromat inadvertently mating with a carrier of the defective gene responsible for achromatopsia is greater than the chance of meeting another achromat, it is still an exceedingly small possibility, (one of the rare exceptions to this rule is on the tiny island of Pingelap, where about 6% of the population have achromatopsia). I do not know of any achromatopic person here in Norway who has achromatopic children or grandchildren, and Norway has a population of just over 4 million. My brother (who also has achromatopsia) has 4 children and 2 grandchildren, and I have 2 children and 4 grandchildren, all with normal vision. Many members of our network can attest to the fact that having achromatopsia is not a devastating catastrophe, although it is not something we should strive for. We can lead very rich and full lives, even though we may not drive cars, fly planes, or pursue vocations where high visual acuity and normal color vision are necessary. Those who choose not to have children should be respected, but those who want to become parents should also be respected. Incidentally, it is not known what beneficial traits achromatopic people may carry. If they did not have children, this might also prevent certain positive traits from being passed on.”

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“I want to share an anecdote about how my teenage son is ‘on’ to my color-blindness. He is always trying out new things with his appearance. His hair is a frequent topic of debate. Recently, when his friend Nat was over, he asked, ‘Mom, can I have my hair just like Nat’s?’ Nat’s hair was parted on the side and cropped above the ears. It looked pretty tidy, so I said, ‘Sure, go ahead.’ He clapped his hands and declared, ‘Yes!’ I couldn’t understand why he was so overjoyed until he revealed that Nat’s hair was dyed purple.”

Coming to Terms with Terms

“When I was growing up, I was often treated as if I were blind and sometimes even called ‘that blind girl.’ I knew that not only was I definitely not blind, but I was a very visually oriented person. I knew that, in fact, I had a great deal of vision in the right kind of lighting. Consequently, I developed a negative attitude about blind people and found it uncomfortable even to be near a blind person. I am happy to say that this attitude changed later in my life.”

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From a woman with achromatopsia: “Regarding the identity crisis which we achromats experience by being labeled ‘legally blind’: I’ve had people who were observing me indoors say, ‘I just can’t believe that you’re legally blind.’ How can these people possibly understand that, while some optometrists are able to get my visual acuity close to 20/100 in a darkened examining room, with the lighting on the vision chart dimmed down, the fact is that outdoors, even with my best tinted lenses on, I can’t recognize faces or notice someone waving at me? The word ‘blind’ seems almost like a profanity when used with regard to me – for instance when someone says, ‘Well, you have an excuse for such-and-such, because you’re blind.’ But, as with so many other things, I’ve had to give people the benefit of the doubt – I have to ‘chill out,’ so to speak, in deference to their ignorance about these matters. Perhaps they don’t know another word to use besides ‘blind.’ And, granted, ‘visually impaired’ does have about 5 more syllables. A better expression for laymen to use might be ‘You don’t see very well.’”

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“I wish that, as a child, I could have been given a word for my eye condition (‘achromatopsia’ would have done just fine), because I always knew that there was a lot more to it than just being ‘totally colorblind.’”

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“I do not use the term ‘legally blind’ with most people, because they don’t understand it. They have enough trouble as it is understanding what ‘totally colorblind’ means. I also don’t like to think that I have to live up to that ‘label’ – i.e., that I should have to come across as incapacitated in some way, because, when the lighting is favorable, I function very well. I describe myself to the general public as ‘visually impaired,’ because that seems to be fairly vernacular.”

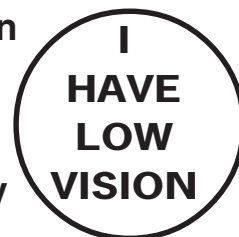
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From an Italian networker: “Here in Italy the title of Oliver Sacks’ book, *The Island of the Colorblind*, is *L’isola del Senza Colore*. This is not a word-for-word translation of the English title. Instead, this Italian version of the title translates as ‘the island of those without color.’ The use of the words ‘senza colore’ means that the islanders who have been written about ‘don’t have access to’ or ‘can’t make use of’ colors. Thus, the word ‘blind’ is omitted in reference to those who have this vision disorder. The use of the word ‘blind’ (which is ‘cieco’ in Italian) would have a stronger connotation here in Italy. Many potential readers here would be uneasy about this connotation.”

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“I was especially touched when I learned about the title of the Italian translation of Oliver Sacks’ book – i.e., the reference to ‘those without color’ instead of ‘the color blind.’ It is a much softer description of our eye condition.”

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From a woman in her 40’s: “On certain occasions I absolutely love having my button to wear that says ‘I Have Low Vision.’ I realize that some people would feel

uncomfortable about broadcasting their vision disability in this way, even if only occasionally, when shopping in certain places, but for me this button is useful in so many situations. For instance, there have been several occasions when I have been suspected of being a shoplifter because of the way I seemed to take forever in fitting rooms or the way I would scrutinize labels an inch or so from my nose in brightly lit stores. I remember one occasion when I could have really used a button like this. A clerk had actually called for a security officer, because I had taken so long and because I was carrying a large handbag. Instead of allowing them to take me up to their office, I just emptied my handbag onto the counter, right there in front of God and everybody. Along with my wallet and my checkbook, out tumbled my monocular, my binocular glasses, my pocket magnifier, and six pairs of assorted glasses and sunglasses, demonstrating beyond any doubt that there was no room in my handbag for anything else. My husband and I were the only ones who were not embarrassed during this scene. But I think that wearing an 'I Have Low Vision' button would have been easier."

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From another networker: "I experimented with wearing an 'I Have Low Vision' pin once when I went alone to a large amusement park. I thought it might help me at those times when I would need to stop at concession stands, shops, booths, rides, etc., because I would frequently be asking for information, directions, or other kinds of help. I wanted to cover as much territory as possible at the amusement park and to minimize any frustrations related to my vision impairment. For the most part, this plan worked. I received prompt, courteous help and directions from most of the park employees, as I had hoped. However, I found that the pin also drew attention from curious people along the way – encounters which I would have gladly done without – so I didn't wear it all the time that day."



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From a man in his 40's: "'Low vision' and 'legally blind' are terms I would like to see replaced with terms that have less emotional impact on others. I cringe when I see one of those terms used in connection with drivers who use bioptic aids. A politically correct term which might be used is 'visually challenged,' but people might equate that with 'handicapped.' I'd be happier with something that sounds more forward looking, like 'advanced optical tool user.' This may sound like a trite point, but public perception hinges on public relations, and I think it would be better if people with low vision were thought of as being like everybody else; they just need a little help from technology."

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From a woman with achromatopsia: "In a recent newsletter issue, a man wrote about his dislike for some of the terms commonly applied to visually impaired people ('low vision,' 'legally blind,' etc.). He is more comfortable with the currently politically correct term 'visually challenged,' and he suggested that 'advanced optical tools user' was more acceptable than some of the terms that have been in use. Well, that term may be fine for him, but it does presume that all of us choose to use advanced optical tools. This is not true for me or for some other people I know. I guess it depends on how you approach things and the kind of work or studies you are engaged in and whether you have enough vision to drive, etc. Personally, I use optical aids as little as possible, and I have no inclination to use the really 'advanced' optical devices. I remember all too well how cumbersome it

felt back when I tried to use optical aids a lot of the time, and I also remember the headaches and tired eyes I would get, until I finally gave myself permission to quit trying to do so much visually oriented work. Also, I can't imagine approaching a store clerk or someone else from whom I might need a little special assistance and introducing myself as an 'advanced optical tools user.' It's so much simpler just to use one of the common and easily understandable terms that let people know that I have a vision impairment. I realize that just about all of these familiar terms strike an uncomfortable chord these days with some people, but they don't with many of us. I don't think that the terms 'visually impaired,' 'low vision,' or 'partially sighted' give us poor status or reason to be ashamed. I'm so happy to have some acceptable options like these to select from; because, back when I was growing up, the terms commonly in use were real doozies like 'she's got bad eyes' or 'she's darn near blind.' I've tried to adjust to the politically correct term 'visually challenged,' but it seems so contrived."

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"I was delighted several years ago to come across a book of articles for optometrists on the subject of low vision and to see that a very funny drawing had been chosen for the cover of the book. On the bottom half of the cover was a drawing of a pair of ankles and bare feet. An eye had been drawn on each toenail. The eye on one of the big toes was closed – as if it was winking. And above the drawing was the title, 'LOW VISION.'"

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From a man with achromatopsia: "'Photophobia' is a word I would like to see banished from the 'dictionary' of words used to describe achromats. It sounds like something that mobsters might have – a fear of having their pictures taken. Most people think of 'phobia' as meaning an irrational fear of something. When people ask, I always just say that my eyes are 'very sensitive to bright light.' This is a concept that most people can understand."

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From a man in his 50's: "About terms like 'legally blind,' etc.: I guess I've used all the different terms at one time or another, except 'low vision.' There are times when I choose to use the term 'legally blind,' when I really need to get someone's attention – for instance, when I have to say that I cannot read a menu at a restaurant or have to explain why I have had to ask the bus driver if his bus is the one I want, since I could not read the sign on the front of the bus. I am sure that, if I were a kid, I would not want to use these terms. 'Partially sighted' seems to have some dignity."

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From a woman in her 20's: "I try not to let terms that refer to my vision impairment bother me. I prefer not to use 'legally blind' in most situations, because I have found that many people hear only the word 'blind' and think that my vision is worse than it is. I don't mind being called 'visually impaired,' because it's true. I am. When people get too caught up in being offended by words like 'visually handicapped' and 'low vision,' I find myself wanting to say to them (as nicely as possible, of course), 'Get over it.' I try to blend in and adapt in whatever ways I need to. I have learned not to be afraid to ask for help when I need it. But I don't think we should be so bothered by how people choose to refer to our vision problem. I just try to be secure in who I am and not worry too much about these things. I have to admit, though, that it has taken me years to get to this point."

Activities of Daily Living

“My worst days are when I’m in bright, crowded places (train stations, fast food joints, malls at Christmas time, etc.), where it’s taking me twice as long as it takes other people to do something simple, like read a sign on a wall. I wonder what it would be like to just glance at something and read it? Or to just look at a shirt and pants and know whether they match? I often arrive home exhausted. I try to be content with the amount that I have been able to accomplish.”
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From a woman in her 40’s: “This morning I went for a jog alone. I’m concerned whenever I jog in our neighborhood that the neighbors will think I’m ‘stuck up,’ because, when cars drive past, I can’t tell if they’re neighbors or just people who are driving by – and, of course, I can’t tell if anyone is waving to me. So I just ignore the cars. Today I didn’t see the man standing beside the road getting his newspaper until I was almost past him. I should have just waved, but I’ve always had trouble with doing that. There’s so much ‘mental gymnastics’ involved in making the decision ‘to wave or not to wave’ that, by the time I notice a person, I don’t have the time it takes to talk myself into waving. Pretty pitiful, I know, but there have been times when I’ve found myself giving a friendly nod to trash cans, so I’m just more comfortable keeping to myself.”
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From a woman in her 30’s: “If you go to a shop specializing in makeup, you can usually ask them to show you application techniques free of charge. You can learn how to apply make-up to the areas around your eyes so that you don’t ‘look like a raccoon’ (a problem familiar to those of us who routinely wear sunglasses). Of course, I can never see the color of the make-up I’m applying – I sort of apply it by faith and then ask my husband or a friend to ‘clean it up’ for me.”
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“When I was growing up, so many of the foods eaten by our family were fried. Since I wanted to help out in the kitchen (and, as I got older, I was expected to), there were many times when I got splattered in the face with hot grease as a result of my need to get up close to the pans in order to see better. I learned to keep my hair pulled back, and eventually I obtained some plastic safety goggles to keep in the kitchen. I also have found ways to get the lighting around the kitchen stove right for me (indirect, subdued lighting is best). As an adult cooking in my own kitchen, I discovered many different gadgets and techniques that help compensate for my vision limitations. For one thing, I make the most of my keen sense of smell. Several years ago, I discovered that I found it soothing to my eyes to look at ironware or Teflon coated pans that were dark colored than to look at shiny metal pans. And when possible, I choose any color besides white for mixing bowls, dinnerware, kitchen appliances, etc.”
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From a man in his 40’s: “On the one hand, I have so many capabilities and, on the other hand, I am incompetent in so many ways. I have tried to do as much as normally sighted men do – and sometimes with success. Other times I have had disastrous results that ended up costing my wife and me more money than if I had hired someone to do the work. Many times my wife has observed that I tend to minimize the truth about my inabilities in certain situations. And, upon reflection, I know she is right. Do other people with achromatopsia break or damage as

many things as I do? My experiments at being a handyman (you know, those ‘guy’ things where ‘fixing’ actually means busting) are especially difficult, because I can’t see as much detail as the task demands. I know that, as long as I continue to try new tasks, I’ll encounter even more situations that remind me of my limitations.”

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From a woman with achromatopsia: “The comments from the man who has been frustrated in his attempts to fix things around the house rang true for me. My kids tease me, because I keep breaking glasses. I’ve broken some lovely pieces of stemware. Our cupboard is now full of Tupperware. But my husband has no handyman capabilities whatsoever, and he has 20/20 vision. A good friend of ours (who also has 20/20 vision) likes to hold up his hands and say, ‘See these? They’re for ornamental purposes only!’”

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In response to the same networker, another member wrote: “What you shared about ‘starting out to fix things and ending up busting them’ is a common experience of many people. It has always been a popular theme of situation comedies on radio and TV. However, you and I both know that our vision disorder is playing a major part in all such experiences. I am so impressed that you at least try to do these things. I almost never take on any fix-it projects, partly because I am well aware of my visual limitations in terms of working with hardware, small tools, etc., and partly because I have no aptitude or interest in such activities and my husband is gifted at handyman tasks. Nevertheless, I have had many similar experiences in connection with other kinds of activities, ones in which I do have aptitude and interest. For example, early in our marriage, my husband and I collected lots of nice kitchen equipment, both old and new. We made everything from scratch – baked goods, ice cream, pasta, ethnic dishes, etc. Because he had a great interest in specialty pans, gadgets, and appliances, I specialized in dishes that made use of these items. It was great – but also frustrating for me, because I was always letting something get chipped, broken, scratched up, discolored, or rusty, etc. Often it would be something old and wonderful which the previous owners had managed to keep spotless and like-new. I felt terrible about this. Also, there were cooking skills which I would consistently be a flop at – like making mayonnaise or folding egg whites into a batter. Eventually I started making myself get up close to whatever I was working on, instead of always trying to work from a ‘normal’ or ‘dignified’ distance. I think that, if we achromats don’t get up close or (when feasible) make use of magnifying lenses while doing manual activities which require visual inspection, then we’re simply not going to have the visual information we need in order to do the task well – whether it’s handyman activities, gourmet cooking, or cleaning of fine objects. Normally sighted persons just take their good visual acuity for granted. We have to work harder at doing the same tasks or else learn to be content with lower standards. I have known totally blind people who are good handymen and good cooks, but these people take their time, give total concentration to what they are doing, and are very organized and very careful with every procedure. We achromats try to go about doing things with the same speed and in the same manner as normally sighted people do things. But we do not see like normally sighted people see, so we need to do whatever helps us see our best and compensate in other ways.”



“My visual problems in connection with being colorblind have been reduced by choosing clothing and furnishings that minimize the need for color coordination. We have a television with an 80-inch screen, and this makes TV viewing more enjoyable for me. My husband and I have planted trees to shade all south facing windows. We have eliminated all fluorescent lamps from our home and have installed only incandescent lighting with dimmer switch controls.”

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“I like wooden blinds to control the light from windows and I keep magnifiers in various places around my home – for example, in my kitchen, on top of my heating and cooling thermostats, beside my bed, and near my chair in the den.”

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“In our household, window washing is a joint effort. My husband washes the outside and I do the inside. He prefers to do his side of the windows during the day, when he (being normally sighted) can see the spots and dirt better. I do my side after sunset. I can see the smudges and spots best when I look through the window from a moderately lit room into the dark outside.”

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“I have very few clear memories from childhood associated with sunny days, while night time experiences and memories of events that happened in the midst of inclement weather provide the greatest recall. I head for the shade when I am in outdoor activities in the daytime. Sunny days with snow in the winter are very hard for me. I tend to get around slowly in those situations. Caving (spelunking) was my pastime of choice in college and beyond. Cycling and traveling are much more comfortable for me at night. And I’ve found that the grocery stores are virtually empty at 2 AM! I have always been a night person. The night provides me with visual comfort. I go fishing between 4 and 7 AM. I only ski at night. I only swim in the evening or in indoor pools.”

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“I enjoy yoga classes, square dancing, and ballroom dancing. For these activities, my vision limitation is not a big factor. I try to stand near the instructor, so that I can see how she demonstrates the steps. I follow the moves and positions in yoga classes and square dancing by listening to the verbal cues. Whenever I need special costumes or outfits (especially in square dancing), I sew these myself with the use of magnifiers, seam guides, needle threaders, and the assistance of someone with color vision who can help me select fabric and thread, etc. I also like to crochet. Working with yarn is not a problem; but, when I use the thinner crochet thread, I need to use my CCTV to see what I’m doing. I attend several baseball games a year. I bring along a small radio and earphones and tune in to the station broadcasting the game. Listening to the plays being announced enables me to know what’s happening on the field.”

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“Some of my coping techniques include pinning my socks together before they go into the washer (*editor’s note: be sure to use rustproof safety pins*), writing color information with indelible ink on the tags of clothing (since I find it hard to memorize the color of every item of clothing), and hanging color coordinated outfits of clothing together in my closet. Because I enjoy cooking, I have a lot of herbs and spices, and I arrange them alphabetically, which makes searching for a particular seasoning much easier.”

“Sometimes I notice a big cobweb hanging down from the ceiling, and then I know it’s time to go around with a broom, sweeping all the cobwebs away (I hope). I don’t have much trouble with cooking, but I have to admit that I don’t always do a good job cutting my toenails.”

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“When I am cooking meat and certain other foods, my husband or my children tell me when the color is right (i.e., when something has been cooked long enough). They also help me by checking whether fruit is overripe or underripe, since I cannot tell by the color. (Without consulting them, I have sometimes served up some real ‘surprises.’) When we go shopping for electrical appliances, we always look for ones which don’t have red lights or red numbers on display and we make sure the display is large enough for me to see easily.”

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From a man with achromatopsia in his 40’s: “Recently I discovered an on-line grocery delivery service in my city. I can now use my PC to order groceries, toiletries, paper products – just about anything – and the items are delivered to my kitchen the next day. I have always hated shopping at supermarkets, because the lights are so bright and because I have trouble reading the product labels, the prices, the cash register displays, etc.”

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“I play piano and hammered dulcimer, sew, read, work logic puzzles, knit, crochet, and occasionally do needlepoint and crewel embroidery (using large needles with big eyes, fat yarn, and large stitches – very little detail work). I don’t care much for outdoor activities during daylight hours. My vision is very limited in such settings, and I tend to get severe headaches when I am outdoors in the daytime for a long period of time. I have not tried Talking Books, as I prefer the experience of holding a book and turning pages, rather than listening to someone read.”

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“I like to order clothing and other items from catalogs like L. L. Bean, Land’s End, and other companies. The color choices are included in the descriptions of the items, so I can plan for coordinated outfits and certain home furnishings. I buy pants or skirts that are dark blue, black, or white, because they can be worn with so many different colors of tops. I buy only black socks and white socks, so have no problem matching them and deciding which outfits to wear them with.”

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“My vision limitation is not much of a problem when it comes to performing housekeeping tasks. There are some things, however, that I do differently from normally sighted persons. I sweep the kitchen floor daily – not because I can see the small crumbs, dirt, etc., that are there but because I know from experience that, if I run the broom over the floor, I will have a small pile of debris that I will be able to see. I cannot see the dust on furniture unless it becomes really thick. However, I dust every week, because I’m sure that dust has accumulated in that period of time. I cannot easily see the small pieces of lint, etc., that are on the carpets, but I run the vacuum over the carpets regularly and make sure to cover all areas. My family knows that they should pick up small things that fall on the floor, so that these things don’t get picked up by the vacuum cleaner. When I clean countertops, I can rely on more than my vision to help me, because I also find the sticky spots by feeling with my hands.”

School Experiences

“On the recommendation of an ophthalmologist, our daughter spent 2 years at the state preschool for the blind, where she was the least impaired of all the children. School officials there were quite upset when we decided that she should attend a public school kindergarten, but we wanted her to associate with normally sighted children as early as possible. The public elementary school has been very supportive. Last year her first grade teacher found that our daughter was falling behind in reading and suggested that she spend a half hour daily with the resource teacher for visually impaired students. This teacher brought a lamp from her home and used it instead of the fluorescent lights in her room for these periods. Now our daughter is reading beautifully. For recess and P.E. many teachers at this school use a ‘buddy system,’ which helps. The layout of the playground is now familiar to our daughter, and she navigates well. It is very difficult for her in the winter, when there is snow and ice on the ground for 3 or 4 months, but she has adapted to this also. It helps that she has an older sister at the school who keeps an eye on her.”

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From a teenage boy with achromatopsia: “Some of my teachers try to provide too much help. They’re always saying, ‘Do you want me to have this blown up for you?’ Most of the time I just tell them, ‘No, It’s OK,’ because I really don’t need as much help (enlargement of materials, etc.) as some of them seem to think I do.”

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From a woman with achromatopsia in her 40’s: “I would like to say to parents: get in there and fight for your children, but do it without ‘babying’ them. That’s a precarious balance, isn’t it? I’d also like to say that there will always be curious kids who will say things like, ‘Guess what color this is’ and ‘Can you see this?’ (sticking some object right in the child’s face). I believe that educating people can help to put an end to all the exasperating questions and wisecracks. Perhaps a child with achromatopsia could do a science project about this eye condition. The project could include the picture of a cross section of an eyeball and one of those colorblindness tests with dots that form numbers.”

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“So far, our daughter (a first grader) has not needed enlarged print, and she is able to read fairly small print without much trouble by just bringing it close to her eyes. There have been times when certain teachers for the visually impaired who were assigned to her have been a challenge to deal with. They mean well, but it has almost seemed as if they have wanted to handicap her in some ways, to make her part of their program. Some of them have insisted that she learn to use a white cane for outdoor travel. Her vision is far too good to need a cane. The last straw came when we were told that she should be blindfolded in order to learn cane travel, so that she would not be distracted by her vision! They all seem to be trying to help, but they don’t really understand her situation.”

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“We have two daughters with achromatopsia. When the older one was ready for preschool, we enrolled her in a regular class. The vision teachers in the local parish wanted her to attend a self-contained classroom for blind and visually impaired students, but my husband and I visited it and did not feel it was right for her. Both girls now attend a small Catholic elementary school. The teachers have been wonderful. They all know the girls and their special needs. Just before our older daughter entered school, the principal spoke to the students concerning

her eye condition. Last year, as a 4th grader, she presented a talk to her class, explaining about her eye condition and answering questions.”

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“At our son’s preschool the teachers are very sensitive to his needs – adapting projects and ways of presenting lessons, giving him extra time to get familiar with things, giving more cues and special attention (like making sure that he is holding the hand of an adult instead of a child when on field trips). Sharing the network publications with his teachers has really helped to bridge the gap in their ability to understand his experience and know how to help him.”

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“Our son attended a Montessori preschool and kindergarten for 3 years and managed very well. He was able to do everything the others did, except for certain color oriented activities (Montessori programs use color a lot). At the start of each year we would explain his eye condition to his class – telling about why the dark glasses were needed, etc. This helped to eliminate so many questions, ‘gawking,’ and the like. He is now a 6th grader at a parochial school, where he has been with the same group of children since first grade, so by now we are beyond having to explain this to the other students. But we do have a thorough talk with his teachers at the start of each school year.”

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From a report by network member Knut Nordby regarding his visit, along with Oliver Sacks, to meet the persons with achromatopsia on Pingelap and Pohnpei Islands: “When I was giving a presentation to the teachers of Pingelapese children with achromatopsia, I offered these suggestions: not having the pupils face a window or any other strong source of light, placing any text or pictorial material where it can be easily inspected (not high on the wall), seating the students very close to the blackboard and anything on display or letting them come forward to look closely at the material (providing an extra set of materials for each student to inspect is even better), letting the pupils choose the optimal writing implement (one that makes a dark enough, high contrast line but not too thick), and being open to accommodating each student’s individual needs. Teachers can also help students learn how to use optical aids. To be really useful for most people with achromatopsia, a magnifier should provide from 4 to 6 times magnification and a distortion-free image (an aspheric lens) with a field of view large enough to see more than one word at a time (i.e., a lens diameter of at least 47 mm).”

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“Last year our son was in a school environment that posed many difficult challenges for him in terms of his vision. He now goes to a progressive school we found that is located in an old building downtown. This school has small windows, small classes, and enlightened teachers. He doesn’t even have to participate in outdoor activities unless he wants to. He is very happy now! So are we!”

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From a mom: “The team of school staff assigned to our son (age 8) for this year has been quite insistent on his using black markers for writing and enlarged reading materials – to which he has strenuously objected. My husband and I had to do quite a bit of arm-twisting at our meeting with this team. We had to explain that other persons with our son’s eye condition (members of our network) have stated their displeasure with the way some well-intentioned people have told them what adaptive materials and methods they were supposed



to use in school, rather than allowing them to make those decisions. After all, none of us can see through the eyes of an achromat. As I quoted from some of the network publications, I could sense a shift from the 'hard line' that this team had been taking on this issue. Happily, our son is now given choices throughout the day. I can certainly tell that his self-esteem has been given an important boost."

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From a dad: "We took our son to our local agency for the visually impaired, where he was given a monocular that hangs from a cord around his neck. He can now read the chalkboard even from the 3rd row. This has made a world of difference to him. Now the other kids want monoculars too."

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"At school our daughter sits up close to the board, but it is a Dry Erase board, and she can only see what is written on it if it is written with bold black markers. The light bulb was removed above her desk. She wears dark sunglasses on the playground, and some of the other children have now started to wear cool looking wraparound sunglasses like hers. There's a CCTV in her school room, but there's no need for it yet, because the print size used in first grade is still fairly large. Her teacher put labels on her crayons that give the names of the colors in large print. In P.E. she has been provided with a basketball and a soccer ball with bells in them. These balls can be found in P.E. equipment catalogs."

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From a man with achromatopsia: "How much easier school would have been for me if I had had a monocular such as I use today! What works best for me is an 8 power monocular, which the vision specialist tells me brings my vision up to 20/20 for 'spot viewing.' However, the field of viewing when using one with that much magnification is more restricted than with a 6 power or 4 power monocular. For instance, if you sit near the front of a class, an 8 power monocular can be too strong, and it takes longer to aim and focus than one not so strong. A child in the early grades would probably do better with a 4 power monocular, since it would be easier to focus. With the 8 power one, I am able to sit anywhere in a classroom and see anything I need to see."

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From a woman with achromatopsia: "When I was in school, teachers would often assume that, because the light bothered my eyes so much, I should be assigned a seat on the opposite side of the room from the windows. The fact of the matter was, however, that, when I sat on the window side of the room, I was able to look at what was going on in the rest of the room and keep some degree of visual contact with my classmates. However, when my desk was on the side of the room opposite the windows, I had to experience some 'bleaching out' of my vision whenever I looked toward the rest of the classroom (i.e., toward the windows), so I often missed out on a lot. Being on the window side of the room was, of course, much harder when sunlight was coming directly into the room and onto my desk; but, at times like that, I could simply adjust the blinds near my desk. Whenever seating arrangements in a room allowed me to have my back to the windows, that made possible the best vision I could have. Corner classrooms, with windows on two walls, presented the worst problems for me."

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"Our daughter used large print books from 4th grade until 9th grade. She seems to be 'weaning' herself away from them now and instead favoring her magnifier. In the lower grades she found it hard having to take those large books back

and forth to school. So, at the beginning of the school year, we would request a set of standard print books to keep at home, and her large print books stayed at school. At the end of the school year, we would return the extra set of books. She also made use of books on tape. I think it's important that reading materials in different formats be available, so students can decide for themselves. As I'm learning about the different levels of visual functioning people with achromatopsia have, I see everyone finding their own way to cope, and this is a good thing."

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"I have been very frustrated because the teachers in my daughter's school (K-3) do not seem to have retained the information I have given them in IEP meetings about the kinds of accommodations she needs, and I don't think they have read the information about achromatopsia that I shared with them. So I decided to use the services of a friend who does desktop publishing. We created an attractive brochure, illustrated by several photos of my daughter, to distribute to them. On this brochure there are brief paragraphs which address the questions that most often come up in discussions with people who need to understand her eye condition. We avoided using too many medical terms or other complicated terms. Some of the questions addressed are: why she wears sunglasses, what kind of lighting is best for her, how she makes the most of the vision she has, and how her colorblindness affects various school activities."

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From a woman with achromatopsia in her 50's: "If large print materials and photo-enlarging equipment had been available in school when I was a student, I'm sure that a lot of things would have been easier for me. However, I think that I benefited in many ways from having to struggle with all the various sizes and kinds of print which I had to deal with in reading textbooks, classroom materials, magazines, library books, etc. I had to work very hard at everything, I had to get close to whatever I was reading, and in some situations I could not keep up with my classmates. But I found ways to manage and, as a result, throughout my life I have been able to use the same kinds of printed materials normally sighted people use – still getting up close, still getting the most favorable light I can get, and using a magnifier if print is very small (like classified ads, bus timetables, TV Guide, etc.). I suspect that I would not have been such a versatile reader or as free as I have been to access printed materials all these years, if I had been issued large print materials from the beginning of school. I feel that it would probably have conditioned me to needing large print in order to read and thus perhaps deprived me of the chance to find out what my eyes were capable of."

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From another networker: "In elementary school I had the services of the program for visually impaired students. The individual attention I received was fantastic, especially in math, and they even taught me how to type. I didn't need large print books or magnifiers, but my involvement with the VH special ed program did sensitize classroom teachers to my presence and my special needs. And, I found that it was beneficial for me to make friends who also had trouble seeing. Through this program I was blessed with a close friend who had albinism. She had her own kind of photophobia. Both of us stayed indoors during the day as much as we could and waited till sunset to go outside. When I started high school, I left the special ed program voluntarily, so it was then up to me to ask teachers for special seating, etc. I found that most of them were very cooperative."

“For exams our son (age 17) is provided with the following special accommodations: a room with subdued lighting, extra time, and enlarged copies of exam papers. His computer is set up with large fonts, and he can use white print on a black screen, which he prefers. He is excused from having to reference books at the library, due to the problems he faces in connection with this, and is allowed instead to reference the Internet for his projects. He is getting excellent grades and becoming somewhat of an expert at tracking things down on the Web. He is provided with Talking Books for any classic literature he needs to read and reader services for recording any other books he may require.”

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From a woman with achromatopsia in her 40’s: “All through grade school I felt that I was so lucky, because I had a friend who wrote with really big letters. She had a gorgeous handwriting! And I would get to copy the notes that she had made from whatever the teacher had written on the blackboard.”

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From the parent of a young adult with achromatopsia: “When my daughter was in grade school, I would always meet with the teachers before school began, so that any large print materials that she might need would be available for her from day one, with seating up front and lighting conditions modified, if possible. This way, the teachers were able to be prepared, and they never had to make a big issue after school had started about the subtle changes that are necessary for a student with achromatopsia.”

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From a mom: “Sometimes I think that we focus so much on making sure that our son (age 12) keeps up with his peers that we forget that reasonable accommodations really are needed sometimes in the academic area. I am reminded of some good advice from a case worker we used to know from our state agency for the blind. Once I said to her, ‘Isn’t it amazing how well our son is doing in school, keeping up with the other students in everything?’ And she said, ‘Yes, but at what cost? Keep an eye on his stress level, and remember that it is his right to have accommodations made for him whenever they are needed.”

.....
From a woman with achromatopsia: “I remember map assignments as being among my most frustrating school activities. But that was many years ago, back when there were no special education resources for vision impaired students. I simply had to rely on the mercy and sense of fairness of my teachers. Most of them did seem to realize that I should not be expected to do all map assignments the other kids were expected to do. We now live in an age in which ‘reasonable accommodations’ are expected to be made for students with disabilities. Especially at the junior high level and beyond, assignments involving maps can be very complicated, requiring color vision and the ability to see small print and other fine details. Normally sighted students struggle with these map assignments. It would be totally unreasonable to expect a blind student to work on such assignments, though such a student would be expected to do a substitute assignment. A



partially sighted student, such as one with achromatopsia, falls somewhere in between, being neither blind nor fully sighted. A reasonable teacher will realize that color oriented map assignments would be unreasonable expectations for students who are colorblind. Also, a student with achromatopsia does not have good detail vision and, therefore, must work

many times harder than other students at map assignments. The Americans with Disabilities Act requires that reasonable accommodations be made in school for students with disabilities. Blind students are routinely given adapted assignments, substitute assignments, or exemptions when there are assignments that are primarily visual, as in map work. Partially sighted students are certainly entitled to the same degree of consideration.”

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From a teenage girl with achromatopsia: “When I experience visual stress, like after doing a lot of homework, I like to lie down for a while and rest my eyes. When I have had to spend time in the brighter rooms at school, my visual stress increases greatly. Sometimes my eyes get so tired that I have to put my head down on my desk for a brief period. When I go into a classroom that is too bright for me, I sometimes ask the teacher to pull the blinds. At other times I don’t do this and then I end up squinting a lot. By the end of the class period, my eyes feel as if they have been strained to the max. Another stress related to my eye condition is when I have to do a presentation in class. I am not able to quickly refer to note cards, like everyone else does. Sometimes my presentation involves a poster that I have made to use as a visual aid, and I can’t see the words clearly enough when I am standing and presenting the information. So usually I memorize my entire presentation. There have been times when I have actually gotten a very high grade in recognition of the fact that I did not use note cards (demonstrating that I had committed all of the information to memory).”

.....
From the mother of a 5-year old girl with achromatopsia: “I am trying to help my daughter’s teachers understand that she needs to be given very clear directions, instead of vague directions such as ‘over here,’ ‘over there,’ ‘go that way,’ etc. Also, I am trying (with difficulty) to get her to communicate to her teachers whenever there is something that she cannot see. I think her preference is simply to find some other way to cope, rather than bringing up the fact that she cannot see something that the other students are able to see.”

.....
“I find that home schooling is the ultimate example of making use of an adapted environment. For our daughter who has achromatopsia, we adapt lighting, work spaces, and curriculum to fit her needs. The state agency enlarges all the textbooks we bring them. Before our decision to home school, our daughter had to struggle with a great deal of peer ridicule and had become a very depressed child by third grade. Because of this, we took her out of school and began home schooling. Besides studying the regular school curriculum, we spend time on subjects like self-worth, positive thinking, and appreciating what we have, rather than concentrating on what we don’t have. Over time, all of this has made an immense difference. Our daughter is 12 now, but she studies 8th grade material, so next year we start high school. She loves to draw and does so with amazing precision. Because she loves horses, she studies her plastic models of horses up close and then renders the details to paper. We recently gave her a set of charcoals, which she loves to use for making her sketches – with these, there is no need to be concerned with color choices.”

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“We are home schooling all seven of our children. Our two sons with achromatopsia are doing very well. They read regular print easily (holding the books

close). We've had to make very few adaptations to our usual one-on-one home education methods that are used with our other children."

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"My 10-year old daughter and I have been doing home schooling for several years. It's great to be able to adjust the lighting and the closeness of school work and to do anything else that is needed to meet her visual requirements. We do lots of auditory learning, with less writing than the public schools require. We move along faster than the public schools. Home schooling has been great for her self-esteem. When she was in school, she suffered quite a bit from feeling so different from everyone else."

.....
"In the middle school years my son had many problems trying to participate in athletics programs. For example, he did his best to play kickball on a blacktop surface using a red ball. But red and black appear much the same to him, and he went through a lot of ridicule before we finally got the school to purchase yellow balls, which he can see so much better against the blacktop."

.....
From a woman with achromatopsia: "P.E. classes were responsible for some of my most negative childhood experiences. They set you up to 'play the fool' in front of your peers. I feel strongly that the stresses faced by some of the kids with achromatopsia in P.E. classes – such as having to be in outdoor situations where a ball is coming at you or negative treatment from fellow students who think that a vision impaired kid will blow the chances of their team winning – are too high a price to pay for keeping them in such classes. Maybe the student with achromatopsia has a friend who could be permitted to run around the track with him or her instead – or do calisthenics. Indoor sports are, by far, the best way to go if the school has an indoor gym. Bug the teacher. Bug the school administration. Tell the school board they can buy the student a stationary bike to ride during certain P.E. periods. Don't give up. If no one bends, maybe the student can go to the library during P.E. or have keyboard lessons instead and then, after school, go to a YMCA program or some other program that offers physical activities."

.....
And from another networker: "I have excelled in quite a few sports, but I always hated P.E. in school. Whenever possible, I would refuse to participate, getting notes from my parents to have me excused. I think one reason the teachers let me get away with this was that they knew I was active in rowing after school and so was not just lazily avoiding exercise."

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"The P.E. teacher at my son's school makes sure to place himself where our son can see him well, and sometimes he will come over to position him or give whatever personal help is needed. Also, we have a lot of para-professionals who help out in schools in our state, and there is always at least one in each P.E. class. There are certain limitations for our son in terms of P.E. participation, but I think it's better to let kids decide what their limitations are, rather than determining all of this for them. If a network family has a mobility specialist assigned to their child, I would suggest that the mobility specialist be asked to visit the P.E. class to help and advise with regard to participation in P.E. activities."

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From a woman in her 50's: "About 10 years ago I decided to go to college for the second time (the first time had been 25 years earlier). This was partly for the purpose of taking up-to-date courses in my field, but also I wanted to experience

what it was like to be a college student in the age of ‘disabled student services.’ I wondered how it would feel – for the first time in my life – to have ‘equal access’ to educational resources? To have my ‘special needs’ accommodated? To have special services graciously offered to me? Well, I am happy to report that it felt absolutely marvelous! In fact, I found going to college the second time around to be a very healing experience. I highly recommend it to other older achromats.”

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“Registration day at my college was always a nightmare for me for all kinds of reasons. Finally one year I phoned the campus Disabled Student Center and asked if I could pre-register. Problem solved. Wish I had done that sooner.”

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“When I first went to college (in the early 1960’s), I had to use the same printed materials other students were using. No miniscopes or photoenlargements, no extra time for exams, etc. I used the survival methods I had always used in school – being super-attentive in class, committing much to memory, accepting the fact of having to work harder than other students, etc. I looked for places in the school library with subdued lighting for studying and requested dorm rooms with shaded windows, instead of sunny rooms. Over 20 years later, when I returned to college for graduate courses, I got to enjoy using the services available to vision impaired students of this generation. At the university copy center I was allowed to order enlarged copies for the price of regular copies – for assignment sheets, chapters in a book, reference materials, etc.” *(Editor’s note: Such accommodations should be common practice by now in any college or university. If not, then whoever is in charge of seeing that disabled students have equal opportunities at the college should be informed about this basic right of visually impaired students to have their reading materials in an accessible format.)*

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From a woman in her 20’s: “When I attended the university near my home, I found out about the Disabled Student Center on campus. With their help I was able to get all my tests done in enlarged print, and I was also able to find people willing to share rides to and from the campus. They even provided me with someone to serve as a reader for a class that had an overwhelming amount of material to be read from a book with extremely small print. I only used a reader’s services for that one class, because I found using a reader to be a huge pain. For one thing, it took twice as long for me to listen to the tapes recorded by the reader as it would have taken me to read the material myself. Even so, how great it was that such a service was available! Also, I was given extra time for taking tests. I recommend that students in our network take advantage of all such available resources. It makes going to school so much more enjoyable.”

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“Our son manages quite well with his reading as long as he is in control of the lighting. At his university there is a well equipped study room for disabled students. When he uses this room, he turns out the lights and partially closes the blinds. No one else seems to use the room.”

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“Our son has a late September birthday, and the year he turned 5 we were not sure if kindergarten was the right placement for him. We finally decided he was not ready, not just because of his visual problems but also because of other developmental factors. We placed him in a ‘Young Fives’ program for kids who, for various reasons, were not ready to start school. It turned out to be a very good

year for him. It provided social experiences and developmentally appropriate activities. If this program had not been available, I still would not have put him in kindergarten that year but would have opted for some sort of preschool program.”

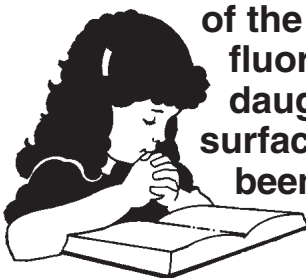
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“The VH teacher helped us to look past the eye condition. She counseled us that our daughter’s eye condition would always be there and that she would find out for herself how to cope and that we should concentrate on her capabilities and deal with each problem as it arose. Once the adjustments were made to meet her needs in kindergarten, things went well. The children did ask about her eyes, things were explained to them, and they were eager to help out. (Of course, there were always a few ‘stinkers.’) Our daughter is going into 8th grade now and her teachers tell me she is a wonderful student, who copes well with difficulties and who is not afraid to speak up when she needs something.”

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“Our son started first grade this year. The first month of school was the hardest. However, everyone was very helpful – sometimes too helpful, so that at times he became a little overwhelmed. But, now that people have adjusted to his needs, things are going well. He is learning to express his needs. Sometimes, when he is too shy to ask his teacher for help, he’ll turn to one of his classmates for help. His teacher and I feel that this is great, and the kids have been wonderful about helping him. Communicating with other networkers about these things has been very helpful. One networker even sent me copies of her children’s IEPs (Individualized Education Programs), which were immensely helpful to have in preparation for conferences with our son’s teachers.”

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From the mother of a kindergartner: “There are so many things a teacher normally takes for granted that, in our son’s case, require some special help or supervision because of his vision. For example, while the rest of his class has continuous exposure to the ABC chart on the wall, my son does not have this advantage. So I asked if a chart could be made for him to keep at his desk, and a teacher’s aide made some large ABC flash cards and number flash cards for him.”

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“Our son is in Pre-K. The school is helping out a lot. They have put dark orange tape on the posts outside to make it easier for him to see them, and they will also be putting some on the edges of the pavement and on the inclines and drops.”

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“Our daughter has had the assistance of a vision teacher since she was 3 years old. When she was in pre-school, the vision teacher helped the pre-school teachers modify the materials they used in their lessons to make it easier for her to keep up with everything. When she moved on to elementary school, more changes were needed. The vision teacher surveyed the kindergarten classroom and saw that the quantity of light coming through the windows could be reduced to some extent by adapting the blinds. And, instead of having a single switch for controlling all of the overhead lights in the room, there are now six, so that the fluorescent lights can be turned off in whatever part of the room our daughter is sitting. She has been provided with a dark anti-glare desk surface. The windows are tinted. For the third year in a row, she has been provided with a classroom aide, who modifies her classwork as needed and narrates for her what she needs to know about what is going on in her environment. She has her own large



screen (19") computer with speech output and a large print keyboard. She also has access to a CCTV. When possible, tan colored paper (instead of white) is provided for her school work to reduce glare. Instead of regular no. 2 pencils, she uses medium point black markers or black (ebony) pencils. Sometimes she uses an easel on her desk top to reduce neck strain when reading and writing. Her vision teacher re-types the text in some of her books in a larger font, and the classroom aide tapes the enlarged text into the books. This way our daughter can have the same books as her classmates. We have found that our public schools here offer the most in terms of modifications to allow her to be comfortable. She is entitled to the services of a vision teacher throughout her schooling. She also has her own classroom aide, occasional sessions with a mobility teacher, and special physical education sessions. Getting this kind of attention for her was not easy. By law, visually impaired students have the right to all of these services, but in actuality there are not always enough services to go around. It is important for a parent with any kind of special-needs child to be aware of the laws. With this knowledge, you will be able to advocate vigorously for your child's needs."

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From the mother of two teenage girls with achromatopsia: "We moved to Mississippi from Louisiana, where the girls had IEPs and an itinerant teacher who visited their school weekly. This was provided by the public school system, even though the girls were in a Catholic school. However, here in Mississippi, the public school system will not provide any services unless the girls attend public school. We enrolled them in a Catholic school and wrote a 504 plan which was agreed upon by the principal, teachers, guidance counselor, and my husband and me. It has worked wonderfully. The girls are allowed to sit wherever they need to and move around the classrooms, as needed. The teachers make copies of their notes to give them and enlarge all tests. They are allowed extra time on tests, if needed. Someone transfers their test answers to any machine-scored answer sheets that are used. When a video is shown in class, they are allowed to work on homework assignments during that period and then bring the video home to watch. They have been issued magnifiers and monoculars by the state agency for the blind. I rarely have to get involved in school related problems. (I did phone one teacher last year when he deducted 10 points from my daughter's map project grade, because she had colored outside the lines at one spot. He just needed to be reminded about how difficult a project such as that was for her.)"

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"My husband and I are getting ready to have conversations with a whole new set of teachers for the Fall. Our son will be starting Kindergarten and will also have a new gym teacher, new art teacher, and new music teacher, and he will be in an after-school program. So we put together something to hand out to everybody. It begins with a paragraph explaining achromatopsia. Then we state that he will need assistance at times and we make suggestions and requests. Following are some excerpts: Check in with him if you are giving directions based on color. For example, saying 'Everyone go to the red mat' is OK, but providing additional guidance (e.g., 'the mat at the end of the room') would be better for him. He will not be able to recognize classmates across the room or on the playground. Encourage students to go up to him if they want to play with him. They need to understand that he is not 'snubbing' them; he just may not recognize them from a distance. Allow him to get close to the materials he works with. Enlarging class

materials and printing in high contrast help. Make sure he is close to you if you are giving directions. In gym class or on the playground you may need to make sure he has a ‘buddy.’ He sees best in low lighting. He typically wears very dark sunglasses outdoors. He usually wears tinted glasses indoors as well, as fluorescent lights bother him. He often squints simply to block out light. This should not be discouraged, as it is a coping mechanism for persons with achromatopsia. Let him decide about when he wears glasses and which glasses are best for him in a given situation (he has many pairs). For example, if he is playing in the shade, he might not need his darkest sunglasses at that time. He has an incredible memory and learns a lot by listening, but he may miss non-verbal cues. Be very specific about what you want him to do. If he is not following directions, go to him and explain quietly what you expect. Don’t single him out in front of his classmates. If need be, assign him a classroom buddy to help out.”

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From a special education teacher: “As a teacher of students with visual impairments, I am familiar with many of the frustrations in school that are experienced by students with achromatopsia: the high lighting level of the typical classroom, the teacher comments written on student’s papers in red or blue ink (so they’ll stand out from the student’s writing, of course – but this doesn’t help achromats at all), and the numerous tasks and activities that are dependent on color discrimination – maps of all kinds, litmus tests and other chemical reactions, the red vs. the green team in gym, bird identification, pie graphs, art work, etc. A forum for identifying problems and sharing solutions for students with achromatopsia is helpful to teachers as well as to the people in your network.”

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“Our daughter, a 3rd grader, reads books for hours at a time. At school she is given large print textbooks. I was surprised to learn that, with large print books, the publishers simply make the text (and, therefore, the books) larger, and all color is removed from the illustrations. She now has these huge books to lug to and from school, and the clarity of the pictures in the books is terrible!”

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From a woman with achromatopsia: “Recently I was thinking about large print books, and I realized why I hadn’t liked them back when I was in school. Besides the fact that the print in those books was inappropriately large for me, a large print book lying open on my desk was, to my eyes, just another huge expanse of white – more glare for me to have to deal with! I can’t remember a single time when I thought, ‘Oh, good! They have this textbook in large print!’”

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From a woman in her early 60’s: “The network families who have children and teens with achromatopsia and the younger achromats in the network are aware that many of us older achromats had to manage without sunglasses when we were growing up, and some of these networkers have expressed sympathy regarding what this must have been like for us. But, so far, not much has been written about this ordeal which we endured throughout our childhood and our teen years, especially with respect to what it was like for us socially and psychologically. Having to go places and do things while being blinded by light was difficult enough in itself. But the humiliation of having to be seen this way by others whenever I was outdoors in the daytime was almost unbearable. At school I lived in dread of having to be on the playground for recess or after lunch. I would stay a long time

in the lunchroom or in the bathroom, or I would wander down the hallway as if I were on my way to or from the bathroom – until I was spotted by a teacher and made to go outside. Then I would walk back and forth close to the wall of the school building (on the shady side), longing for the bell to ring, so I could go back inside – anything to avoid having to come face to face with other kids outdoors or being drawn into games on the playground which I could not possibly follow, due to my very poor vision in the sunlight. I felt like such a freak, yet I wanted so much to play with the other kids and be a part of what was going on.”

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From a network member in her 40's: “In the special ‘Partially Sighted’ classroom where I spent my elementary and junior high years, no one even recommended dark glasses for me, nor was any attempt ever made to accommodate my need for lower lighting. I remember struggling so hard to see in this room which had ostensibly been ‘designed for those who could not function visually in the regular classroom.’ My younger sister (also an achromat) managed in regular classrooms until 4th grade, when she eventually ‘got caught’ and placed in the special class too. None of my special education teachers had a clue as to the nature of my eye condition. The room was very bright and so, in order to read, I would practically have to put my face down on the book to block out the overhead lights and use my arms to block off the light from the sides. To top it off, they would only give me large print books. The print was too big for me to read comfortably with my face as close to the pages as it had to be for blocking out the light. And the books were so big that I had to keep moving my head from place to place over the pages, while continuing to block out the light with my arms. I recall asking for books with regular size print and being denied this request, because I was ‘partially sighted’ and was ‘supposed’ to use large print. It didn’t occur to me until I was older that even cheap sunglasses could have helped me in that room. Of course, if I had gotten hold of some sunglasses, I’ll bet that I wouldn’t have been allowed to use them. I stayed in the special classroom all day, except for the dreaded lunchtime recess. I loved being outside but had no one to play with except the others in the ‘special class.’ Everyone else kept away from us as if we had the plague. During recess I would invent games, which probably looked weird to others. I would, for instance, play on the walkways leading up to the school, pretending I was adventuring. It was an elaborate system of steps and walks. Sometimes the lunchtime supervisor would tell me I had to get back out on the playground. But I played this game as often as I could, alone.”

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Notes from the editor Regarding playground time at school: Those of us who grew up without sunglasses survived as best we could on the playground, usually by finding safe (preferably shady) places to hang out until it was time to go back inside the school building. But these days visually impaired kids are provided with special accommodations, such as the assistance of a teacher’s aide or being teamed up with a ‘playground buddy.’ Sometimes they are permitted to spend recess time playing indoors or in some well shaded area of the school grounds. Also, these days one can obtain dark sunglasses for a child with achromatopsia, along with a cap or visor, to provide enough light protection to permit active participation in many playground activities.

Regarding writing implements, one networker states, “I don’t like to write on the kind of paper with thick lines that is used by many visually impaired people. I find those bold lines annoying and distracting to my eyes. They actually make it harder for me to read what I have written. However, most of the lined writing paper sold in stores has lines that are too faint for me to see clearly. Occasionally I find notebook paper with lines that are ‘just right’ for me. But, best of all, I like to write on unlined paper, because I don’t have to be concerned about keeping my writing on the lines, and I find that reading what I have written on unlined paper is so much easier than reading what I have written on lined paper.” And from a man in his 60’s: “I like writing with broad nib fountain pens using black ink.” Another networker recommends medium fiber-point pens with black ink for general use and Pilot brand Precise pens with black ink for producing clear, easy-to-read handwriting when writing in small spaces. Many achromats have average size handwriting. Others have large handwriting. Some routinely use broad-tipped felt pens, but most networkers report using such pens only for special purposes, such as when creating written material they will need to read from a distance (such as notes for making a presentation to a group). Some report liking writing paper that is some color other than white (for reducing glare), and others prefer white paper (for the best contrast). All networkers who have reported on the subject of writing say they prefer using pens with black ink.

CCTV’S – A PERSONAL ACCOUNT by Frances Futterman

Many network families have reported that their children with achromatopsia have been provided with a CCTV to use at home or at school. Often these very expensive devices have been provided by a state agency, a school district, or a Lions Club, on the assumption that such a device would surely make a significant difference in the life of a visually impaired child. It can be a big disappointment to parents and teachers (and to the providers of the CCTV) when a child with achromatopsia resists using this very impressive magnifying device. But there are a number of reasons why CCTV’s are not suitable for most achromats, at least not for ordinary reading tasks, and these reasons need to be understood. (I say “most achromats,” because there have been reports from some network members who often make use of a CCTV, especially those who do some form of fine detail work or who have other vision problems in addition to achromatopsia.)

CCTV’s (Closed Circuit Television Systems) have truly been a godsend to many persons who have very low visual functioning, but they are limited in their usefulness to sight impaired persons who have a high level of visual functioning, such as persons with achromatopsia. Some adult networkers have reported that CCTV’s have been useful to them for certain reading tasks (fine print), but none have reported finding them suitable for their everyday reading tasks.

I used a CCTV on a number of occasions several years ago when I was enrolled in graduate courses and had access to various kinds of adaptive equipment at the disabled student center of the university I was attending. I have also tried out several CCTV’s that have been exhibited at professional meetings I’ve attended over the years. While I have been very impressed with what CCTV’s can do, I have always found it very frustrating to try to use them for ordinary reading tasks. As

an achromat, I do not need as much magnification as is needed by persons with other eye conditions which cause more severe vision impairment (i.e., persons for whom CCTV's were designed). Moreover, I found that the print displayed on CCTV screens was never as sharp as the print I was accustomed to reading on the printed page. CCTV's provided more magnification than I really needed; and, because of this, I was always acutely aware that my field of vision was being restricted when using them. I value very highly my good peripheral vision and resent ever having to give up any of it. Also, instead of relating to a machine, I prefer the familiar experience of relating to a book or other printed materials I can hold in my hands and bring as close to my face as needed.

I have always been able to scan pages rather quickly, in spite of my impaired vision. But, with a CCTV, whenever I would try to read or scan pages at my usual speed, unreadable flickering images would appear on the screen, because I was moving the page under the camera too fast. To prevent this, I would have to slow down my speed of reading. In addition to these inconveniences, I found it very hard to endure the bright light that was directed downward onto the movable platform where the material to be magnified was placed.

I experimented with various options in positive output and negative output and found that I preferred reading black print against a light (but dimmed down) background on the CCTV screen, rather than reading white print against a black background. This was partly because reading black print felt more natural to me and partly because, in order to see white print against black background clearly, I had to keep the brightness level high and found that continuously reading bright, white print was tiring to my eyes. I also found that it was necessary to use a greater degree of magnification in order to read white print against a black background, and this restricted the amount of print that I could see on the screen at any time. However, I have learned that some other achromats prefer white print against a black screen. This is evidently a very individual matter.

If CCTV's had been around during my school days, I'm sure that I would have gladly used one whenever I had to work with maps, charts, graphs, pages from math textbooks, encyclopedia pages, or science diagrams. If I ever own a CCTV, I will probably turn to it for easy viewing of items such as these and also for scrutinizing photographs or filling out forms that have fine print and small spaces to be written in. My personal choice in a CCTV would be one of the hand held devices that can be hooked up to a TV monitor, because these devices are portable, they are not so expensive, they don't take up so much space, and they offer the option of less magnification. Less magnification means clearer images and more print on the screen. Also, with one of the portable systems, one does not have to endure the bright light which many standard type CCTV's direct downward onto the movable platform under the monitor.

On the following page, network member Dr. Knut Nordby, a complete achromat, tells about some of his school experiences. Dr. Nordby is an internationally recognized vision scientist, lecturer, and writer.



KNUT NORDBY'S EARLY SCHOOL DAYS
(excerpts from the book *Night Vision*, pp. 296-300)

When the time came for me to start school, the nearest school for the blind and partially sighted was in Stockholm. My parents did not want to send me away to a boarding school at such a young age, so it was decided that I should try attending regular school and see if I could manage. At this time it became obvious to me that my vision was different from that of other children. They could see things I could not. They could also take part in activities and sports that I could not.

I must have been a very difficult pupil – inquisitive, talkative, always avoiding any activity that my vision might prevent me from performing well. I did learn the alphabet but did not really learn to read properly in grades 1 and 2. So I resorted to a reading hoax. I had developed a keen memory, and it was usually sufficient if someone read my assignment aloud to me once or twice, in order for me to remember it and to perform a convincing reading behavior in class.

Then we moved to Stockholm and I started 3rd grade in a large school. This did not work out very well. With large classes, the teachers had little time to give me the special help I needed, and it was decided that my sister (also an achromat) and I should attend the school for the blind and partially sighted. At this school we were, in all practical matters, treated as if we were blind. Although the staff must have known that I actually could see quite well in some situations, a régime was set up to teach me to read and write Braille. Reading with the tips of my fingers was not easy, so I developed the knack of reading Braille by sight, because the raised dimples cast shadows on the paper, making them much easier for me to read by sight than by touch. For this I was punished; it was considered cheating, and for a week I was confined to my room after classes. For the next couple of months I had to wear a heavy, lined, black mask covering my eyes in class when reading, in order to keep me from peeking. Eventually my Braille proficiency increased, so the mask was dispensed with.

Although I had become a leader at this school, having a definite advantage over the genuinely blind and the gravely partially sighted pupils, I was quite unhappy there and strongly resented being treated as blind. So one day I ran away. Completely on my own I crossed Stockholm, from the north to the far south of the city. I reached my home by midnight, after more than ten hours of walking, retracing the exact route my father used when driving us home on weekends.

It was decided that I should again try to attend a regular school. In this school I was fortunate to have a teacher who had an understanding for my handicap and who really tried to help me. He was in many ways ahead of his time. He let me move my desk close to the blackboard so that I could see what was being written, breaking the regular geometric order of the desks that was so much cherished by other teachers. Also, he let me move around during lessons, so that I could inspect at close quarters things that were being demonstrated – something that was unthinkable among his colleagues, who took pride in having their pupils always sitting attentively at their places. And he always told us what he was writing on the blackboard, which was of great help to me. Because of this outstanding teacher, I soon managed to catch up with my peers, regaining much that had been lost in the years I spent at the school for the blind.

Vocational Experiences

From a man with achromatopsia in his 40's who is a social worker: "I have learned that the better you become at using the vision you have and the more practice you have at taking risks, the more comfortable you will be in whatever kind of work you choose to try. Life is full of risks that have nothing to do with vision. As for the risks that are related to being visually impaired, you need to develop as many coping strategies as you can, if you want to achieve your vocational goals. The more you learn about how to make use of tinted lenses, methods of shading or otherwise reducing the light level, using contrast to enhance visibility or readability (for example, using black pens instead of blue pens), and, with computer screens, learning how to change background and foreground colors, etc. – these and other coping strategies can be applied to vocational situations. Also, knowing who you are as a person is critical for anyone deciding on a vocation, whether they are sight impaired or not. I think that young people should take advantage of as many entry level jobs as possible. My first job was washing dishes in a restaurant. That taught me how hard it is to make a dollar. Now I have a government paid position in the upper range of my profession. Another bit of advice I would pass on to young people who are trying to decide on a vocation is to ask yourself what kind of work you would like to do if you were fully sighted. Then try to find out if there are other partially sighted persons who are doing that kind of work and, if so, what kinds of adaptations they have made. It takes more effort for a partially sighted person to achieve many of these things, and it's best to simply acknowledge that fact from the start and get on with whatever needs to be done, even when life seems very unfair. If you don't put out the effort, then you will only end up poorer and less satisfied. I believe that there are many kinds of jobs that an achromat cannot do well, but there are many other kinds of jobs that we can do very effectively. Choose something that makes you feel good. I was a career counselor for vision impaired persons for 5 years, and I learned a lot about all this from my clients, as well as by reflecting on my own life."

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From a woman with achromatopsia: "I have had many different kinds of jobs in my life. I have worked in school settings, in a hospital, and in offices – and once I had a job teaching exercise and giving massages at a women's fitness center. My favorite jobs have been those I have managed to do in my home. I very much like being able to fix up my work areas so that the lighting, work surfaces, etc., are conducive to my being able to see as well as possible."

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From a woman in her 30's: "I want to share information about how I have managed in various job situations. I've thought a lot about this, and I think I am really a bad example. The fact is that I do very little to help my situation. I don't know if it's laziness or if it's my tendency to not want to bother anybody. Perhaps it's my upbringing. In my family, expressing any need for help was seen as either a sign of weakness or a desire for special attention. To encourage this was seen as 'spoiling' or 'pampering' a child. I think this has greatly influenced me in relation to work situations. First of all, I grew up convinced that nobody would want to hire me – and so, when they do hire me, I find that I am willing to knock myself out just to show my gratitude. I find it difficult to stand up for my rights, because, deep inside, I am convinced that I am basically undeserving."

“During my college years, there were several people who tried to discourage me from becoming a teacher, saying that I would not be able to cope because of my eyesight. Had it not been for my parents’ support and their belief in me, I don’t think I would have stuck it out. For the last two years I have worked at a special school for disabled children. The only special aids I use are my very dark contact lenses, which I am totally dependent on.”

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From another networker: “As far as adapting to different work situations, the best advice I can give is to be open about your limitations and your needs. When I taught preschool, I was very up front about my vision, and I found that everyone was supportive. I did whatever I needed to do as far as adapting. If an activity had to do with color, I asked for help. When I found myself to be the only teacher on the playground, I kept walking around in order to keep an eye on what the kids were up to. On such occasions, I would remind the director of the preschool that I preferred that there always be another teacher on duty whenever I was on the playground. She was very understanding and accommodating. Later on I did substitute teaching, and this was harder, because each day I was in a different class or a different school. Again I did not try to hide my sight limitations, but I did avoid working at the schools that had the dreaded combination of white walls and fluorescent lights. Overall I have found that, when co-workers see that I am adapting to my limitations and that I make it clear what I need (for instance, getting something enlarged), they tend to be very helpful.”

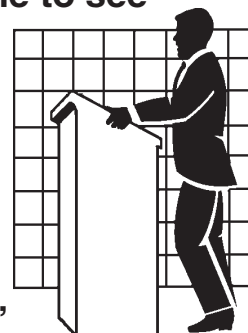
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And from another: “For a number of years I was a special education teacher, in both residential and public school programs. My biggest concern in terms of how my vision impairment might affect my ability to do my job was in connection with activities outdoors – i.e., supervising students during recess, fire drills, or field trips. My greatest fear was that some child might get hurt because of my inability to supervise well visually. Fortunately, there was always a sufficient number of other teachers on hand to help with the supervision. I learned to be open with other teachers about the reasons for my concerns about playground duty. I also made use of paid and volunteer aides and student teachers who could be called on to help out at certain times of the day or on field trips. I found that, in special education programs, a teacher with a disability is usually well accepted and accommodated, both on principle and also because of the positive attitudes toward the disabled which are prevalent among special education professionals. When I worked in VH programs, my vision impairment was even perceived as a ‘plus.’ Also, class size tends to be quite small, so there isn’t the problem of needing to oversee a large number of students. My only experience with regular classroom teaching was the student teaching I did in 2 schools, which was made easier by the fact that my supervising teachers were both wonderful and accepting – and by the fact that, as a student teacher, I had limited responsibilities. I can imagine many challenges that would need to be dealt with in working as a regular classroom teacher, especially with large classes.”

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From a woman in her 20’s: “I started working at summer jobs at age 17. My brother was a chef at a hotel, and through him I got a job helping out in the kitchen, mostly loading and unloading the dishwasher. I remember being so nervous at first, anticipating everything that could possibly go wrong, but it turned out to be

one of the best summers of my life. I continued working weekends throughout my first year of college, and the next summer I was promoted to chef trainee. I did not really want to become a chef, but I learned a lot, and my limited eyesight did not come into the picture. During my final summer in college, I worked at a seaside resort as a pastry chef. This was the only time I had to disclose to an employer about my vision (the job interview was conducted outside on the patio).”

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From a man with blue cone monochromacy who works as a prison chaplain: “I have recently obtained some very dark wraparound sunglasses, which are great for me outdoors on sunny days. They help me to recognize people’s faces on the compound yard at the prison, as long as the people are no more than 10 or 15 feet away. (*Editor’s note: blue cone monochromats tend to have significantly better visual acuity than rod monochromats.*) I wear lighter colored tinted lenses indoors and am always getting comments like, ‘Hey, Stevie Wonder!’ or ‘What’s happening, Ray Charles?’ or ‘Take those glasses off, so we can see who you are,’ etc. Some of these comments bother me, but in my type of work I’ve learned to just move on. After I tell people that these are medically prescribed glasses, most of them say no more. I also carry around a 6x Walters monocular on my belt. I need this not for reading signs but for security purposes. For example, if there is a man down on the ground or some kind of uprising or some other security problem, I have the means to focus in on that situation. The inmates think it is a can of mace or pepper spray. They ask why a chaplain should carry that, and I simply say that I have to take care of business too. I never tell them it is a visual aid for security purposes. I also carry a 5x pocket magnifier. I can read most print without a magnifier just by holding reading material close. But, when it’s newsprint or smaller, I use a magnifier. As a state chaplain, I have to do considerable paperwork, and some of it has very fine print. I also have to type a lot of sermons, Bible studies, documents, letters, and inter-office communications, using my computer and keyboard. I have a 21-inch monitor, which is a blessing. When I type sermons or Bible study notes, I make the font 28 points. Notes printed in this size font are easy for me to read from my pulpit without having to bend over or hold the pages close to my face (which I believe would make my listeners uncomfortable). I have ZoomText 6.3 computer magnification software, which lets me magnify from 2x to 24x. I use it mainly when I have to type numerous pages of study notes. This helps my posture. I don’t have to bend over and stare at the monitor closely, so neck and shoulder stress are greatly reduced. I like to make the monitor background gray with black letters. This eliminates glare and prevents eye ‘burnout.’ I also have a CCTV in my office next to my computer. I can put any kind of document, letter, or textbook under the CCTV monitor, and it magnifies it for me. I ride my bike to work in nice weather. With my extra dark sunglasses, I am able to see stoplights and traffic signs. In bad weather my wife drives me to work. Overall, I feel that, using these adaptive methods and devices, I function very normally. I love my prison ministry. It is very rewarding. At times some of the employees have made cutting, degrading remarks about my eye condition. Others make comments that are done in friendship and jest, which do not bother me. The inmates have a high respect for me. I think they respect me because they see how I am overcoming my handicap with God’s grace and mercy.”



From a man in his early 40's: "I work as a technical writer. I am responsible for writing corporate policies and procedures. I require a 17" computer monitor with the screen colors set for white text on a black background and with the screen resolution set to 640x480. I have to sit embarrassingly close to the screen. At my request, I have been assigned a workspace that is away from windows, with the fluorescent overhead light fixture removed. When I started working at my present job, I required some special help with the photocopy machine, the printers, and the fax machine, so that I could memorize the buttons which I would most frequently need to use. The hardest thing for co-workers to understand is my reluctance to go out for coffee, lunch, or other events in locations where my vision would put me at a disadvantage."

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"I do a lot of public speaking in my work, and in these settings I like to be 'up front' about my vision, because the people in the audience won't be listening to me if they're wondering about my eyes. But I don't want this piece of information to be uncomfortable for them, so I usually back it up with a joke. I try to make the lighting as comfortable for me as possible. When I have a speaking or singing engagement, I'm not shy about having curtains drawn or spotlights toned down."

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From a networker in her 30's: "To young people looking for employment: please tell your prospective boss about your vision. We can fake it pretty well, can't we? And we think we won't get hired, if they know the truth. Legally there's no grounds for that. I used to be very secretive about my vision. Then I got hired to work in library administration, where I had to file the blue copy and retain the pink one (or was it the other way around?) What a mess! If I could live my early life over again, I would tell people who needed to know exactly what my situation was – in medical detail, with complete confidence and with my head held high."

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From a woman with achromatopsia in her late 70's: "I managed to do office work most of my life. For the past 20 years, I have been doing after-hours emergency telephone work for two local veterinary services."

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"I am a homemaker and a mom, and I am also a freelance writer. I spend a lot of time at the computer. I have a 17" monitor and I set my computer on 'high contrast.' I like to use a dark screen and large white letters. For regular income, I provide respite care for handicapped children in our home."

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From a new networker: "Our daughter, who is 20 years old and in college, has achromatopsia. She is an amazing person. She is a certified dance instructor in ballet, jazz, and tap. Her art work has won awards, and she has always been an honor student. She has tremendous determination, drive, and motivation.

She has just returned from Haiti, where she was part of a group of students who worked in an orphanage and also studied Haitian art. She has grown up experiencing many triumphs and many frustrations. We would like to share a message of encouragement to others in the network who may be concerned about these matters."

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From another networker: "In my profession as a ballet teacher, I hide my vision problem. Only a few close friends know. However, the problem is there, and I find it increasingly difficult to deal with. I realize more and more that it limits me, especially in social situations."



After learning that one of our members, a man in his 30's who works in the field of information technology, is very enthusiastic about an optical device called the Ocutech, I asked him to prepare a write-up about this device. It is important for readers to understand that this person is an incomplete rod monochromat who has visual acuity that is considerably better than that of most rod monochromats. He writes, "The Ocutech, a 4x magnification telescope (which is actually a periscope) is mounted horizontally on spectacle frames adapted with a mounting bracket along the bridge (i.e., centered above the nosepiece). It's about 4 inches long, half an inch high, and less than three quarters of an inch deep. It is light-weight and can be adjusted on one's frames to suit individual physical characteristics. I found that it did not take long for me to get accustomed to using it. You can have it mounted so that the eyepiece is level with the lid of your dominant eye (I use my left eye for looking at something through the Ocutech). Whenever you need to 'zoom in' on something in order to see it better, you simply raise your eyes slightly in order to look through the Ocutech lens. This often means lowering your head slightly, since the telescope is aligned just above your normal line of sight. You adjust a small wheel on the front of the device, which allows you to focus on objects from one foot to infinity. I use the Ocutech a lot at work, mainly for looking at my computer screen. It allows me to sit at a normal viewing distance from the screen, and this means less strain on my upper body and on my eyes. I also make use of some enlarging software, some special fonts, and altered colors on the screen. I have found that the Ocutech has been invaluable to me in classroom environments, and I have used it at the theater, at sporting events, and when I am watching TV at a distance (though I prefer to sit up close to TV). Also, it allows my hands to be free for playing the piano.

"I do not tend to walk around wearing this device on my frames. Instead I put it on when I begin an activity in which I will need it. There are a couple of reasons for this. (1) The periscope appears as a dark line about the size and thickness of a finger in your upper peripheral vision and so is a bit distracting. It becomes something of a 'barrier' when I talk with people. Therefore, I tend to take off the adapted glasses, so that I can look at people without distraction and so that they can see my face without this little 'visor' across my eyebrows. (2) As with most low vision aids, it looks somewhat odd (though certainly not as odd as the 'bug-eyed' lens-mounted binoculars I used as a kid in school!). In some ways, it's quite discreet, though people are distracted by it the first couple of times they see it. Many of my colleagues have gotten used to it, so I don't feel the need to 'lower the barrier' so often now. Also, it is a very expensive piece of equipment, so I am careful about where and when I wear it. When I first learned about the Ocutech, I was able to borrow one at my low vision clinic to try it out. When I decided I liked it, one was ordered for me by my optometrist. Someone who doesn't have access to a low vision clinic and who wants to try an Ocutech can contact the company directly in order to be put in contact with someone who can help – Ocutech, 109 Conner Dr., Ste 2105, Chapel Hill, NC 27514, (800) 326-6460. The biggest barrier to using something like this might be the embarrassment of looking a bit odd, but I think that people need to get used to seeing this kind of thing, just as they've gotten used to seeing wheelchairs and white canes. This device has made such a difference in my life.

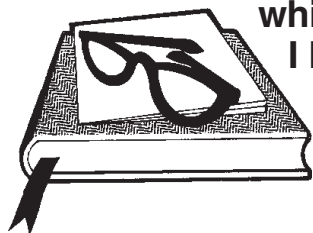


I'm more productive at work, less physically stressed (no more nose-to-the-monitor), and more confident about tackling visual challenges in a variety of situations. In the company where I work, there is one other person who uses an Ocutech aid. He just purchased the Auto-focus model, which is much more expensive. I realize that there can be advantages in having an optical aid which focuses automatically, but I personally would not want to relinquish control of the focusing, and the Auto-focus model is a bit bigger than my manual version. Still, this person has found it to be a great device for his needs."

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"Our son, age 23, has achromatopsia. He works for an electrical construction company and is in an apprenticeship program. If he continues with this, in about 3 or 4 years he will have a great trade. He has already completed many work projects around the house. We were surprised at how well he manages with all the different colors of wires. He has developed his own system and only occasionally needs to ask us or his co-workers. Two months ago he was invited to become manager of the warehouse, so now he is salaried and has 2 people to supervise. It's not a great paying job, but it is great experience for him. He is very well organized, and that quality, along with a good work ethic, led to this position."

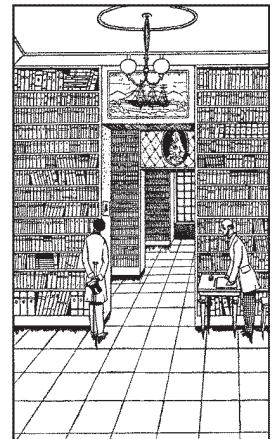
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From a member who has a Ph.D. in physics and whose professional experience has included work as a physicist and software engineer, as well as teaching and writing in these fields: "Ordinary eyeglasses (Rx lenses) have never been of much use to me, but I find spectacle mounted magnifying lenses helpful. The first time I got to experience using adequate magnification was when I was an undergraduate and a fellow engineering student showed me his optical aid and told me where it could be obtained. From 4x to 8x works best for me. I have successfully modified commercial binoculars and monoculars to focus on nearer objects by adding an extension between the eyepiece and the body of the instrument, but the best solution is to obtain something like the Walters close focus monocular. I also use a 4x pocket magnifier and 4x spectacle-mounted monoculars. I wish that, during my school years, I'd had the aids I have now. Helpful and understanding teachers and fellow students made the difference between success and failure for me in school. I had to give close attention to teachers' lectures. Friends helped me by letting me consult their notes taken from blackboard presentations when I was unable to acquire complete information from the verbal presentations.

"I have always been an avid reader. Because I use magnifying lenses, I find it more comfortable to read in a reclining position with the text close to my face. My spectacle-mounted monocular lets me read everything necessary in my work environment, but at home I only use it for computer work. For reading ordinary print, I use from 2x to 4x magnification, but I need 4x to read mathematical symbols and dictionary print. I do not work in brightly lighted conditions if I can arrange for indirect and/or subdued lighting. I have had mostly positive experiences with co-workers and work supervisors once I have been on a job long enough for all parties to become at ease about my vision. There have been some job situations in which, during the early stages of adapting to a new work environment, I have had to find ways to give my employer confidence in my ability to do the job. However, I have a continuing problem whenever I need to become involved in a job search. I must admit that I still do not know how to (or whether to) discuss my vision difficulties



in a job application or in an interview. My inclination has been to be forthright about things, but this has not always worked out well. I have tried it both ways. In some cases, doing so has worked against my receiving a job offer. On the other hand, I was able to keep my first job, despite the attempts of the company medical and personnel departments to terminate me, and the reason I was able to do so was that I had been completely frank about my vision with the engineers who had interviewed me. They didn't hesitate to go to bat for me in those circumstances – and this was decades before the Americans with Disabilities Act. I am sure things have changed for the better because of that law. The single biggest problem for me has been my inability to drive a car. As a teenager I did learn to drive on deserted country roads at night, but I could never drive safely in other circumstances. I depend on ride sharing, walking, and public transportation.”

A section focusing on job experiences would not be complete without some input about the kinds of utterly embarrassing situations that most (if not all) of us achromats have found ourselves in at various times. The following was shared by a woman with achromatopsia: “Something that has been puzzling me for a long time is the concept of ‘equal opportunity’ in employment, as it applies to persons like myself who have impaired vision. What exactly does this mean? I’ve been told that, if you can do a job just as well as someone who does not have a disability, you should have an equal chance of getting the job. That sounds great! But can we do some of these jobs as well? In college I got a job at the university library shelving books, I know that I shelved them just as well as anybody else – it just took me six times as long. Other shelvees would step into the stacks, flash their eyes left and right, and presto! Here a book, there a book, and soon their carts were empty. Meanwhile, I would be lying on the floor trying to find NBE 96.361, crawling along to the end of the bottom shelf. Oops! Better go to the top shelf of the next row. Go find a little stool to stand on, then stretch – and, after 5 minutes of eyestrain, I would get one book shelved! So I couldn't really blame them when they dismissed me from that job. They were nice about it. They sent me to the front desk to try a different job. My task there was to organize the books into categories according to the color on the card. Need I say more about how I handled that job? After that I got transferred to the check-out desk where, even with my nose pressed to the screen, I couldn't see the print on the screen as well as the students who were on the other side of the counter checking out books. So much for being able to work at the library!



“Then I went to work at Taco Bell. They were desperate for workers, as their summer staff were all back in high school. I was assigned to the cash register. I had to memorize a whole keyboard of buttons on the register, each representing a different item on the menu – but they weren't marked. I had nearly mastered it after about 3 weeks, though I was still making an occasional mistake. I had great admiration for my co-workers, who had all memorized it very quickly. It was much later that someone explained to me that the keys were color coded. On one occasion, my job was to stop the timer on the deep fryer. Tacos, fajitas, etc., were fried for different amounts of time. There was a different black button for each item. When the bell went off, the item was to be removed from the fryer. There were

about 8 little black buttons up high on the fan over the fryer. I wondered how anyone could be expected to always remember which button had been pressed. I was at the cash register with a line of customers waiting when the bell went off. I ran to the fryer to stop the bell, but I didn't press the right button. So now 2 bells were going. I began frantically pushing all the buttons in the hope that they would shut up. By this time, the customers were laughing at me, and my co-workers were cursing at me. One co-worker finally left his onion chopping and, with one touch of the finger, stopped the whole screeching farce. After all the sniggering customers and angry, head-shaking co-workers had gone, I found out that the way other people knew which black button to push was that a red light would come on in that button when the bell sounded – something I couldn't see. Previously I had been asked if I could see the buttons, and I had said, 'yes,' because I could indeed see them. After this experience, I realized that what they had meant was whether I could see the red light in the button when the bell would come on, letting me know which button to press. It isn't always easy to know what people mean when they say, 'Can you see this?' How stupid I must have looked to the customers, who could – even clear across the room – tell where a red light had flashed on!"

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From a woman in her 40's: "When I first started working, I found out how bright the lighting in most offices was. That was back in the 70's and 80's, long before the Americans with Disabilities Act. I got no cooperation whatever from the company I worked for, when I asked to have the overhead lighting turned off and to be supplied with a lamp for my desk instead. I was told that it would constitute a 'threat to their on-the-job safety record' to dim the lighting. I always wondered why they didn't acknowledge that not dimming the light was a threat to my personal safety and productivity – which could statistically affect the company's records. So I wore tinted lenses to alleviate my problems in coping with the obnoxious (standard) office lighting, the computer screen glare, and the very light printouts I had to read. Sometimes I would climb up onto desks and unscrew the fluorescent tubes, then (if asked) claim that they had burned out. Unfortunately, the maintenance department was very efficient."

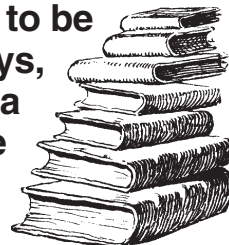
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"I work at home and use a Macintosh computer. When I was shopping around for a computer several years ago, I consulted a lot of people who were familiar with different kinds of computers, and many of them advised me to get a Macintosh, because it is so 'user friendly.' For the word processing which I do, I use a program called ClarisWorks (now called AppleWorks). With this program, I can make whatever I am typing appear as large as I need it to be on the screen. It can enlarge in 1% increments up to a maximum of 800%. I set the size of print for the screen to 250% or 300% enlargement and the font size at 14 point, using the Helvetica Bold font, and I can easily see what I am typing without having to strain or lean forward. When I print out the material I have typed, I can easily read the material, because it is already set at 14 point type. ClarisWorks (AppleWorks) also has modules for working with a database, a spreadsheet, drawing, painting, and communications. I also make use of Closeview, which is part of all Macintosh computers' operating system software. I use Closeview when I want to switch from black print on a white background to white print on a black background or to enlarge the menus or anything else on the screen when I'm not



using ClarisWorks. I prefer reading black print against a white background that has had the lighting dimmed (normally sighted people would probably call the screen color gray). I simply adjust the contrast dial and the brightness dial to get the most comfortable contrast for reading the monitor.”

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From a woman with achromatopsia who works as an attorney at a disability rights center: “It is important for those of us who have impaired vision not to be silent about what we need in the workplace. Most employers do not know much about what the Americans with Disabilities Act requires of them (though they may act as if they do), so I would never accept at face value an employer’s assertion that she or he has no obligation to provide a particular accommodation that is needed, as long as the accommodation is a reasonable one. It may not be reasonable, for example, to expect a small, struggling, 2-person office to hire you, if the job requires that you be on the road a lot, thus necessitating the expense of hiring a driver for you. But it may be quite reasonable for a large corporation to provide this type of accommodation. I receive various special accommodations in my workplace. For example, I receive help with filing. I have to keep track of many documents, and I cannot easily scan my desktop or table to see what’s there. Memorizing where things are and doing clerical work that involves organizing, copying, typing, etc., are definitely not where my strengths are – although things are vastly improved for me now that I have glasses with a mounted telescopic aid. These glasses are a ‘must’ for me for typing and computer work. Also I have been provided with a special lamp with a dimmer switch, which I use instead of the overhead light.”

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From a woman with achromatopsia who works as a librarian: “When I started working in a large metropolitan area, I felt overwhelmed by the competition in the workforce. So many people were looking for work, and I had to be especially good at what I did. I found myself working long hours in order to keep up with normally sighted people doing the same kind of work. I manage fine working with standard print, if it’s not too small, but I now enjoy large print materials for my leisure reading (though I did not like using large print when I was younger), and I also enjoy listening to books on tape for relaxing. I can enhance print on the computer so easily, using Microsoft programs that are geared to that. I make full use of any magnification programs available to me at the library where I work – Closeview on the Macintosh and ZoomText for PC’s. I use hand held magnifiers a lot. Print has been getting smaller in reference books to save on publishing costs. There is more and more information which has to be included in these books, so smaller print has been used to accommodate this. When I started working as a librarian, there wasn’t much assistive technology available. I find it a treat to use all of the devices and aids that are available now. My biggest problem at work is when someone is in a hurry to get some information. I can’t just snap out something for them as quickly as a normally sighted librarian can. So I’ve learned to be as personable as I can be, sometimes making excuses for my slow ways, trying to get people to back down a little and to sense my frustration a little too. I don’t drive, so this has limited my job opportunities. I have always needed to find work in places that are accessible to buses or subways, and I can’t be used as a ‘gopher,’ driving here and there to



pick up books, documents, etc. My employers know that, if I can't get someplace by walking or by using public transportation, they have to rely on someone else for pick-up or delivery."

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From a woman with achromatopsia: "I teach young children. My work can be frustrating at times, especially during outdoor play time. But my co-workers at the school are very nice and helpful. They arrange the schedule so that I am almost never the only teacher on the play yard. When I am there, I sit in a shady area, I keep my ears open, and I take frequent walks around the yard, so that I don't miss anything. Quite often I rely on the children for information. For example, I might ask, 'Ashlee, who is playing in the drinking fountain?' She'll eagerly answer, 'It's Danny,' and then I can call out, 'Danny, come away from the drinking fountain!' The little ones still think that I can see clear across the play yard. Few of the children have actually caught on to the fact that I have a vision problem. Some of the parents know. Our director encourages me to speak up whenever I need help. I do have some trouble with art projects which involve color. Often I turn this into a learning experience for the children. For instance, I might say, 'Kenny, show me the green paint.' The director of our program just stands back and laughs when she hears this. The other teachers can always tell when I am the one who put the caps back on the marking pens. The blue cap may be on the green marker, the brown cap may be on the red marker, etc. It wasn't until recently that I fully realized why I so often tend to come home exhausted. There are times when it is very clear to me that I have to put out at least twice the energy and effort that the other teachers do. But the problems don't keep me from enjoying the children and my work."

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From a man who works as an occupational therapist: "In my work I am continually being an advocate for people with various kinds of disabilities, yet I find that I face difficulties among my own co-workers who, like myself, routinely advocate for the disabled. For instance, some of my co-workers have been unwilling to accept the lighting changes that would help me in my workplace. The administration and the head of my department agreed to the changes I needed. They said, 'Anything you want. What do you need done?,' etc. But the attitude of my co-workers was different. They didn't want desks to be moved or anything like that. Finally, my desk was moved. A large monitor was obtained for me, partitions were bought, and an overhead fluorescent light was turned off over my new work area. They're even trying to figure out a way to dim the overall lighting of the area surrounding my desk. It was interesting, though, to observe that some of these people who regularly go to workplaces on behalf of persons with disabilities to help them get what they need in order to function at their jobs would resist so strongly any changes that would affect their own work environments. As I was trying to find ways to get rid of glare around my computer screen, I tried making a cardboard frame to fit around the computer, and I velcroed it on. One of my co-workers said, 'Why don't you just put a sheet over you or the kind of covering that is thrown over a photographer's camera, when you're using the computer?' Right away I said, 'No!' I knew that I didn't want to be under a covering and to be seen that way. But I also knew that it would not be right for me to have to do that."



There would be lots of ‘functional’ considerations too, like being able to answer the phone while using the computer or going to get some notes and then putting them down on the desk – or being able to fully see, hear, and feel what’s going on around me. Then I read about my rights under the Americans with Disabilities Act and about stuff related to dignity. I found myself feeling more and more appalled that someone would even suggest that this should be the way my work environment should be adapted and that I should be secluded and hidden from everyone else this way. I began to feel furious about this. I am so glad now that, when I met the resistance from my co-workers after simply asking for a change of desk arrangements, I went directly to my supervisors and presented a list of my needs. I told them: ‘This needs to be taken care of immediately.’ Within a couple of hours I was in the office of the higher supervisor, who said, ‘No problem.’ They had to go through the office environment consultant, but before long I had all the ‘reasonable accommodations’ to which I was entitled.”

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“I am interested in knowing whether other networkers reveal their disability in job interviews. When I first got out of college, I did not do this. I grew up with the belief that I would be discriminated against if I revealed my vision impairment during an interview. I always felt a little uptight as a result, especially when shown something at a distance which I was expected to see. Later I began telling about my vision in interviews and consequently felt a lot more comfortable about the interview process. Also, employers knew what to expect when they took me on.”

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From a woman with achromatopsia: “I think it is important, when one has a disability, to get the best education possible and to identify a profession or a ‘calling’ in which one can make a unique contribution, because a lot of so-called ‘unskilled’ jobs require, instead of a special skill, certain physical attributes such as good visual acuity or physical strength. I once worked as a counselor in group residences for persons with developmental disabilities – planning activities, teaching living skills, etc. I never discussed my vision disability, except to say that I was very nearsighted, and it never came up as a factor in my work performance. What mattered in that job was how I related to the people with whom I worked.”

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“I think that what I need is vocational counseling that is very specific to my situation. Whenever I think of a job I want to try, it is hard to know ahead of time what kinds of visual demands will be placed on me in that kind of work.”

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“Soon after I got out of high school, I got a job as a darkroom technician in the X-ray department of a hospital. Whenever I stepped out of the darkroom, I had to wear red goggles, in order to stay dark adapted. I didn’t realize that I had found a great job for an achromat. I often got to guide normally sighted persons (X-ray technicians, doctors, etc.) around, when they had to enter the darkroom without having time to dark adapt. I didn’t feel at all visually impaired in that job.”

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“I avoided taking jobs for as long as I could, because I was afraid that my performance – whether bagging groceries or mowing people’s lawns or whatever – would be inadequate and that I would feel ashamed and be castigated by a ‘boss.’ My first job was in college, as a counter attendant at a library, and I didn’t last even 2 days. It was obvious that I couldn’t handle the filing easily, and people were impatient with the slowness of my work. The person assigned to work with

me simply protested that I wasn't good at this kind of work. I was then placed at a different library on campus, where there were several people around me doing the same kinds of tasks. Sometimes I would ask them to do certain things for me; and, since I related to them easily and there was always a lot of laughter going on, they didn't seem to mind helping me. I would do my filing when no one was at the counter to be helped. I felt I had to do whatever was necessary to keep from looking incompetent in front of others. The hardest part was working in the business section of the library, where I had to find stock quotes, interest rates, etc. As much as possible, I did not read in front of people. When it was necessary to do so, people could tell that it was hard for me, and I think they sometimes demanded less of me because of this. To my mind, this raises an ethical question: Is it right for a person with low vision to choose a career in which other people will feel as if they have to compensate for you? To what extent is that acceptable? I guess it's an individual matter. I'll let others compensate for me to a certain extent, but at some point it gets to be ridiculous."

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From a networker who works with blind adults at a center for developmentally disabled: "My work is challenging and rewarding. Frequently someone will ask why I am so knowledgeable and understanding about the needs of our blind clients. I simply tell them that at times I am almost as blind as these clients are. Then I explain why that is."

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"I work in a hospital setting. My office now has a 'dimmed' corner, which is partly partitioned, and I have been provided with a 21-inch computer screen to make documenting easier for me. Obtaining the lighting that I need for visual contrast and minimizing glare has actually led to the administrative planning persons giving more consideration to lighting factors throughout the hospital, whenever additions or changes were being made."

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"I have worked for 12 years doing medical coding/data entry for ambulance services. I once worked in a huge office where there was one wall entirely of windows which received the morning sun. I asked to have my desk placed so that I faced the opposite wall; and, even then, I had to wear tinted lenses while I was typing. Thankfully, now I work from my home via modem telecommuting. I do the same work that I did in that office, but now everything about my work station at home has been arranged to meet my needs."

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"Many years ago, during a performance review, I had a confrontation about my eyesight with my supervisor at work. He said that I needed to work on not coming across as so 'unfriendly.' I was stunned, as I had many friends at work and had the reputation of being a problem-solver. When I asked him to explain, it turned out that he was referring to the fact that I had failed to acknowledge his nods and waves in the halls. Well, it had previously been suggested to me that I not wear my usual 'indoor sunglasses' when away from my desk, so that people wouldn't think I had a drug or alcohol problem – so, naturally, out in the bright hallways, I couldn't see properly. By the way, this was a long time before the Americans with Disabilities Act. I explained my eye problem to this supervisor, but I don't think he ever really understood. This same supervisor had refused to allow me to turn out the lights over my desk, which forced me to wear sunglasses while I worked. Today someone like



him would probably be hauled in and dressed down, but 20 years ago this kind of thing was all too prevalent. My next supervisor was very understanding and allowed me to turn off all my room lights. I worked with a table lamp set several feet to the side of my desk – and I noticed that soon other people where I worked began doing the same.”

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From a man in his 40's: “Up until the last 10 years or so, I would always say that the worst part of having achromatopsia was my extreme light sensitivity and poor vision and that my colorblindness wasn't a big issue. However, in recent years, the emergence of LED chips in everyday products, PC software, color printers and copiers, websites, etc., my colorblindness has become a big problem.”

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“I was a teacher for a number of years in the field of special education for the visually impaired. The classrooms assigned to me at different schools where I taught varied a great deal in terms of lighting. In one school there was a wall of windows in my classroom, and the way I managed was to (1) situate my desk so that I didn't face the windows, (2) position myself with my back to the windows whenever I worked individually with the students at their desks, and (3) wear my 'indoor tinted lenses.' The windows faced east, so in the afternoons I no longer had to wear the tinted lenses. This was before the ADA and the recognition of 'reasonable accommodations' for employees with special needs. The idea of requesting special lighting modifications never even occurred to me back then. Even if that had been a possibility, it wouldn't have been an easy choice to make, because so many of my students had eye conditions which caused them to need as much light as possible in order to see. I could at least do things that allowed me to see better. They could not. Luckily, in some of my teaching jobs, I had classrooms which had lighting that was very favorable for my vision. My favorite classroom was a basement room that had short windows in the upper part of one wall. Outside the windows was thick shrubbery which provided shade.”

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“In a recent newsletter I read about the teacher who was having problems getting the administration to provide the lighting she needed in her classroom. I am also a teacher, and in the past I have had many problems in terms of classroom lighting. The classroom I currently work in has windows covering an entire wall. It is like working in a conservatory. As one way to deal with this problem, I have hung posters, charts, and maps on the windows. I also mounted the children's art work on black paper and hung these on the windows.” *(Editor's note: the teacher whose situation is referred to by this reader had devised a scheme for achieving the lighting she needed in order to maximize her vision without diminishing the vision of her students. Her proposal to the school administrators involved installing adjustable draperies for the windows and 4 separate dimming devices for controlling the light in each of the 4 sections of the room.)*

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From a man in his 40's: “I do computer training. Usually I'm standing behind people and using my scope to see their screens. But recently there was a woman who wanted me to show her how to use a particular program. At one point she got up and asked me to sit down and demonstrate the program, so that she could watch. But the situation changes when I am in front and the student is behind me. It's very uncomfortable for some of these people to watch me struggling to

read the screen. I even feel that it is ethically wrong for me to subject them to this, if it is not absolutely necessary. Some of them literally cringe at the experience. This particular woman said, 'It makes me feel so uncomfortable to see you straining at that.' So I said to her, 'Don't worry about it. This is the way I see.' If I had it to do over again, I think I would have asked this woman to remain seated, explaining that I could direct her better from behind, using my scope to view her screen. But, for some reason, I was determined at the time to see it through – and it became pretty uncomfortable. She began saying things like, 'Man! This computer work is making you blind! You'd better find another line of business,' etc. It came as something of a shock to me to be so rudely addressed. It brought back memories of being back in grade school and being harassed by other kids.

"I think this experience underlines the need for me to be judicious and to present myself in the best possible light in a professional setting; because, if people feel stress as a result of watching me grope around, it's not very considerate to them. This person was letting me know the discomfort she was feeling. She wasn't being mean-spirited. She was just a plain-spoken person who was genuinely uncomfortable. Once last year, when I was with a woman I was dating, I began working on my laptop computer, and it was easy to tell that she was extremely uncomfortable watching me as I was looking at that screen. At one point she said, 'It looks so laborious the way you have to strain so hard at that!' The funny thing is that, to me, it's actually not straining – it's just the way I read.

"Occasionally I lead seminars in which I must read from a projection screen as well as from printed materials from time to time. Recently a participant in one of these seminars really lashed out at me in her written responses on the form that participants use for giving feedback about the seminar. She expressed criticism of the way I had to look so close at whatever I was reading. In the introductory part of these seminars, I usually say something like, 'I'm about the most near-sighted person you're ever going to meet, so you'll be seeing me get really close to the screen as I tell about the demo I'll be showing you. So, if you have questions as I'm doing this, just shout my name. I'm not at all bothered by this, and you will get my attention.

"Even when I explain to people ahead of time about the scope I use, I have found that, while some of them seem comfortable with it, others seem very uncomfortable about my using it. So, for purposes of developing rapport with a new group, I find it's best to postpone or minimize use of the scope, at least at the beginning of any group activity I'm leading. For awhile, after first getting my scope, I remember thinking that I didn't care if people are comfortable with it or not. But later I decided that, if I wanted repeat business from clients, I needed to come up with the best balance I could in terms of using the scope. I need to consider my skills in human relations as well as my visual skills, and I need to fit into these situations as well as I can. I think that sensitivity to the feelings of people who have absolutely no experience with low vision persons or low vision devices is warranted. If other vision impaired people choose to use low vision aids most or all of the time, they are entitled to follow what seems right to them, but in my own situation I think I'm better off using the scope just now and then."



From a man with achromatopsia who is a social worker: “I have found that a useful book for career planning is Richard Bolles’ *What Color Is Your Parachute?* A key exercise suggested is to think about what your ‘vision’ for your life is and how you plan to ‘get there.’ It helps you to evaluate what your strengths, weaknesses, aptitudes, and needs are. Those of us who are visually impaired also need to be well aware of what our visual abilities and our visual limitations are. We may look to others to help us get the adaptations and accommodations we need in the workplace, but it is mainly up to us to make this happen. Unless you are very well placed in society, careers have to start very humbly. When I was a career counselor, I was dismayed at how many visually impaired clients avoided entry level employment. It’s fine to want meaningful careers; but, first and foremost, people need to be able to make a living. A partially sighted mechanic I met used to say, ‘Don’t give yourself yet another disability by not getting an education.’ Some advice I often gave to visually impaired clients was to practice describing their abilities and limitations in a way that clearly communicates how they have adapted. It puts others at ease about this subject. When to disclose information about your vision impairment is the biggest challenge for job seekers. Like so many other partially sighted persons, I had to work hard to establish myself in my vocation. I had periods of unemployment and I struggled with many issues.”

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From a woman in her 30’s with achromatopsia: “My father was assistant headmaster of the school I attended in kindergarten and first grade and headmaster of the school I attended in second and third grades. My parents were very much involved with my school work, communicating continually with my teachers to ensure that I was learning and having the same experiences as the other children. My mother would ‘write over’ those ditto sheets that had light blue (so hard to read) print with my homework assignments on them. We moved to another state when I was in fourth grade, and I attended public school. For the first time, I felt like an outsider at school. The fourth grade teacher was very custodial in her treatment of me. I was placed in the lowest reading group, but within a month I was moved to the highest reading group. Because I could not read the blackboard, I had to stand at the side of the board and copy down what was written there. School work assignments at home were fairly easy for me, except for encyclopedia assignments and those little bitty math equations. In my sophomore year of high school, I was introduced to the services for the blind in our state, and I obtained an 8X monocular that I fell in love with. Using it I could read the board even from the back row! I could go to plays and see the facial expressions of the actors. It was very exciting! By the time I was in college, I was very independent, and I never asked for special accommodations. I felt strongly that accomplishing the same tasks assigned to other students by using some sort of alternative technique was the way to go through life – not asking for accommodations that would give me any special privileges that others didn’t have. I received the National Federation of the Blind’s top national scholarship one year. I utilized every service for which I was qualified. The first year out of college, I was hired as Special Project Coordinator for a waste management system in a large metropolitan area. I wrote grant applications and did liaison work with local municipalities. Whenever I had to attend meetings alone instead of with other staff members, I had to hire a driver.

This was before the ADA (Americans with Disabilities Act), so the company I worked for did not provide transportation for me or compensation for my drivers. I always paid the drivers myself. I realized that this left me open to the possibility of huge legal and insurance liabilities. Fortunately, there was never an accident. To and from my office, I would take the bus or carpool with a co-worker. When I was transferred to another office, my husband and I had to find a place to live in the vicinity of the new office. Our choices regarding where to live were always limited by my need to get to and from my work location using public transportation or carpooling. My new job required even more traveling. Many times I would miss meetings because the cabs I called would not show up or would be very late. It was extremely frustrating. Later we moved to a city with a good subway system and I found a job that was accessible by one of the subway lines. Even though it took an hour each way on the train, I was 'in Heaven'! I was able to get off at different stops along the way for doctors' appointments, grocery shopping, and shopping at the mall all by myself! I didn't mind the long rides, because I always had lots of books to read, including recorded books. During those years I wore the Vuarnet sunglasses with PX-5000 lenses that were available then (only 4% light transmission) for outdoors. For indoors, I wore Serengeti Drivers' Sunglasses, which had Corning yellow/orange lenses (supposedly good for drivers, because they cut down on glare). These lenses were light enough that I didn't 'offend' anyone by wearing them indoors, and they took away the glare and discomfort of fluorescent lighting. By this time I had completely given up on prescription glasses, which had never really helped at all with my vision and had severely reduced the options of sunglasses I could wear."

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From another networker: "I have been in between jobs recently and am somewhat embarrassed by the economics of it. Initially it was great, especially for my health, to have time off. I am finding, however, that it is taking much longer than I had thought to find a situation for myself. Worries in connection with my vision do tend to come to the forefront at such transitional times. But I want to say that just knowing – as only the Achromatopsia Network Journal makes possible – that there are people who manage to cope quite successfully with achromatopsia and its frustrations is incredibly helpful. I am choosing to be optimistic."

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From a woman with achromatopsia in her 30's: "This past year I worked as a teacher in a new program called Life Skills. I taught children who are mentally challenged. It was a difficult year, since this was a new program and I had to develop it from nothing. I am very tired! I think going to college was just as tough. I don't think people with vision impairments ever really get to take a break. It takes so long just to get organized for everything that needs to be done. I hated doing papers in college. Doing a research paper was the worst part. I love the kids I've been teaching, but all the paperwork I have had to do was the pits. No one ever tells you when you go into Special Education that 90% of your job will be paperwork. For nine years before I took this job, I provided a day care service in my home. It was convenient in so many ways – the location, the lighting, very little paperwork, and I got to be with my own kids while I worked. I could adapt the environment in any way I wanted. The school where I have been teaching this past year is just down the street from my home, but right now the disadvantages

of this job outweigh the advantages. I feel that I am always having to work so much harder than someone with normal vision. I stayed late after school every day in order to get everything done. I also brought home work to complete every night after my kids went to bed. I worked until midnight or later whenever I had to write an IEP, progress reports, lesson plans, etc., or fill out report cards. I just want anyone who is thinking of going into this profession to know that it takes a lot of stamina and patience in addition to having love for children and the other things that motivate one to enter special education. Devices I have used in my education and in my work include stand magnifiers and a distance magnifying aid. And the commission for the blind gave me a CCTV, which I can use to enlarge anything in print and in any color I choose. Of course, I can't distinguish the colors, but I was told, when I was training in using it, that green on black seemed to offer the best contrast for me. White on black created too much glare for me. In my computer work I have used Zoom Text. It's great but takes some time to practice and get used to. I put black caps with bold, enlarged letters on my keyboard, and this helps considerably. I used my tinted contacts in my classroom, since a lot of sunlight comes into the room. Sometimes when I go down the hall to the teachers' room, I have to take my contacts off because the light is sometimes off in there, and I find it too dark with my contacts on. It has gotten easier for me to take them on and off than it was after I first got them."

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From another woman with achromatopsia who has also worked as a special education teacher: "Many years ago when I first started teaching, I could just go into my own classroom and make whatever accommodations I needed for myself. Now everything in this program has become so much more integrated. Increasingly, I found that what I did affected others and what others did in their teaching affected me more than it had in the past. My vision has always been an issue in my work. I tried to keep myself in the lower grades, where the print used in school work is larger, but this was not always possible. I did a lot of individual reading instruction as part of my job. It was always difficult for me to see what students were reading while they read so that I could help them with words they got stuck on. With the older kids, this was basically an impossible situation for me to manage. I got by as best I could. Being a special education teacher for students integrated in various different classes instead of having a class that I was solely responsible for throughout the day, I was often called upon by the school district to be a substitute teacher. Talk about stress! Having to go into someone else's classroom, try to read someone else's lesson plans, and manage a bunch of kids wearing name tags that I could not read! I always managed to get through the day one way or another. Eventually I learned not to worry so much about lesson plans but instead just to keep the students busy with enrichment activities that I was experienced in using with my special education students. All of us in this group of teachers who were called on when a substitute teacher was needed were unhappy about having to do this. The others seemed to look as frazzled as I did after a day of 'subbing.' I never tried to get out of it by bringing up the additional problems I faced due to my vision, because I felt I should pull my weight. Another problem was that, as years went by, more and more of the information and paperwork I



needed to work with were on computer. Even with a large monitor, I had trouble getting my work done on time. The other special ed teachers in my district were given laptop (instead of desktop) computers, so that they could work at home, if needed. The monitor on the laptop was too small for me to use, yet I could not stay as late as I needed to at school to get the work done on the desktop computer, because I had a ride to and from work with another teacher who did not need to stay late at school. Working with IEP forms was always hard, because the print on those forms was so small. Eventually an even more inclusive special education program in our school was implemented, and my work became increasingly harder. I had to go from classroom to classroom most of the day, providing services to students in their homerooms. In my last year of teaching there were more and more times that I had to tell the classroom teachers I could not manage this or that task because of my vision. I tried everything I could think of to get the job done without shortchanging the students. But I was under a lot of stress; and, no matter how hard I tried, I could not perform all the expected duties of my position as it had become – which was significantly different from the position I had started out with – so I decided to retire from teaching. I did not want to give up the salary. I did not want to give up the career I had worked so hard for and my place in my profession. But I thought it was only fair to have someone in my position who could do the whole job, who could give the students what they needed. I had observed other teachers with disabilities who had not pulled their weight, and I did not want to do that to the children or to my colleagues.”

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From another networker: “When my husband and I (and our newborn daughter) moved to another state to be near family, I started (half-heartedly) looking for a job. My past experiences with job-hunting had been seasoned with so many experiences in which I had encountered discrimination. I did not want to go through that whole process all over again, and so I felt extremely anxious. I didn’t want to have to explain the complexities of my vision disability. I didn’t want to have to explain the alternative techniques I would use to get the job done. I also didn’t want to go for interviews for jobs I really wanted and could do well only to find that they required a lot of driving or something else that I couldn’t resolve easily. Within 3 months I fell into an opportunity that worked wonderfully for me. I became an independent consultant and group leader for a company that sells scented candles and decorating accessories through home parties. I realize that sales work is not for everyone, but it’s been a very good fit for me. I tell my ‘hostesses’ and ‘guests’ at these parties that I have finally found a job I can do in the dark! The benefits of this career for me are many. I can set my own schedule and be with my kids as much as I like. I do most of my work from my home. I don’t have to answer to anyone about what I can or cannot do. I get to make my presentations at the parties in low level lighting. The downside is that driving is necessary for getting to and from the parties. My husband has done the driving for these events, and he would hang out with our kids at the mall until I was finished. Recently, however, I had a minor crisis. My husband got a new job and had to start working swing shift (3PM till midnight). I was afraid that my new career was over. But my parents and my sister came to my rescue, providing the driving and taking care of the kids. I don’t like having to rely on other people this way, but I always try to reciprocate by helping them in some way.”



From a man with achromatopsia in his 40's: "I work part time as a music teacher at a private music school. I offer private lessons in guitar and piano. In the past I have had various jobs, including being a church music director, bookkeeper/computer operator for a construction company, and rehabilitation aide in a program for developmentally disabled persons. I wear high quality sunglasses outdoors. I had the optometrist make them darker than they were 'off the shelf.' In full sunlight I usually wear an additional pair of sunglasses on top of my regular ones. In situations where I don't have to keep my hair looking presentable, I also wear a hat or ball cap. I use a variety of magnifiers and an 8X monocular when I need it. When I was doing a lot of independent travel on busy streets, I carried a white cane, so people would look out for me when I crossed streets at intersections. I have a B.A., a Master's degree in music, a diploma in computer programming from a business college, and a certificate in database programming from a community college. My hobbies include vegetable gardening and black and white photography."

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From another man with achromatopsia: "I work as an Information Technology professional for the Italian branch of a major U.S. computer company. I have had this position for 14 years now and have found it interesting, rewarding, and fairly remunerative. One reason I like my job is that I feel that my vision disorder does not hinder my productivity in any significant way. I am an 'architect' in software configuration management. Essentially, I deal with methods and tools to ensure that, when developing or changing a computer software application, all necessary application pieces are present and current, that they are processed according to pre-defined rules, and that they fit together as planned. My path to getting this job was quite a winding one. Such a job did not seem possible for me back in the mid-70's, when I was at the age when one usually makes vocational choices. Work with computer technology was still restricted to a close circle of specialists, and having a job in this field was not even conceivable to me. Back then I actually had no clear idea of what kind of work I would be able to do. I had not had an accurate diagnosis of my eye condition, so I grew up with the feeling of being 'neither fish nor fowl.' My main concern had always been to reassure my parents that I could accomplish whatever my normally sighted peers could accomplish. This goal kept me motivated, but it also kept my self-esteem low, because it always seemed that I was 'one step behind' my peers – always having to work harder to achieve the same things. Still, this was preferable to being categorized as 'blind' or even 'partially blind.' That's why I fiercely rebelled against making either of the 'classic' vocational choices for the blind in Italy at that time – i.e., being a switchboard operator or a masseur. When it came time to go to the university, the choices I made were more to challenge myself than to pursue realistic, informed plans for my life's work. I majored in Natural Science and got my degree, with good grades. My ability to memorize information and to accomplish most of the lab activities helped to compensate for my colorblindness and low visual acuity. But I had no idea what to do next. With my degree I was supposed to become a teacher; but, in order to do so, I would have to overcome fierce competition. At first I could only get temporary jobs, such as substitute teacher or assistant teacher of disabled students. From these experiences I learned a lot about my abilities as a communicator and as an educator. For example, I found that I could easily establish good rapport with my students, overcoming the limitations imposed by my vision

impairment in the classroom. But I could not get a permanent teaching job. The road to obtaining one was very difficult, and there was much competition. I decided to practice humility and do what I had previously refused to do – to ‘disclose’ my vision disability and apply for vocational assistance to the Italian services for the blind. I was even ready to accept the kinds of jobs I had disdainfully rejected in the past. But, to my surprise, I was offered a brand new option – to attend a special course for blind and visually impaired computer programmers sponsored by an association of private companies. I learned later that offering this program allowed these companies to be compliant with the Italian law for employment of disabled persons and, at the same time, assured them of having well trained professionals they could hire. The course began in January and lasted through November. Those enrolled were required to live in the residence building of a school for the blind, where the course was held. Those of us who were print readers were provided with materials in large print or regular print, and the others were provided with tape recorded materials or materials in Braille. Adaptive equipment was provided. I made many lasting friendships in that program.”

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From a woman with achromatopsia: “After completing a Master’s Degree program in Sociology, I got a job at Harvard University in the Faculty of Arts and Sciences Computer Services Department. It was a dream job in many ways. I had an office in the basement (no windows!) and could set the lighting any way I chose. I had assistants who would work the computer during my lectures in the computer classroom. I was provided with a 21-inch monitor and screen enlargement programs for both the Mac and the PC. The staff was enlightened and I felt very comfortable working there. Here are some things I have learned through my work experience which I would like to pass on to others: (1) Always ask for what you need. (2) Develop alternative techniques (such as using special eyeglasses, monocular, magnifiers, large print, etc.) so that you can survive in any situation. (3) Create a plan for transportation. Hire drivers when you need to or use public transportation, when available. My own strategies once included buying a house that was close to places I needed to go. (4) Tell a potential employer you can do the job – if you really can – and worry about the other stuff later. You don’t need to share every detail about your alternative techniques with potential employers. They just need to know your work will be done on time and correctly. (5) Utilize all services available for persons with disabilities. Let’s face it. In so many ways, the things we must do to live a life comparable to persons who don’t have vision problems cost money. If you are eligible for services through your state, Social Security, the IRS, or private agencies, take advantage of those services.”

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From a woman with achromatopsia who teaches ballet: “At this time in my life my eye condition is not such a big problem. I teach in my own dance school and I also teach a class for a professional modern dance company. In both places, there is no direct sunlight coming into the studio, and the number of students/ dancers in the classes is limited. I wear commercially available tinted contact lenses (Lunelle Solaire 90% brown soft contact lenses). I’ve been wearing them for over 15 years now and am very happy with them. Outdoors in sunlight, I wear sunglasses as well, but in supermarkets, classrooms, etc., I wear just the contacts. Sometimes I have to take them out indoors, when they make things too dark.

Recreation and Sports

From a woman in her 30's: "Recently I've discovered something new about myself – that I actually do like sports and I like keeping physically fit. Recently I started jogging on a treadmill at an indoor gym. It's great fun, and it's exciting to watch my speed and distance gradually increase. Best of all, I don't have to worry about how bright it is outside or about traffic or crossing streets or watching out for holes in the path, etc. All the energy that I had previously channeled into seeing I can simply put into the jogging itself. I'll bet if someone organized a night game of volleyball or basketball, I would enjoy that too."

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"I have found that good sports activities for me include indoor swimming, bowling (I look at the dots, not at the pins), all gymnastics except balance beam (we achromats have poor depth perception), horseback riding, ice skating, roller skating, and weightlifting. In my school years the adapted P. E. class was not challenging, and in regular P. E. they expected me to do archery and tennis!"

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"One of the first ways it became obvious to me as a child that my vision was different from that of other children was that they could take part in certain sports (especially ballgames) and I could not. When teams were set up, I was always the last one to be taken on. Hitting a ball with a bat or catching a ball thrown toward me is next to impossible for me, except under the most optimal light conditions, such as at twilight."

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"We have 2 sons with achromatopsia. Our boys enjoy bike riding, rollerblading, and weightlifting and are now taking ice skating lessons. They have a very normal life, with a few adjustments here and there."

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"Our daughter was excused from outdoor activities involving balls coming at her, but she participated every year in Field Day activities, including track events."

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From a young woman with achromatopsia who has won a number of athletic awards: "I've always felt the need to be physically active. Somehow I managed to play softball in grade school. When I started, no one my age was very good at it anyway, but I watched my friends improve much more than I ever could. In the outfield I could not see the ball coming if it was in the air. I could get the ball if it was on the ground, but I had to have other outfielders cover me. I loved the really cloudy days on the field. As for batting, the pitcher used to move up very close to me. Luckily, in softball the pitches were slow enough for me to bring them into focus. In grade school I also took part in gymnastics, soccer, bowling, basketball, ice skating, and roller skating. And I loved riding my bike at dusk. In high school I chose a non-contact sport – track and cross country. But the cross country meets always took place on bright, sunny Fall days. I often tripped and fell over rocks and other things. Once I cut my hand open. I had problems going the right way. I usually tried to stay behind someone else but occasionally found myself at the front. Once I led several people in the wrong direction for a while. They were not very happy with me when they found out. Outdoor track was my least favorite sport. Running in circles was boring, but at least there was usually nothing to trip over. Indoor track was much better for me; I didn't even need my glasses for indoor races. I believe that, in place of the good vision I have not had, God has given me strength and courage."

“Our son is a 6th grader at a parochial school where he has been a student since 1st grade. He loves sports. I tried to steer him towards band and scouting, not knowing how he would fare in sports with his vision limitation, but he pursued sports anyway. He plays basketball and football on his school teams. For football he wears a visor on his helmet along with his sunglasses or tinted sports goggles. The coaches have tried to place him in positions on the line compatible with his vision. In basketball there have been times when he didn’t see a quick pass coming, but overall he has done fairly well. There have been some lighting problems in certain gyms, but he just does the best he can. In our own school gym we arranged to have a few windows covered that were particularly bright. He also ran track this year (including the long jump) and really enjoyed it. He tried to play baseball for a couple of years when he was younger. On a good day, with the coach pitching underhand, he could hit the ball. Fielding was difficult for him. When the other students began doing the pitching, we had to have him quit, because we felt that there was too great a risk for serious injury. This was the only sport in which we did not let him set his own limits.”

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 “So that our son could participate in competitive sports, we connected with our state chapter of the Association for Blind Athletes. Members of this organization (which is for both blind and partially sighted athletes) may participate on a state, regional, national, or worldwide level. Activities include swimming, track, wrestling, goalball, weightlifting, gymnastics, and beep baseball. Our son has participated in most of these sports for several years and, at one point, won 4 national gold medals.” (U. S. Association for Blind Athletes, 33 N. Institute St., Colorado Springs, CO 80903 or phone (719) 630-0422, <http://www.usaba.org/>.)

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 “As a prize for school achievement, our 11-year old daughter got to go to a skating rink party. This was exciting for her, but she did not know how to skate. So we arranged a family outing to the same roller rink before the day of the party. Indoor skating turned out to be a lot easier for her than her previous attempts at outdoor skating had been. The lower light levels indoors were great!”

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 “Our teenage daughter learned how to slalom water ski this summer. She wears a dark pair of swimming goggles over her tinted contacts to block out the sun. The only serious problem she had was knowing when the water was smooth enough to cross back and forth. She could not see when it was smooth and when it was rough. We tried yelling at her, but the motor of the boat was too loud. Then we had a brainstorm about using a whistle. I hung a whistle around my neck; and, when the water was smooth enough for her to cross back and forth, I would blow the whistle once. When the water was rough, I would blow the whistle twice, and she would get back behind the wake of the boat. It worked out great. Her brother, who also has achromatopsia, does not water ski, but he does kneeboard, and we use the same technique with him. He also plays roller hockey and loves it. The people who organize the league always ask him which hockey puck color is the easiest for him to see. They are very accommodating.”

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 “I was very shy as a child and had a hard time establishing friendships. During recess and after school I could not participate in the vigorous outdoor activities on the playground and elsewhere.



This affected my chances to get to know – and to be known by – the other kids. I recall trying my best to make up for this by participation in non-athletic activities in school and after school. To some extent, I was a ‘loner,’ and I tended to form friendships with other kids who were also ‘loners,’ or who were just not athletically inclined. I dealt with some similar concerns when my son was growing up. He has no visual or other impairment, but he simply has never been interested in sports, has always been a ‘loner,’ and was small for his age as a child. Because of these and other factors, I sought the best organized after-school and weekend activities I could find, so that he could associate regularly with other kids his age. Over the years I found YMCA programs, after-school programs in different schools, non-competitive sports programs, and programs at community centers (all the time wishing that I’d had access to such programs when I was a kid). Often, when he would establish a friendship, it would be with another kid who was a ‘loner,’ and these friends have included some really terrific kids – kids who simply never cared for organized sports activities. I remember a story from the autobiography of Tom Sullivan, the blind singer-songwriter-actor-musician-writer-TV host. Tom had been a very sociable child, but there was no way he could participate in after-school sports. One year his dad bought him a pony, and naturally the school kids would gravitate to his home after school. Buying the pony wasn’t intended as a way to ‘make friends’ for him but to create a situation in which he could be where kids would regularly hang out. Sure enough, Tom developed close friendships with many of the kids who routinely came by. He had the chance to be known by his peers for his other qualities – he wasn’t just ‘the blind kid at school.’ Not many people can keep a pony, but, for concerned parents in the network, this story might be a springboard for other ideas.”

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From the mother of a 6-year old: “I found a bicycle called ‘Trail-A-Bike,’ made by Adams. It is a small bike that connects to the seat post of a leader bike. The trailer bike has a set of pedals and handle bars, so that a child can actively pedal and participate on a family bike ride, without the need to worry about traffic. It is designed for children from 5 to 10 years old. It does not have brakes, so there’s no need to worry that the child might sit back and ride the brake while the parent tries to pedal. The child is free to pedal or coast, as desired. The item cost me around \$200 for a 1-seat version. It is also available with as many as 3 seats. It can even connect with a tandem bike, so a family of as many as 5 people can bike together.” *(Editor’s note: check with your local bike shop for details about this and other brands of trailer bikes and tandem bikes.)*

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From a man in his 40’s: “When I was in 5th grade, there was another boy in my class who also couldn’t participate in sports. I don’t know what his physical problem was. He and I would go to the chin-up bars when the other kids were playing softball, and we’d just hang upside down like bats. It made us dizzy, but it was kind of fun. It was a way of taking a break from the normal reality. Teachers would sometimes come over and try to get us to do something else. They would warn us that we might fall and hurt ourselves, and sometimes they would forbid us to do this, but we’d go back to hanging like bats. We liked it.”

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“Our son, age 15, is finally becoming a self-advocate for his needs at school. He listens to books on tape at school and reads magazines and favorite authors

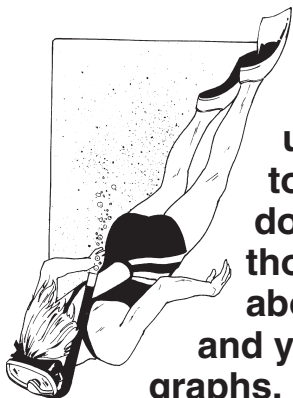
at home. He is not playing basketball this year for the first time in his school years. He finds that it is a faster game now, and he always has to position himself in order to see what's going on. This is a lot of work, frustrating, and a difficult maneuver at every gym. He is a good athlete, but his real hobby is music. He plays regular guitar, bass guitar, and keyboard. He takes lessons weekly and practices faithfully. He also bought a drum set, and he plays a 69-year old trumpet that his grandfather gave him."

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"Our daughter excelled in horseback riding throughout junior and senior high school. Riding, as long as your horse is reliable and not too green, is a sport for which good vision is not essential."

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"If card games are played by color, we mark them with shapes that denote certain colors. Also we put stickers on the black checkers and the checkerboard spaces, so that our daughters can tell the red from the black."

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"Some of the happiest memories of my childhood had to do with going to the movies. What could be more ideal as far as the special visual needs of achromats are concerned? Being at the movies meant getting to spend time in a darkened theater and getting to look at hugely magnified, well-focused images projected on a giant screen, and this often meant getting to see in great detail wonderful outdoor scenery, such as I was never able to see when I was in real life outdoor settings. Even when the scenes were very sunny outdoor scenes, it wasn't the way I experienced things outdoors with sunlight all around me, dazzling me and depriving me of most of my sight. Instead, it was like being able to look through a large picture window – except that I could see everything so much better on the screen than I could ever see when looking outdoors through windows, thanks to the high quality of the images on the screen and the darkness that surrounded me in the theater. I nearly always got to select where to sit for optimal viewing – which, for me, was usually in the 3rd or 4th row. Going to the movie theaters of my childhood was like visiting paradise. I loved going to the movies. I still do, although movies and theaters have changed a lot over the years. I miss the large, beautiful, and comfortable theaters of the past."

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From a woman with achromatopsia: "When I first tried scuba diving, my feelings about it were ambivalent. On the one hand, I had great fun with the sense of being in another world; on the other, I had to live through some frightening experiences at first. What I like best about diving is the feeling of being weightless. Hovering above an underwater landscape is something special. Obviously I cannot see clearly under water. Since I have achromatopsia, I can never have the 'detail vision' which normally sighted people have, and such visual acuity as I do have is reduced under water. Water is usually a bit dim, like fog on a misty window. Often it is impossible to get near enough to something in order to see it better, the way I do in other environments. Whenever people ask me why I dive, even though I cannot see what other divers can see, I simply explain that above water I also don't see as much as normally sighted people see, and yet this doesn't keep me from going to the cinema, taking photographs, etc. And I tell them that there is more to being under water than



just seeing fish and coral. Another problem is that, in the shallow water, the light is very bright, blinding me in spite of my tinted mask. And going into really deep water or into a cavern or a crevice, I can't see distances, rock formations, or sea growth. Even so, I love scuba diving and hope to connect with others in the network who share this interest."

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"Life has taught me that there's usually a way around any obstacle – you just have to keep working at it. Thus, I've developed a very obstinate streak, and it's paid off many times. I can be pretty tenacious when it comes to pursuing ideas that might help my vision, such as new types of glasses or other contraptions that might help me in some way. One example was the day I finally got to play a game of volleyball – first time in my life. No special assistance, no breaks for the visually handicapped girl. I was so happy that I was crying, and the people I was playing with couldn't possibly understand what a big accomplishment it was for me. For someone who had never made contact with a ball before – and in the daylight! – it was terrific. Why I hadn't thought to do this before is beyond me. I just asked to be placed on the side of the net with my back to the sun, and I wore a close-fitting, wide brimmed hat, my sunglasses, and 2 sets of tinted clip-on lenses. It looked terrible, and I felt extremely self-conscious, but it worked!"

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"Recently my husband and I took part in a dramatic performance at our church. One nice thing about drama is that lines can be memorized (no need to get close to read the words), and the stage is generally dark, with only spotlights to contend with. Because I was acting, it was easy to pretend that I was on equal ground with everyone else. I was playing the part of a normally sighted person. My only other big dramatic endeavor took place in my teens, when I played Helen Keller. That was a different form of acting altogether, because, not only did I not need to see well for that part – I actually needed to pretend that I couldn't see at all. In acting you often must make people believe that you see something that isn't there (for example, looking out a fake window and 'seeing' a car pull up), and so it doesn't really matter whether you can actually see well or not! Anyway, I loved performing in the drama. I found it very freeing."

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"Our daughter, age 13, just experienced her first stage performance as an actress. In the past she has auditioned for quite a few parts, and she finally got one this past December. I was somewhat concerned that the stage lighting might be too much for her, but she didn't care. She loved it. When the spotlight was on her, she opened her eyes wide, even though it blinded her, so that she would look 'right' to the audience. She loves to draw and loves using high quality charcoal for her drawings (no colors to have to figure out). Perhaps her vision allows her to see form and design better than us folks who have color vision. Her drawings have become wonderfully detailed and complex."

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From a woman with incomplete achromatopsia: "I've been around horses all my life, and I think horseback riding has been the best thing in the world for building my self-confidence. Horses have been my feet and my eyes in many places where I had trouble seeing. I was safe as long as I could hang on. My mom first teamed me up with her experienced mare and then gave me a small pony of my own. With



them I developed more physical skills and dexterity than any gym class at school could give me. The National Therapeutic Riding Association is an organization whose members volunteer their time to assist physically or mentally challenged kids. I have donated quite a bit of time in the past to my local chapter, and it has been a very rewarding experience for me. It allows me to give others the same kinds of opportunities that I have had.”

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From a man with achromatopsia: “I wonder if the reason so many kids in the network are good at drawing detailed pictures has to do with the fact that, when you’re creating pictures, you get to make things up. You don’t have to reproduce the visual details from actual people or actual objects (details which are usually hard for us achromats to see). I’m wondering if the children who draw with such detail are actually recording observed detail or if they are creating detail to provide the feeling of reality about the pictures they draw. I’ve created a lot of music in my life, and I find that it’s much easier for me to sit down at a piano and make up a song from scratch than it is to read sheet music.”

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From a networker in her 30’s: “Every year I go on an annual Ladies Retreat with my church. This event took place this past weekend. This has been the first summer of my life that I have had sunglasses dark enough to make it possible for me to see fairly well outdoors. I found that I was actually able to play ‘pool basketball’ and even won in my small group. Also I played ‘putt putt golf’ in the daytime instead of only at night. It was great to open my eyes outside in the sunlight. It has made a big difference in my life.”

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From a networker sharing information about having completed horseback riding lessons in preparation for her upcoming vacation, which was to include horseback riding daily at twilight time: “I tried out my ‘gear’ for riding. I wore a hiker’s vest with numerous pockets and had my darkest sunglasses strapped on my head, while there was still a considerable amount of daylight. For the transition to twilight, I had a lighter tinted pair of sunglasses available on a cord which hung around my neck, and I had yet another pair of sunglasses in my pocket. Other people really have no idea how much organization it takes for us just to enjoy the simple pleasures, do they?”

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From a man in his 50’s: “When I was a teenager and trying to do sports, dark glasses were never enough for me to be comfortable playing basketball outside, and sports that involved smaller balls were impossible for me in any light. My sports are now restricted to cycling and running. My cycling is usually along known routes with very little traffic, and the running I do is sometimes on roads, but I use great caution. I like using wraparound sunglasses because of the added peripheral vision, plus the fact that light is reduced over a larger field. Sometimes when I am biking or running, my glasses get fogged up. This does not always happen and I haven’t figured out what it is about the weather and/or the glasses that brings on the fogging, but it is exasperating – and it can be dangerous. Recently I went cycling on a wilderness trail which traversed meadows and forests. I found that my sunglasses made things too dark for me in the woods, and yet it was hard for me to stop frequently to take them off and then stop again very soon to put them on again. What worked for me was not to use sunglasses at all on

that kind of trail. My tinted contacts gave me an adequate base, so that, with blinking and squinting, I could manage OK in the sunnier areas and could see quite well in the shadier areas. The trail had no ruts, few obstacles, and no other traffic, so all I had to do was keep on the trail.” *(Editor’s note: Some networkers who don’t use tinted contacts report that they manage in the same way with their lighter tinted sunglasses when hiking, running, or biking along safe routes that feature abundant shade but also have occasional bright spots.)*

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“Last year my husband and I took a ‘Full Moon Tour’ of Chimney Rock near Durango, Colorado while vacationing in that area. This tour takes place on the night of the full moon, and it is a wonderful kind of outing for someone with my eye condition. There is a lecture given about the Anasazi Indian ruins there, beginning just as the sun is going down and the moon is beginning to rise over the mountains. What a beautiful sight! We all had flashlights to find our way down from the summit after the lecture. However, I preferred to turn my flashlight off and was able to see by moonlight all of the features of the climb that I had missed on my way up (having made the ascent in daylight). It felt very odd during that night time descent to be seeing better than nearly everyone else around me. We’ll be returning to Colorado for a vacation this year. With the help of all the newsletter information, I now have an array of sunglasses to choose from for every possible activity and setting. I couldn’t even imagine myself taking a 2-week outdoor vacation in previous years, I would have been stressed out just thinking about such a thing, and now I am eagerly looking forward to it.”

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“Our son, age 12, teaches Karate classes to little kids age 3 and up. He is a Black Belt in the United Fighting Arts Federation and a 2nd degree Black Belt in American Martial Arts. This has done wonders for him. When he tested for his black belt at the age of 10, he had to write an essay on ‘Why I want to be a Black Belt.’ He explained that, as a young child, he thought he was not as good as everyone else because of his vision disability, and that, through the martial arts, he has proved that he can do anything he wants to do and that he is as good as everyone else, even though his eyes don’t work the same as other people’s eyes. He believes that this is his ‘gift,’ not his ‘disability.’ His father and I believe this too.”

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“With the help of our optometrist, we have obtained tinted swimming goggles for both our children. Getting this done was not an easy project, but it has been a most rewarding one. With the goggles they are able to be in outdoor pools for hours at a time. Getting the right tint has been difficult but well worth the effort. Sometimes the padding on the inside of the goggles starts to wear out, but we have extra pads and replace them periodically. The area around the lenses is not completely opaque and lets some light in, so we use very fine sandpaper to ‘rough up’ the frame, and then we paint it with very dark nail polish. After a few coats, the frames don’t let light through. The nail polish lasts all summer, even if the kids go in the pool every day.”

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“Last summer our daughter went to a Girl Scout horseback riding camp for a weekend, and she also went to a week-long camp for visually impaired kids sponsored by the Lions Club. It was the third summer she had gone to a Lions Club Camp. I would encourage anyone with a visually impaired child to send them to

one of these camps if such opportunities exist where they live. This has always been a wonderful experience for her. *(Editor's note: check with your local, state, or regional agencies for the visually impaired to find out about such camps. Some of them have sponsors other than the Lions Clubs.)*

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From the husband of a woman with achromatopsia: "We recently returned from our summer home, which is located in a forest at the base of a river. In addition to being a cooler, shadier place to live during the summer, this location offers my wife the opportunity to see up close: hummingbirds, mule deer, raccoons, squirrels, jays, and javelina (wild hogs)."

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From the grandmother of a boy with achromatopsia: "Some great gifts we have found for our grandson in recent years have included a big screen microscope, a personal cassette recorder, high quality adjustable binoculars for children, telescopes, a trampoline with a safety bar for young kids, and (our favorite) a 35mm Mega View camera. The large viewfinder of this camera makes it very easy for anyone to use, even someone wearing sunglasses."

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From a woman with achromatopsia: "As I was growing up, my family often played domino games, so I learned to play dominoes early on and loved it. Black dominoes with big white 'dots' (these are actually white impressions in the dominoes) were perfect for me. I could easily 'read' the dominoes anywhere on a card table, so I was not at a disadvantage due to my vision, the way I was with so many card games or board games. Later on, I found out that some domino sets are white with black dots. These are not as easy for me to 'read' across a card table. A dark colored table top makes playing any kind of table game easier for me."

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"Sometimes I have concerns about my footing on hiking trails. Going uphill is fairly easy, but going downhill can be risky. Years ago I bought a handsome wooden hiking cane with a curved handle and a pointed end for getting a good grip on terra firma. These can be found in stores that sell equipment for camping and outdoor sports and in stores that specialize in equipment for walkers. I also invested in high quality hiking boots, with soles designed for secure footing. It's nice to have a good hiking companion who understands about how I see; but, most of the time, I do not need special assistance on hikes, especially if I carry along a good hat or visor and any optical aids I'm likely to need. However, I do appreciate help in spotting poison oak on a trail."

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From a man in his 20's: "I think I've discovered a great hobby for achromats – ballroom dancing. I decided to take a class in it this semester and started hanging around with the university dancing club. A bunch of us went out one evening to a dance hall, and what a great situation it was for me! The lighting was very dim – just perfect! No matter where you practice the art of dancing, what is most important is the ability of people to interact with one another and with the music in an elegant and sophisticated manner. Visual acuity matters very little. I'm not sure anyone in the dancing club even knows that I have a vision impairment. So many 'social' hobbies involve bright light and the need for good vision; it's neat to find one that doesn't. As for following the teacher's instructions, whenever I am learning something new, I always situate myself near the teacher (who thinks



I'm just being a good student). The dance hall we went to doesn't serve liquor, and there was a good mix of ages. One problem is that, since a lot of dancing takes place in the evening, transportation can be a problem for someone who doesn't drive. In my case, I was able to ride with others from my university dance club."

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From a man with achromatopsia in Italy: "When I hike, I use standard hiking canes made of aluminum. These have handles identical to those on sticks used for skiing. Each cane consists of 3 pieces, which can be extended or telescopically retracted, and a sturdy metal tip which resists continuous contact with rocks and stones. These are not to be confused with white canes that are used as mobility aids by blind people. They are found in most sports equipment shops near popular mountain towns here. They look like plain aluminum, with a colored adhesive spiral strip around them to make them more visible. These are meant to be used as a pair, but one could be used alone. People normally use them just as a support for walking along mountain paths. They fit my needs perfectly. Before I had them, I had to be much more cautious on descending trails. Sometimes I had to choose between making a good guess about how deep the next step was or sitting down on a rock and reaching out with my legs until my feet encountered a solid surface. Now all I have to do is to lean slightly forward and use my canes to determine how much higher or lower the next step will be. I don't need to use them to locate obstacles in front of me, as a blind person uses a cane."



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From an 11-year old networker: "Since first grade I have been in the same P. E. class as the rest of the kids in my school. I play all sports except for baseball and lacrosse. When I am not playing, my teacher lets me work the scoreboard or serve as non-playing captain. In sports like handball and floor hockey, my gym teacher lets me use a dark colored ball so that I can see it better against the background. I love sports more than anything else and, ever since I was in kindergarten, I wanted to play the same sports as everybody else did. This year I was captain of my football team and starting guard for my basketball team. These sports have always been tougher for me, but I do the best I can."

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"I love listening to Talking Books. When I was growing up, I didn't know about Talking Books or that I was eligible to receive them and the equipment to play them. But, even if I had known, I probably wouldn't have taken advantage of them, at least not as a child or as a teenager. I would not have been interested in listening to books, because I could read print books just fine, even though I had to get close. And I would have associated Talking Books with blind people – and, at that time in my life, I didn't think I had much in common with blind people. I discovered Talking Books late in my 20's and was quickly enthralled with the experience of hearing the really fine and well trained voices of some of the narrators of Talking Books. Some narrators are not so good, but many are extraordinary. When I got into my 40's and experienced 'middle age vision,' finding my eyes getting more tired from doing lots of reading, I developed even more appreciation for Talking Books. Also, I found that they were great at bedtime, when I had difficulty getting to sleep." (Editor's note: see page 123 of the book "Understanding and Coping with Achromatopsia," 2nd ed., for information about the Talking Books program.)

“Our son is finishing up 1st grade, and it has been a growing and learning experience for all of us. His teacher has been wonderful about helping the other children accept him for who he is. They are eager to help him when needed. But outdoors he cannot play any ball sports, since he cannot see the ball approaching. Even a soccer ball or large red ball presents problems. So at recess he spends most of the time by himself. If I ask him why he doesn’t find his friends, he says he cannot see well enough to find them on the playground. So he plays on the swings or the jungle gym, which is fine for now, but I worry about what he will do as he gets older. He has a great deal of self-confidence and self-esteem, which we will continue to focus on, and for the present he doesn’t seem to be concerned about being alone at these times. He participates in activities outside of school (gymnastics and karate classes, a church group, etc.); but, even in those situations, he can’t tell me who is who. I find myself worrying about lots of things in his future, and I know I could drive myself nuts thinking about these things before their time. On a positive note, he participated this past weekend in the regional Junior Olympics for the Blind and won 3 first place medals and one second place medal. He received a round of applause from his classmates for his efforts, and he was very happy with their response.”

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“Our daughters, ages 6 and 9, each began skiing at the age of 3, and both are progressing nicely, on a par with – or better than – most skiers their age. When skiing, they usually wear their dark sunglasses under a regular pair of tinted ski goggles, and they can see just fine, even on the brightest days. We use a good de-fogger solution on the ski goggles as well as on the sunglasses. One of our daughters prefers to wear a large sportlens with visor, instead of ski goggles, over her sunglasses. A helmet, which is a good safety idea anyway, does double duty as a sun visor, to some extent. We have found that the ski instructors are usually very cooperative; and, with minor accommodations, the kids do fine. The only problem is helping the kids to recognize us or the ski instructors from a distance on the slopes or the lift line. Since skiers tend to look very similar on the slopes – i.e., they all wear a bulky jacket, cap, gloves, goggles, and skis – people tend to recognize others by the colors of their outfits (which our kids can’t do), so we have taught them to look instead for patterns on clothing (a vertically striped cap, etc.). When I am skiing with them, I use my voice to keep in contact with them. They find this reassuring. This must be brought to the attention of the ski instructor in advance, so the kids won’t get lost. I tell the instructors to stay reasonably close to them and not to assume that our daughters will be able to identify them from a distance of more than 15 feet.”

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From a teen with achromatopsia: “I prefer to go to the swimming pool, the beach, or the lake, etc., when it’s getting to be toward evening or else when it’s very cloudy. I can see so much better then.”

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From the mother of a 5-year old girl with achromatopsia: “On our vacation this year, my husband and I decided to take our daughter and her cousin (whose family we were visiting) to the beach at twilight. We had never taken a trip to the beach at this time of day before. It was amazing to see the difference! She was actually climbing rocks, catching crabs, and moving with confidence everywhere we went on the beach.”



Orientation and Mobility

From a man with achromatopsia in his 60's: "When I was five years old, my circle of activity expanded into parts of town near my home. I developed a system for finding my way back, which I still use. I would count the streets I had crossed, keeping count of right and left turns, counting doors and shops, forming a mental topological map. When returning, I would reverse directions, retracing my path, making turns in the opposite direction, and counting backwards the streets I had crossed. I learned to make use of prominent landmarks – parks, churches, overpasses, etc. Even today I find it much easier to become oriented in cities that have rivers, overground railway lines, and other conspicuous, easily identifiable 'boundaries.' I have never lost my way returning from a place I have first located myself. When traveling with others, it can be more difficult to keep track of the route, especially when traveling by car. I only cycle when I have access to reserved bicycle lanes or where traffic is very light. Traffic lights sometimes pose a problem. Early in life I learned that red is at the top, yellow is in the middle, and green is at the bottom. At night, in the evening, or when traffic lights are in a shadow during the day, I have no problem detecting which signal is showing, and so I can be a law-abiding pedestrian or cyclist. In full sunlight, however, detecting signals can be quite impossible. In such situations I have to watch the traffic, and often I follow other pedestrians when they cross the street. This could lead to a dangerous situation, if I should happen to follow someone crossing a street against a red light."

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From a woman with achromatopsia: "I like to go places with my kids. They're old enough to travel independently, so when we go places together, I just follow them instead of vice-versa. I find them indispensable for crossing busy streets, finding people in a crowd, and locating restroom signs. They seem to experience a sense of importance because of how much they truly are helping me."

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And from another: "For those of us with achromatopsia, the most serious problems in terms of mobility are in bright conditions. Even with our dark glasses, we still have problems sometimes with steps or uneven surfaces. I have never wanted to use a white cane; but, when I fell one day and broke a toe, I knew I had to do something. So I decided to get a guide dog. As a social worker for the blind, I have observed guide dogs from most of the training schools. Guiding Eyes for the Blind (in Yorktown Hts., N.Y.) proved to be the most amicable. They produce quality guide dogs, and they were willing to work with my particular needs. I have always loved dogs but had felt that I had too much vision to use a guide dog. The admissions director was understandably surprised after seeing how well I function indoors, but I explained that I had reduced vision outdoors and that in my work I have to go into many different neighborhoods, so I was given a chance to try. Traffic has always scared me; but, with my dog, I am never hesitant to cross streets. Many times people who see me indoors ask if I am training the dog. I explain briefly that I am 'legally blind' and that I see better in some situations than others. I feel that my choice to get a guide dog was one of the best decisions I ever made. My dog seems to understand that I need her most in bright places."

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From a man in his 60's: "It can be difficult to find my way in unfamiliar surroundings. I always carry with me a small 8-power monocular, and I use it for reading street names, flight departure indicators, and other information that must

be seen from a distance. I also make preparations for travel by studying maps and travel guides, and I ask people for directions when I need to.”

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“Mobility outdoors is difficult for my two children, who have achromatopsia. Crossing busy intersections cannot be done solo. Usually they cannot see the ‘walk’-‘don’t walk’ signals. Both of them have to be accompanied by a normally sighted person in such situations. Bike rides are also done with a companion because of traffic and the chance of drivers backing out of driveways.”

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From a woman with achromatopsia: “Once a rehabilitation worker gave me a white cane, saying that I could get on regional buses free if I carried one. I didn’t even know how to tap the thing, let alone how to use it to navigate steps onto a bus. I felt like such a fake! I didn’t use it much. However, I sometimes wish I could quickly pull a cane out of my pocket on a very bright day, especially when there are lots of concrete steps and no shade. Crossing busy intersections is my biggest challenge. A mobility instructor warned me not to cross just because others are crossing. That’s sensible advice, but I feel so much better when crossing with other people. Folks who know me well will take me by the arm when we cross, and I appreciate that. At night I’m like a bird let out of a cage and could probably cross a freeway without a second thought. I have a terrible sense of direction and can get lost easily, so I have to learn a route really well and not deviate from it.”

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From an woman in her 50’s: “I have to say that I have honestly never wanted to drive a car, so I have never gone through a period of anger or depression about this particular limitation. I suspect I am unusual in this respect, or so it seems from my interaction with other sight impaired persons. I have certainly been keenly aware of the disadvantages of not being a driver, especially when I have lived in (or visited in) cities with poor public transportation. So I have chosen to live in metropolitan areas where there is good public transportation. Also, it has helped a lot over the years to get to know normally sighted persons who have chosen not to drive a car for one reason or another – reasons such as the health benefits of walking, limited finances, the stresses connected with driving, environmental concerns (the concept of ‘living lightly on the earth’), etc.”

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“I have traveled a lot, using public transportation in many different cities. While traveling, I have seldom needed to make anyone aware of my vision impairment, except for bus drivers (when I needed help in locating a stop or identifying the bus number). Whenever I did need to talk about my vision with a fellow passenger, it nearly always turned out to be a good experience. For example, once I was on a bus on my way to register for university classes, and I began telling a woman sitting next to me my concerns about finding my way to all the places I needed to go to on campus that day. This person (also a student), for reasons I will never know, stayed with me for several hours, until I had registered, found every campus building I needed to locate, and moved into my assigned dorm room. It was a hectic day, and I’m not sure how I would have managed without her help.”

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“When I’m not sure of my footing, I ‘shuffle.’ This is a good way to navigate a series of steps when I’m in a bright, sunny place. We achromats don’t have the severe mobility problems that many other low vision people have. We have problems related to lack of visual contrast in bright light (for instance, not seeing curbs

clearly sometimes, because they ‘blend’ into steps or the street) or problems related to our inability to see things off in the distance. I think the problem with distance is the most worrisome, because there’s not much we can do about it. I find that standing on a street with a monocular, trying to get a street sign in my sights is extremely frustrating. This is something I still cannot do while wearing sunglasses, so I end up removing my sunglasses in order to see through the monocular and suffering further eyestrain. It’s often easier just to walk the half block or so and read whatever it is without an optical aid.”

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“Some of my worst mobility problems occur when exiting a building into bright sunlight. Usually I will stand still until I have my sunglasses on, which allows me a brief adjustment period. Unless I am walking alongside another person outdoors, I probably walk a little more slowly than normally sighted persons do.”

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“My husband makes wonderful maps for me, and yet I get mixed up when I try to use maps. I should just expect to have to ask for help sometimes when traveling around town on my own. There is nothing wrong with seeking help. I believe human beings were not designed to function alone, not even the completely able-bodied ones. It’s not as if I have to win some medal for managing to get to the other end of the city without anybody’s help. And, since I now believe that one of the most interesting things about me is my unusual vision (I didn’t used to feel this way), I usually don’t mind telling someone that I don’t see well, in order to get some needed help. This is particularly easy to do when it’s someone who’s competent at giving directions and who’s used to working with the public. The down side of this is that I’m afraid they’ll scrutinize me to make sure that my claim of being visually impaired is true. We achromats don’t really look vision impaired, especially indoors. When there’s reason to believe that this kind of scrutiny is going on, we have to decide whether to ‘fake’ being more vision-impaired than we actually are in order to appear to ‘deserve’ help. Mobility instructors have no idea how complicated all this can be for achromats!”

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Last year my husband took a new job and we had to move to the outskirts of a small city. Now nothing is within walking distance. Fortunately, I have learned that this city provides cab service for handicapped persons, permitting them to be transported anywhere within the city limits at a very reasonable cost. My suggestion to other networkers is to contact your city offices to find out what may be offered in the way of transportation services for the disabled. Also, if there’s a program you or your child has an interest in, contact whoever is in charge of that program, explain your situation, and see if they can help you find transportation with others involved in that program. I have found that many people are genuinely glad to help someone who has a disability.”

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From a networker in his 40’s: “I watched O&M teachers working with friends of mine in high school and learned about cane travel techniques, but I said then that I would never use a cane. However, when I was in my 20’s, I was staying in Hawaii and found it so bright there that I decided to get a cane. I had a lot of fun in Hawaii when the sun went down, but at the other times it was just so hard for me to see that I was glad to have a cane. I did not have good sunglasses back then. Years later I took cane travel lessons from an O&M teacher. I found that

mobility techniques are cut and dried for someone who can't see at all, but it is a different matter for those of us with partial vision. For my instructional periods with the O&M teacher, I would stay blindfolded for 6 hours at a time. When the blindfold was off, I didn't rely much on the cane travel techniques I had used when I was blindfolded. For a long time, I denied being as visually impaired as I actually was. But, when I moved from a city with excellent public transportation to one which offered very little, I had to begin thinking seriously about my mobility problems. I have at certain times used a white cane and have had mixed feelings about it. There have been times when I've wished I had a cane with me and didn't, and there have been times when I've had a cane and wished I didn't. White canes are great for crossing busy streets and for times when you have to ask for directions or give the impression of needing help, but there are times when it's not so good to be carrying one. If I'm standing on a corner, for instance, and a good looking lady goes by and glances at me, I would rather not be seen as a guy with a white cane. The cane becomes part of my image, even though I only occasionally need it. Once I was waiting in line at a store with a blind friend and we were both carrying canes. I commented to my friend about something I saw, and the guy behind us reprimanded us for 'pretending to be blind.' And one time I was waiting for a bus and had my cane with me, because I had busy streets and a highway to cross that day. When the bus arrived, I motioned to a lady to board the bus first, and the driver, noticing that I could see, would not permit me to use the discount that disabled passengers are entitled to, assuming that I was pretending to be blind. I have run into this kind of reaction a lot."

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From a network mom in the U.K.: "I obtained some mobility training for our 10-year old son, and they introduced him to the white cane. At first I was uneasy about his using a cane, because it is something people associate with the blind, and I did not want people thinking that he was blind. Our son, on the other hand, thought the cane was wonderful. He found that people would move aside instead of bumping into him, and people were patient with him at road crossings. When we went places together, we got a few stares from people, but this didn't worry him, because he couldn't see their facial reactions to him. He has found the cane especially useful now that he wears tinted contacts; because, without the dark sunglasses he used to wear, he looks more like a 'normal' child, and carrying his cane helps people to see that he does, in fact, have a vision impairment."

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From a woman with achromatopsia: "I found a white cane at a garage sale about 10 years ago. Just as an experiment, I carried it on several occasions, and I was amazed at some of the experiences I had. Because I was wearing dark glasses and carrying this cane, many people assumed that I was blind. Some of my experiences were scary. While I was standing in a crowd at a park, some rowdy guys came up to me and began to taunt me (I learned later that this is not an uncommon experience for blind people). Later, while I waited alone at a bus stop, a shady looking character walked up close to me and scrutinized me, obviously assuming I couldn't see. I think he was trying to decide whether to grab my purse. Other experiences were pleasant. People on buses were very helpful to me – whether I wanted their help or not – but they were very nice about everything, even the bus drivers. The only time that day that I recall needing to use the cane in the way it is

meant to be used was on a block where the sidewalk was all broken up. A few years later I used it when I was traveling in a city where there were lots of complicated intersections I had to cross. In general, though, I found that it was a nuisance to carry a cane, because I was always wishing that my hands were free.”

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From a woman in her 30's: “Recently a mother wrote about being pressured to have her 6-year old daughter take cane travel lessons. I agree with her hesitation, and I would encourage her to follow her instincts as a mother. My parents faced the same issue when my sister (also an achromat) and I were growing up. They chose not to have us take cane travel lessons. That decision had partly to do with the fact that my sister and I didn't want to be seen as ‘blind.’ Also, it is important for kids with sight limitations to make the most of whatever vision and natural mobility skills they have. Hopefully, this little girl will have a mobility teacher who knows how to help her get around safely without the need of a cane.”

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From an adult achromat in response to a network mom who was wondering how her teenage son was going to deal with not being able to drive: “The teenage son will hopefully get really good at taking the bus – or bicycling, as I did. When I was a teenager, my mom bought me the bike of my dreams, and I had a blast with it. In high school I was required to take ‘Driver's Education’ (the classroom portion of driver's training), and it actually turned out to be very helpful, since cyclists are bound by the same laws as motorists. Of course, for cyclists who have achromatopsia, a visor or cap and adequate tinted lenses are a ‘must.’”

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“I rely on public transportation and taxicabs. During daylight hours I prefer to travel only in areas I know well. When going to unfamiliar places, I nearly always go with a friend or a family member in order to have some assistance in orientation.”

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“I value the increased ability to see my surroundings which I experience as a result of shadows and shady areas. I like to walk on the shady side of a street or in the shadow of an awning, a building, or trees whenever I need to see my best while I am walking outdoors or just to give my eyes a break.”

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From a woman in her 50's: “We have just moved from a rural area, where we lived for 18 years and where there was no public transportation at all, to a home in the city, where public transportation is close at hand and where we are within a half mile walk of many conveniences. I cannot adequately express how happy and relieved I am to finally be able to be so independent!”

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From a man in his 20's: “I grew up in a large urban area. I was able to transport myself around using the buses and the subway, just as so many other people did. Stores, movies, arcades, etc., were close at hand and, if they weren't, public transportation came to the rescue. Taxis were always available. Then, when I was in high school, my family moved to a small town. All the freedom I had previously enjoyed was gone. It was almost like being on a different planet. All social activities centered around ‘the mall,’ which was nowhere near where I lived. Sidewalks were almost non-existent, because walking anywhere was practically unheard of. Also, getting a driver's license at 16 was considered a ‘rite of passage’ – a huge deal and something I could not participate in. Taxis were rare, and they were not used by young people. Needless to say, small towns and suburbs do not appeal to me

as places to live. My views might have been different if I had not first known the freedom that a large city offers. For college I moved back to the city and have lived in the city ever since.”

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From a woman with achromatopsia in her 30's: "I want to share with other networkers an idea that has worked for me in connection with mobility problems. When I moved out of my parents' house, I wanted to be as independent as possible, but I was having difficulty getting to work. The bus system did not go to where I worked, and I found cabs unreliable and expensive. I decided to place an ad in our church bulletin advertising for a driver. The ad went something like this: 'Visually impaired young professional seeks reliable senior citizen or other to assist with transportation from 'point A' to 'point B' several times a week. Good pay.' You wouldn't believe the number of responses I got! I interviewed several people and chose the ones who best met my needs. It has been a wonderful experience for me. Not only was I able to get the help I needed, but I found that I was helping other people too. Many of my drivers told me that they appreciate the money, because they are on fixed incomes, and that they get a lot out of helping someone this way. I have one driver who has been driving for me for eleven years. She is my 'adopted grandmother.' She has enriched my life in countless ways."

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"When I take buses, I find it's less stressful just to tell the driver that I don't see well and need help in knowing where to get off. I have to trust the driver to help, because I do not have a good sense of direction and invariably miss my stop."

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"Often I choose to walk a great distance rather than catch a bus, because on a bus the scenery goes by too fast for me to identify any of it. But on foot I can enjoy the scenery and can even choose to back-track, if I want to."

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"A problem that seemed more serious to me earlier in my life than it does now is that I cannot have a driver's license. My brother (also an achromat) and I have ridden bicycles and mopeds. He actually took driving lessons once but had to give up after attempting to drive down a flight of steps in a park. Today I only cycle when I have access to reserved bicycle lanes or where traffic is very light."

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"If you're supposed to meet someone in a crowd, like at a train station or at a mall, ask them to bring along a dark-colored helium balloon. My sister thought this one up once when I was getting off a plane and meeting her at the airport."

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And from another: "I wish I had some good news to give to younger achromats about the inability to drive. The truth is that I did not come to fully accept the fact that I could not drive until I was in my thirties. For me, it has been the most difficult limitation connected with this vision impairment. It was very hard for me, when I was still in my teens, to watch my sister – two years younger than me – get her driver's license, her car, and her freedom. I would like to put a positive spin on this subject, and I can find some good things to say about being a non-driver. No car payments, no car insurance, no looking for a parking space, no tolls, no car washes, no parking tickets, no car repairs, no stops for gas, no accidents, no safety issues, and never having to be the 'designated driver.'"

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From a networker in New York: "I live in a big city. Life without a car here is actually easier than life with a car, and it is certainly more fascinating. Lots of

people here make the choice not to drive, so a non-driver does not fall into the category of being 'different.' And there are many options for getting around."

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From a woman with incomplete achromatopsia: "My number one frustration connected with achromatopsia is not being able to drive a car. My husband prefers to live in a small city, and so I don't have access to public transportation. I must rely on others to take me places. I am a slow shopper and prefer to take my time. This can be a real problem when someone who has given me a ride has to wait for me. My husband drives me to and from work, but, I know there are times when he gets tired of doing this. I've read about other networkers who say that their husbands or wives are glad to do the driving. My husband often says, 'I wish you could drive,' and this just makes it harder for me not to be able to drive. Once I tried an idea contributed by a networker about putting an ad in a company newsletter hoping to find someone who could drive me to and from work and offering to pay. I did receive a few calls, but this didn't work out for me."

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"We achromats lead lives of paradox. We need to become independent, yet we often have to turn to others for help when we need to get from here to there or match clothing, etc. I think it's important for us to learn to accept help graciously, without feeling bad about it. We should remember that there are ways we can give to others in return. When people have helped me out with transportation or in some other way, I bake something for them or find something else appropriate to give them or do for them. The bottom line is 'Everyone needs help.'"

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From a man in his 40's: "My wife and I both have full time jobs. Since she does the driving, we have organized the chores so that I clean house while she does the shopping. I don't do the housework because I want to but because it offers a way for me to offset the accommodations she has to make for my inability to drive. The fact that she had to do all the driving was more of a problem for our family until we moved to a small town. Now I can bike anywhere in town with our two sons. This way the boys and I have been able to spend more time together."

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From a woman with achromatopsia: "To single persons in the network who find that there are barriers to having relationships because of the inability to drive, my advice would be to move to New York, where mass transit is so extensive that many New Yorkers do not even know how to drive. This particular barrier to dating would disappear. The freedom you would have in that setting might overshadow any hesitations you may have about such a move. I lived in Chicago for a few years and really enjoyed the transportation system there, but I understand that New York is even better. There is also the added benefit of all those tall buildings blocking the sun, which helps an achromat to see better outdoors."

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From a married man in his 40's: "Not being able to drive is especially difficult for a man, but I think there are things a man can do that can compensate for this limitation. One is to be especially understanding and attentive to the things that the woman enjoys or needs. My suggestion to vision impaired singles is to ascertain early in a relationship the value someone places on whether or not you can drive. Not necessarily on the first date, mind you – maybe not even on the second. But the problem has to be dealt with. Don't postpone it too long."

“I was most hard hit by the driving issue when I turned 17 and was living in a suburban area. At that time in my life, I could not envision the rather independent lifestyle I have been able to create for myself in the vibrant urban setting where I now live. The important (though difficult) lesson for me was learning to focus on what is possible and to let go of that which is not possible. However, it is important to acknowledge the very real sadness and anger that can come along with the struggles we face as vision impaired persons. I don’t know what kind of advice to give to young people in the network about not being able to drive, except to say that not seeing well is a tough deal, and yet we can thrive in spite of it.”

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“During the years I worked as a teacher, I used public transportation to and from work whenever possible. When this was not possible, I found someone at work who lived near me and was willing to work out a ride-share arrangement. (My employers were always willing to help me find transportation if I was at a new job and didn’t know anyone yet.) In exchange for being picked up and brought home every day, I would compensate them financially. Usually I tried to pay them enough to cover their gasoline for a week at a time. I also tried to stay flexible in my schedule so that they could stop on the way home for an errand or leave at a certain time for an appointment. If that person was sick or, for any other reason, did not go to work on a given day, I had some back-up people to call on for a ride. I would always present the plan as a one-year plan (this was a natural arrangement, since I was working as a teacher). At the end of the school year, I would either decide to ask them if I could ride with them again next year or would ask someone else, depending on how things had gone during the year. Compatibility is a big issue in these kinds of arrangements. It can be very stressful if you are riding with someone and it is not working out well. Whenever this happened, I would look for a natural break in the work schedule and find someone else.”

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From a man in his 40’s: “Several years ago I travelled solo around the world. It wasn’t exactly a ‘breeze’ for me, considering my vision impairment. There were maps that had to be read, etc. I basically ‘flew by the seat of my pants.’ Everywhere I went, I found an airport bus to the center of town. I kept moving. I never ‘dillied’ or ‘dallied.’ In some cities where protection for Americans is not in strong force, it makes sense to move right along – or else you might end up in a dumpster and nobody would ever know. It seemed to me that, in some ways, traveling by myself would be easier than going with someone else, because the indignities of having to read everything up close and sometimes just missing the point completely when something was explained to me – well, I would rather experience such things by myself, so I could ‘edit out’ that kind of stuff and just remember a pleasant trip. I have found ways to either cope with or ignore most of the problems that come up in such situations. So my advice to other achromats who may want to travel internationally is to have yourself a good time on your own terms with your own ‘perceptual apparatus.’ That’s the way I did it. My trip around the world was a public transportation trip, and that’s the kind of trip I always take here in the U.S.”

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From a man with achromatopsia who is also a vision scientist: “Side shields on spectacle frames shut out unwanted light, but they also prevent motion detection in one’s peripheral visual field, which is important for moving about safely, so I don’t use them. Outdoors in the sunlight, whether I am blinking my eyes rapidly

in bright light or not so rapidly at lower light levels, I experience a visually stable world in which I can orient myself and move about. At higher light levels my peripheral visual field is much more affected than the central part of my visual field; I am still able to detect movement in the far periphery, but I have much more difficulty in identifying what is moving and then reacting adequately to it. This causes me to move in a rather stiff, hesitant manner, sometimes bumping into people, and to be overcautious when moving in agitated surroundings or when encountering unmarked steps. However, as soon as I am in the shade or indoors, I again move in a relaxed and confident way.”

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“One of the advantages for folks who drive is being able to carry in their cars items they may need when away from home – everything from facial tissues to rain gear. Those of us who don’t drive have to resort to backpacks or tote bags. Another option is to wear clothing with lots of pockets. Visually impaired persons tend to have even more things to carry with them than the average person. As an achromat, I often carry 2 or more pairs of tinted lenses, a magnifier, a monocular, and a visor or foldable hat. Coats, jackets or “cargo pants” that have roomy, secure pockets can serve this purpose. Sometimes I wear a multi-pocketed vest. These vests may be called ranger vests, photo-journalist’s vests, or trail vests.

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Editor’s note: the following resources are worth knowing about:

On Greyhound Bus Lines (1-800-231-2222), two people can travel for the price of one, if one of them has a disability and states that the other person is his or her travelling companion. And Amtrak (1-800-872-7245) offers a discount to passengers with disabilities, whether or not they travel with a companion. You can phone Amtrak and request a free large print copy of “A Guide to Amtrak Services for Passengers with Disabilities.” Also, local and regional transportation systems offer substantial discounts for passengers with disabilities. Certification of vision impairment is required for all such discounts.

Finding Wheels: A Curriculum for Nondrivers with Visual Impairments for Gaining Control of Their Transportation Needs, by Anne L. Corn and L. Penny Rosenblum, a 103-page paperback published in 2000, is available from Pro-Ed in Austin, TX, 1-800-897-3202. This book was created to help teachers, O&M personnel, parents, and others explore with visually impaired young people strategies for coping with the challenges and frustrations of being a non-driver. Included is a presentation of preliminary procedures for pursuing a license to drive using bioptic systems. For more details, see <<http://www.proedinc.com/>>.

Some “walking sticks” are quite elegant. They have a long history, especially in Great Britain. Partially sighted walkers have many uses for the walking stick – e.g., as an occasionally needed mobility aid for negotiating steps or irregular walking surfaces. Available in wood or metal, these are not to be confused with orthopedic canes (though these have also been used as mobility aids by some networkers) or white canes. See: House of Canes <<http://www.houseofcanes.com/>> and Canes and Such <<http://www.canesandsuch.com/>>. (Continued on the next page)





From a man with complete achromatopsia: “Looking back, I can see that my ability to travel independently has unfolded in a progressive, step-by-step way. Until I was 14, my dad drove me where I needed to go or my mom traveled with me by bus. Then I began to use buses independently. Also, I began to ride my bicycle and my moped longer and longer distances. I could do this because I lived in a small town with light traffic. I don’t believe my parents ever let their anxiety stop me from seeking independence, and I am deeply grateful to them for that. At the same time, they were careful to warn me about risks. I would ride my bike on familiar streets and cross major roads at pedestrian crossings and traffic lights. When riding my bike or moped, I have always kept to a speed low enough to enable me to perceive any obstacles I might encounter. Also, I wear my sunglasses when riding in the daytime and am ever mindful of my vision limitations. Whenever I need to reach a new destination in unfamiliar territory, I have always been cautious until I get familiar enough with new surroundings to include them in my ‘topographical repertoire.’ My orientation strategies – whether walking, biking, or traveling by bus – have included spotting conspicuous structures I can easily recognize, such as a very light or very dark building or special sequences of buildings (e.g., a low building between high buildings). The next step in my quest for independence was to start traveling by train, which I began to do in my early 20’s. My main problem was how to find out which platform my train would leave from. I didn’t have a monocular back then, so I could not read the signs in the station or the posted timetables. But the ‘changing message’ signs on the platforms were white text on a black background and low enough for me to read. My strategy was to reach the station early enough to have time to familiarize myself with the trains and platforms. Sometimes I would be lucky and my train and its leaving platform would be announced. Otherwise, I’d just walk around the platform and inspect each sign until I found the right place. This is how I managed when I was living in a nearby city during the week and traveling to my home town on weekends. I could not ride my bike or moped in the city because of the heavy traffic. To reach my office in the morning, I had to walk to the station (a 20-minute walk), take a subway train, and then take a private shuttle. After work I would usually just ride the shuttle and then walk the rest of the way home. I preferred walking as much as possible and didn’t like using buses or trains, because they did not give me the chance to get familiar with the city where I was living. Eventually I got a job in a smaller city, and my mobility options increased. In a small city I can ride my bike or moped and use public transportation when it is rainy or snowy. Sometimes I also travel internationally. I work for a multi-national company, and traveling is something employees are expected to do. Perhaps, as a visually impaired employee, I could ask to be assigned only sedentary work. But why should I? I am able to travel independently and am far more concerned about having full work opportunities than about the extra trouble I must go to when traveling. Early this year I flew to Paris to attend a work conference and was able to confirm my belief that, using my Eschenbach monocular and asking for directions, as needed, I can travel independently anywhere – at least anywhere that the languages I know are spoken.”

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Editor’s note: Information about ordering material pertaining to achromats who drive can be obtained by writing to one of the addresses given on p. 164.

Getting Diagnosed

“Ever since our daughter was diagnosed with achromatopsia, I’ve tried to learn as much as I could about it. When I’ve looked it up in books about vision disorders, I’ve been lucky to find even a few paragraphs, so we were so pleased to learn about the network. We didn’t get this diagnosis until we took her, at age 5, for a low vision evaluation at our state school for the blind. Before that we had been to 3 other ophthalmologists. One had us coming every 6 months for eye exams. When she was 2, he told us that she was ‘legally blind’ but that he couldn’t explain why her nystagmus caused her to have such poor visual acuity. When we finally decided to drive the distance to the school for the blind to apply for their preschool intervention program, the eye doctor there gave her a comprehensive eye exam and listened to what we had to say. When she asked if the light bothered our daughter, I was so accustomed to being told by her previous doctor that I shouldn’t be so protective and should just get her out in the sun that I quickly said, ‘She hates to go out in the sunshine, but I make her.’ Then, when she asked how our daughter was doing with color recognition, I said, ‘I’m trying to work with her on her colors – but she’s very bright about other things, like shapes.’ It was such a revelation when this doctor said she believed our daughter had a vision disorder causing all of these problems. She gave her a simple color vision test. My husband and I were amazed to see that she could not see the figures in the tests (formed by the dots) that we were able to see so clearly.”

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“The road to my son’s correct diagnosis was long and rocky. His pediatrician referred me to an ophthalmologist, and the ophthalmologist suggested a neurologist. Some of these visits were frightening, because they did not have an answer. Among the incorrect theories were a brain tumor, a psychosomatic disorder, and insinuations that I, the mother of this child, might need psychological help! My son now sees an eye doctor who is knowledgeable and supportive.”

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“The network newsletter was instrumental in our son’s diagnosis. At 6 months of age, he was diagnosed with ‘congenital nystagmus.’ His aversion to bright light and poor distance vision were obvious to us at an early age. We took him to several ophthalmologists who ‘specialize’ in nystagmus. They said that, because his nystagmus was mild, then he could see fairly well and that he wasn’t really photophobic, so we should just let him wear a hat outside. They treated me like an over-reacting, overly protective mother. We then took him to an optometrist – a low vision specialist – who did a more thorough job of testing his vision and declared him legally blind. He said he suspected achromatopsia. This was the first we had heard of this condition. Although way back we were told that there was a slight chance he could be colorblind, we now strongly suspected it. The possibility that all of his visual difficulties could be caused by a single eye condition was a revelation. My mother had met someone whose child had an eye condition which sounded like our son’s, and this person passed on to us one of the network newsletters. I received it 2 days after our visit to the optometrist. It described our son’s experiences exactly! Why hadn’t anyone mentioned this eye condition to us before? When we returned to the ophthalmologist for a final diagnosis, we felt much better prepared to discuss and ask questions about our son’s eye condition. He sheepishly agreed with ‘our’ diagnosis of achromatopsia.

The newsletters have helped immeasurably in understanding what our son goes through and why he acts the way he does. No doctor or medical book has even come close.”

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From another mom: “We knew something was wrong with our daughter’s eyes when she was 2 weeks old. Her eyes would rapidly move back and forth. Our doctor said it could just be an immature nervous system. As she grew, more symptoms showed. By age 3 she had CAT scans and then was sent to an eye doctor, who suspected achromatopsia. He sent us elsewhere to have this diagnosis confirmed. Our doctor did not want to tell us right away that our daughter had this genetic eye condition, because at the time, I was 7 months pregnant with our second child, and he knew that there was a 1 in 4 chance that the second child could also have it (as it turned out, she didn’t).”

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“I wasn’t diagnosed until I was four years old. My parents discovered my visual problem early in my infancy, but they could not get any good answers from any of the doctors. One of the doctors I was taken to tried to explain away my ‘shaky eyes’ by saying that I was ‘spoiled’ and was doing it for attention!”

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From a man in England: “I was not properly diagnosed until I was 33 years old. Prior to that, I was told simply that I had nystagmus. From the age of 6 months, I received regular hospital checkups but was not given any practical assistance with my special visual needs, mainly as a result of the incorrect diagnosis. I was not, for example, given any help in obtaining dark glasses, because the people at the hospital could not understand why I needed such a heavy tint. And, although I knew I was colorblind, this was never mentioned in my records at the hospital. Low vision aids were never offered to me. Eleven years ago, after hearing a radio program about nystagmus, I arranged a visit to the Institute of Science and Technology in Manchester, where research into a new treatment to help reduce eye movements was being carried out. It was during this visit that the research team discovered I was a rod monochromat, rather than simply a patient with nystagmus. The help I received from them, including the introduction to low vision aids, made a big difference in my life. However, I still had very little information about my vision disorder – until I discovered the Network.”

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From a man in his 30’s: “My parents began taking me to see eye specialists at the age of two. Over the years I think I received every misdiagnosis imaginable, from the unforgivable ‘merely looking for attention’ at age 9 to the truly laughable (and frequent) diagnosis of ‘optic myosis.’ (*Editor’s note: the term myosis means having unusually contracted pupils.*) I stopped seeking medical advice at age 17, having been told by a world famous American specialist that my condition was optic nerve atrophy and that I had a 50% chance of being completely blind by middle age. My sister-in-law sent me a copy of Oliver Sacks’ book *The Island of the Colorblind*; and now, 2 months later, I still have not recovered from the experience of finally getting to read about my eye condition. After having lived all my life in a world in which I appeared to be the sole person suffering from an unnamed and difficult to describe condition, to be finally reading about numerous other people who experience the world as I do – well, I can only say that ‘world-shattering’ seems a reasonable assessment.”

“Our daughter was first clinically diagnosed with achromatopsia by our family doctor at about 3 or 4 months of age. The doctor had us take her for testing to make sure. My wife and I endured the next couple of years of hearing various different possible diagnoses, which included leukemia, brain tumor, and others equally horrific. And some of the tests used to determine these diagnoses were not accurate. When medical science finally agreed with our family doctor’s diagnosis (albeit with reservations), we were relieved, to say the least. Throughout this period, our daughter remained happy, healthy, active, and too completely normal to be terminally ill, regardless of what the experts pronounced.”

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From a man in his late 20’s who had previously expressed immense relief at having found out, through joining the network, that there was a name for his eye condition: “I was finally given the diagnosis of ‘achromatopsia’ during a recent eye exam. Amazingly, I learned that the word ‘achromatopsia’ had actually been in my file at my doctor’s office for 7 years. When I confronted him about why I had never been given this term before as a name for my vision problem, he told me he hadn’t thought that it would have much meaning for me. Apparently he had decided not to overburden me with such bewildering terminology. But I believe that I, a college drop-out, know more about achromatopsia than he does.”

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“My son was recently diagnosed with achromatopsia. Although my husband and I are not happy about this diagnosis, I think the shock is lifting. Recovery began when we switched pediatric ophthalmologists. The first one was intent on turning our son into some sort of invalid encumbered with all sorts of paraphernalia. Our current one seems much more balanced in approach, willing to accommodate the actual needs of the child and not just the research literature. I thank heaven our little guy is so bright and happy. One specialist we saw said to me, ‘You and I could sit here thinking of all the things your son will probably never do because of this vision disorder, but we could also think of all the things that we ourselves will never do. What you need to do is to focus on the sight that he does have and all the activities that he is able to pursue.’”

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From a network parent whose reports regarding her son always indicated that there was considerably more vision than one would expect with typical (complete) achromatopsia: “Thank you for urging me to take our son to yet another specialist for more complete diagnostic information. We did this and, after a long day of testing, we learned that he has blue cone monochromacy, instead of rod monochromacy. I have a much better understanding now about his eye disorder.”

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“When our daughter was 4 weeks old, her pediatrician referred us to an ophthalmologist, because he feared she was blind. After a year of MRI scans and endless appointments with specialists, it was determined that her vision was perfect and that she just had nystagmus, which would disappear with age. A previous diagnosis of albinism was overturned when she appeared at the doctor’s office with a suntan. By the time she was 2, we realized that all was not well. She functioned perfectly well indoors but could not stand to be outside, where she continually tripped and ran into things. At that point, we sought another opinion from a doctor who performed an ERG and diagnosed her with achromatopsia. This doctor referred us to the state school for the blind and suggested sunglasses. We

then traveled to another state to see another leading eye specialist, who confirmed this diagnosis but made no suggestions about anything that could help her. Finally we traveled to California where an optometrist researching achromatopsia helped us understand everything and obtain the lenses our daughter needed.”

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“When our daughter (now age 21) was 3 months old, we noticed her eyes were jiggling at times. The doctor we consulted said she had nystagmus. He didn’t know if her sight would be affected. When she began to crawl, she would zoom through the house but would stop dead in her tracks whenever she encountered a sunbeam on the floor. We had no idea why and thought this was somewhat humorous. About this time we also noticed she would go into somewhat of a trance whenever we took her outside. We would wave our hands in front of her face, and she would not react at all. Again we took her to the doctor, who sent us to specialists, who performed various tests. An ERG was administered, because doctors suspected she was having epileptic seizures in the sun. Ultimately we were told that her eyes were simply very sensitive to light. As she got older, we tried one specialist after another, including two leading neuro-ophthalmologists in our state. Both told us that her eyesight was poor, that Rx glasses could not help, and that she would probably not be able to read or attend regular school. Two doctors we saw thought her optic nerve was atrophied and that the difficult labor I experienced when she was born had probably contributed to this. She started wearing inexpensive sunglasses at 10 months. She progressed well in school. She reads with a book practically up to her nose, but she reads very well. At age 15 she was finally properly diagnosed with achromatopsia by an optometrist, who even took a picture of her optic nerve to show us that it was not atrophied but fine. He gave us information about her eye condition and helped us get various kinds of tinted lenses for her to try.”

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From another mom: “You must get a lot of ‘horror stories’ from networkers about the ordeals families have gone through when babies and small children undergo ERGs. My son’s horror story never should have happened; and, if I had been warned, I wouldn’t have let it happen. When he was 6 months old, I took him in for the ERG to be done. Since he was so small, I had to hold him up to the chin rest. He was put to sleep for the test. Later I learned that he received third degree burns on the back of his hand, because his hand was against one of the three boxes on the ERG machine. There was no sign from him that this was happening, because he was under the anesthetic and did not feel the pain until he awoke from the anesthetic. There was a doctor doing the test and a nurse helping me, but at no time was I told that the machine would get hot. Later I was just told that nothing like this had ever happened before. I just want to warn people with small children to be sure that the child’s hands are kept down at his or her sides. I wish someone had warned me about this.” *(Editor’s note: Although this parent’s story stands out as being especially unfortunate, others have also reported distressing experiences. Since ERGs are recommended routinely for infants who show signs of achromatopsia, it is important that networkers’ experiences with ERGs be shared. The purpose of sharing these reports is not to scare people but to offer such information as may help to prevent or minimize stress and trauma.)*

“Our daughter had an ERG done when she was about 3 years old. For her the most uncomfortable part of the whole procedure was getting the anesthetic into her eyes. After that, all the rest went relatively easy. I sat with her on my knees, watching the flashes, counting them, singing children’s songs, playing little games. The doctors were very relaxed too, and they took a lot of time with her to make her feel as comfortable as possible.”

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“Our son had a rather traumatic experience when they were trying to diagnose his eye condition. They wanted to do a test that required placing some things under his eyelids while he was awake. He was about 2 years old. He fought so hard that they had to abandon the test. This left him with a long lasting fear of anyone putting anything in his eyes.”

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“Although my son’s ERG was, by far, the most harrowing medical test that any of my children have had to endure to date, it went smoothly and with as little physical or mental trauma as possible. Once the test was well underway, my then 3-year old actually slept through the rest of it. My recommendations to parents whose children will be having an ERG are: 1. If possible, find an ERG laboratory where a pediatric ophthalmologist will administer the test – or at least an ERG laboratory where they have had a lot of experience with children. 2. As a parent you need to remain calm and as ‘matter of fact’ as possible. This is extremely hard, considering what your child is going through. But, if you can convey to your child, through your own demeanor, that it’s not such a big deal, then your child will pick up on it and be calmer as well.”

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“I decided to write in about our son’s first ERG – which was a very traumatic experience for us all – because maybe some doctor will read our story and think more carefully about how to handle infant patients. Our son was only 3 months old when a pediatric ophthalmologist told us there was a chance that he might be blind, deaf, and mentally retarded and that we should schedule an ERG immediately. We went home in shock. She never explained what she was going to do or what the rush was all about, and we were so upset by what she had said that we didn’t think to ask the questions that occurred to us hours later – questions like ‘What’s an ERG?’ and ‘What are the risks of general anesthesia for small infants?’ We learned later that her speciality is retinopathy of prematurity, a vision defect that often does involve severe disabilities. I will never forget the sight of our 3-month old son screaming as they fumbled to find a vein, then screaming as they wheeled him away. This was after not getting to breastfeed at all after midnight before the ERG, at an age when most babies are not able to sleep through the night. We learned later that the doctor had ordered the ERG because she was trying to decide between two diagnoses, neither of which was treatable anyway! A few months later we went to another doctor for a second opinion. His method of administering an ERG was totally different – calm and friendly staff, no general anesthetic, parents staying in the room. And his cheerful and helpful way of talking to us made us feel confident and optimistic about our ability to raise a child with a vision impairment. I especially appreciated the way he said to us, ‘You are really the experts here, because you will be coming to me and telling me about what your son is able to do and what he tells you about how he sees and what works and what doesn’t work for him.’”

Experiences with Vision Care Specialists

“Because I get my eye checkups at a teaching hospital, I get seen by a different doctor each time I go. During my recent visit, I could tell that the doctor who was examining me was trying not to appear overly fascinated with achromatopsia, while at the same time relishing his first opportunity to examine a patient with this rare disorder. I really think we should charge admission!”

“I feel as if we achromats don’t quite fit into anyone’s program. Those eye charts that are beamed onto the wall with a projector do nothing for me. And why do they shine that little pen light into my eyes before testing my visual acuity? I have always dreaded the retinal examinations in which my eyes are subjected to very bright lights. During a recent eye exam, I expressed this concern to the medical student in charge of me. He was sensitive and actually nervous about examining me, so he called in his supervising doctor, who apologized for any discomfort I might have to endure and then stood back and proceeded to shine a really dim light through a weak magnifier. It was a blessing to be treated so carefully. I’m not going to be a ‘wimp’ anymore when it comes to this.”

“It annoys me that, when you’re legally blind (i.e., have serious vision impairment that cannot be corrected or ‘cured’), so many eye doctors do not seem to find it worthwhile to look for ways to help you with the vision problems. I guess they feel it’s not worth the trouble. They’ll check your refraction and just shake their heads at the rest.”

From a networker in her 30’s: “There’s something I wish that ophthalmologists and low vision specialists could understand, and that is that only about 50% of our problems have to do with vision itself. The other half of the package has to do with how we are perceived by others and how we perceive ourselves. We would like to ‘blend in,’ to be socially accepted. Yet all of these specialists expect us to readily accept low vision aids that are either very weird looking or just plain ugly – like the spring-loaded glasses I got when I was 13, which had a scope sticking out from one of the lenses (I never used them). I can’t blame teens one bit for not wanting to have anything to do with low vision aids or heavy duty sunglasses. Are there some of us to whom vanity is not an issue? I suspect that, if someone had enough money, he/she could get optical aids so good looking that they could start a trend. Then there’s the side of me that’s resigned to always looking a bit ‘different.’ Even so, just once, I would like to hear a doctor ask, ‘How do you feel about the way you look wearing these glasses?’”

“Many years ago I had a pleasant discussion with an eye doctor who was very open about admitting the limited amount of knowledge regarding achromatopsia among vision care professionals. During a routine eye exam, I raised a question regarding my vision disorder; and, to my surprise, this doctor said, ‘You know, you’re the expert on this subject.’ He stated that, while he could provide information about the health of my eyes, it was I, the patient living with this rare disorder, who was qualified to educate medical professionals like himself about the non-medical aspects of it. I remember feeling so much respect for him for acknowledging this. What I had consulted him about had to do with tinted lenses. I had begun wearing some sunglasses that had been made very dark and was experiencing

remarkably improved vision outdoors, but I was noticing that my light sensitivity indoors had begun to increase, so that I was having to wear tinted lenses more of the time. I wanted to know if my use of the extra dark lenses outdoors could be responsible for my increased sensitivity to light indoors and what I should do about it. He listened carefully (one of his many fine traits as a physician), agreed with my suspicions with regard to my recently reduced tolerance for light, and then advised me to follow my instincts about what to do. It was at that point that he made the statement about my being the real ‘expert’ on achromatopsia.”

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From a mom: “I just cancelled a routine eye exam appointment for my son. They never do anything for him, so I feel it’s useless. I know more about his eye condition than the doctors we’ve gone to. In a way I feel bad about cancelling the appointment, and yet I know that all that has ever been done for him that has really helped has come through my own efforts and research.”

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From a woman in her 50’s: “Throughout my childhood and teens, my mother would take me, every 2 years, to have my vision checked by a highly regarded eye doctor. This meant an hour’s ride on the Greyhound bus, a long walk from the bus station to the medical building, and several hours of waiting at the doctor’s office – first waiting to have my eyes examined and my vision tested and then waiting for repeated examinations after the eye drops to dilate my eyes took effect. Many Rx lenses were tried out with me to see if any of them helped me to see better. The doctor never really talked with me, and he said little to my mother. He always had a grim expression on his face, especially when he would make the inevitable pronouncement, at the end of each office visit, that there was nothing that could be done for me – except for the reading glasses that he prescribed. My mother and I would always leave his office feeling very sad, and my self-esteem, already quite fragile, would hit rock bottom on those days. To make matters worse, the eye drops used for dilating pupils were very slow to act and slow to wear off back then, so I had to endure many hours of much worse vision and even greater light sensitivity. Our next stop would be the optical dispensary, where an optician (usually a pleasant middle-aged man) would try to convince me that wearing the new reading glasses would make me as pretty as a movie star. I knew better, of course. With resignation, I would accept the new glasses (even more expense for my poor mother, who had so little money but who believed in doing whatever the doctor said to do). When I got the new glasses, I would try to be good and wear them. I knew that they ‘corrected’ something (later, I was to learn that it was a refractive error called farsightedness and also astigmatism), because they did make things look ‘different.’ But I really didn’t like the way they made things look, and I especially didn’t like the way that wearing the glasses for awhile caused everything to look so blurry after I took them off. But, most important, I knew something that the doctor did not seem to understand – that the glasses had no effect at all on whatever it was that was seriously wrong with my vision. It would be many years before I was to understand about cones and rods and achromatopsia. I would also come to understand about how adaptable the eyes are and how easy it is to become dependent on Rx lenses. Back then I only knew that, whenever I would wear those glasses for even half an hour and then

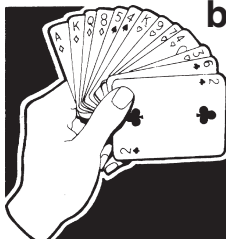


take them off, everything would look very blurry to me – but, within an hour or so after taking them off, the blur would clear up and I would begin to see in my familiar way again. I knew, without a doubt, that it was important for me to be able to choose not to wear those glasses, yet I felt guilty for rejecting the only thing that my mother had gotten for all her trouble and expense.

“When I was 18, I went looking for a new eye doctor. I recall my mother’s sadness when I made an appointment with someone new. To her it was like an act of betrayal and disrespect for the doctor she had taken me to for eye exams since the age of 2. The new doctor I found was all I had hoped for and more. He was cheerful and a good communicator, and he treated me in a very positive, considerate manner. He even gave me a name for my eye condition, and he answered me reassuringly about the hereditary aspects which concerned me. He always introduced me to his assistants as a ‘very special patient.’ He respected my choice not to wear prescription lenses. He understood that, while they created a slightly sharper image for me indoors, they had no effect whatever on my primary vision problems, and yet routinely wearing them would eventually make it difficult for me to manage without them, unless I was willing to live with the blurry (unfocused) vision which I would experience after taking them off. This, I felt sure, was too high a price to pay for the slight improvement in visual acuity that they offered. He introduced me to an optometrist who helped me obtain good sunglasses, which helped me with my serious problem of light sensitivity. My new ophthalmologist encouraged me to go to college, and during my college years, when I had no medical coverage and no income except for my college funding, he insisted on providing all eye care services to me without charge. He was a distinguished eye surgeon and a teacher at the medical school – and he was an extraordinary human being, who made a tremendous and lasting difference in my life.”

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“I have come to the conclusion that it is not the more knowledgeable a specialist is that counts but rather how interested that person is in helping you. I have been to numerous specialists in my life, including a prominent retinal specialist, and yet it was a regular optician who obtained the best results for me, in getting both tinted contacts that would work for me and also some good sunglasses. He assigned a student optician, who was training under him, to my case, and actually it was the student himself who took the trouble to phone around to the different companies asking for samples of various tinted lenses.”

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From a man in his 50’s: “I am mulling over the idea of getting glasses with something less than my ‘official’ prescription. This idea seems alien to my doctor. I asked him why I needed such a strong prescription when I really don’t use my Rx lenses very much and they do not make that much difference in the way I see. He just said something about how that is what my prescription should be. Seems a bit rigid. I do not care for wearing thick, heavy lenses, and I can see almost as well without my glasses as I can with them. Many years ago, when an eye doctor suggested I try red contact lenses, I actually had to get clearance through the FBI, because it seems that some card-sharps (gamblers) were using pink contact lenses, which somehow allowed them to see marks on cards that others could not see.”



Using Resources for the Visually Impaired

From the parent of an older teen with achromatopsia: “We have tried to obtain help and understanding everywhere we went in search of services for our son, and we have been amazed to find that so many people (counselors, teachers, etc.) hear about light sensitivity and take it with a shrug of the shoulders. They just can’t seem to understand why glasses won’t correct the vision problem.”

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From a man with achromatopsia in his 40’s: “I have dealt with a number of agencies for the visually impaired; and, in my experience, it is usually like being invited to a party where someone takes some Lincoln Logs, an Erector set, and a Candyland game and just dumps everything on the floor, then stands there and says, ‘Okay, let’s play.’ The kids at the party don’t know what they can do or should do or what they can expect. There’s no structure, direction, or anything else to help. One needs phenomenal ego strength to get anything out of some of these agencies. They’re supposed to be there to help, but somehow certain factors seem to make it so hard for them to do this as readily or as intelligently as a new consumer of these services needs.”

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“We received ‘social help’ for our son from the local blind association, but they treated him as if he were blind. Such help as we would find at various agencies was never quite right, but we would always check these services out anyway. At these places serving the visually impaired, do they just not listen to you, or is it that they don’t understand about achromatopsia?”

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From a dad in the U.K.: “During the summer the Royal National Institute for the Blind organized a special program of outdoor activities for vision impaired children who are in mainstream schools. Our son (age 14) had a great time rock climbing, canoeing, snorkeling, and generally doing the things that normally sighted people his age enjoy. He is now in touch with several visually impaired acquaintances as a result of this program. None of the others have achromatopsia, but one of them has worse photophobia than our son has.”

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From a college student with achromatopsia: “My advice to others in the network is to believe in yourself and take all the benefits you can.”

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From a network parent: “Our optometrist told us that, in the state where he used to practice, children are provided, free of charge, with glasses, contact lenses, telescopic aids, etc., if it is deemed medically necessary. Since that isn’t the case in our state and since we as a family do not have optical in our insurance plan, this optometrist has obtained assistance for us from The Lions Club. Patients with achromatopsia do require some specialized optical aids – the kinds of tinted lenses that can help with the light sensitivity outdoors – and I believe that these should be provided for by medical insurance and state assistance programs.”

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From a woman with achromatopsia: “I wonder what other networkers’ eye doctors and optometrists put down on records and forms, so that insurance companies will pay for tinted lenses that are made for them? For us achromats, having good dark sunglasses for outdoors is a medical necessity, and yet I’ve always been told that medical insurance programs do not see it that way, so I’ve always had to pay in full for tinted lenses that have been made for me.”

“I find that some ‘sources of help’ actually hinder instead of helping. For example, some ‘helpers’ keep pressuring all partially sighted persons to use a white cane, even though many of them do not want or need to use a cane!”

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“Several years ago, I took a class in self-defense for disabled persons, sponsored by a sports organization for the disabled in our city. There were only a few of us in the class who were vision impaired. Most of the participants had mobility impairments. Nevertheless, I found that most of what we were taught was applicable to all of us in the class. It was a very valuable experience. Later I took a series of self-defense classes at a center for the blind and visually impaired, and this was also a great experience for me. This course included some different approaches to self-defense. About half of the participants were partially sighted and the other half were blind. This was, by the way, during a period of my life when I was doing a great deal of independent travel. Now I have learned that there is a new book entitled, *Safe without Sight: Crime Prevention and Self-defense Strategies for People Who Are Blind* (published by the National Braille Press). The authors include a sighted self-defense instructor who has designed various programs for people with disabilities, a blind clinical psychologist specializing in trauma and assault issues, and a blind director of a rehabilitation center. I am looking forward to getting a copy of this book, and I expect that a lot of the information in it will be as applicable for persons who have limited vision like me as it is for the blind, just as was true in the self-defense classes I took.”

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From a network parent whose 6-year old daughter has achromatopsia: “The IEP meeting that was scheduled for our daughter was attended by a representative of the School for the Deaf and Blind in our state. She talked as if she was an expert on matters pertaining to our daughter, even though she had only been with her once and that was for about 15 or 20 minutes. She said she would like to see our daughter learn Braille. I’m sure that Braille would be a good thing for her to know if her vision should ever get worse due to an accident or developing some serious eye disease. But, as of now, I feel sure that she would just try to read the dots by sight, rather than by touch. She has so much good vision to use for reading.”
(Editor’s note: A child who is accurately diagnosed with achromatopsia – and who has no other serious eye condition has no need of Braille instruction.)

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From a woman with achromatopsia in her 50’s: “I can relate to the comments of networkers who tell about being treated as if they have much less vision than they do by some of the professionals who work in programs for the visually impaired. Over the years I have encountered many such professionals, people who often have had a great deal of experience in working with the blind or the nearly blind but who have little or no experience with the partially sighted. Almost always, they have never heard of achromatopsia. Teachers and counselors who routinely direct all persons with low vision toward using a cane or Braille, etc., are inclined to interpret any resistance to their recommendations as indicating that someone is ‘in denial’ about their vision impairment. Sometimes I have had to work hard to convince some of these people that I do not need to use the same kinds of adaptive methods that blind or nearly blind people need. I wish that more O & M teachers would explore some O & M techniques that really are useful to achromats, instead of just offering them instruction in cane travel.”

“Recently I attended a convention for members of the American Council for the Blind in my state. I went with two other vision impaired persons I know from a low vision support group I’ve participated in. There were blind people there with canes and guide dogs, and there were some people like me who had partial vision. This was the first time I have ever been to one of these conventions, and it was a really positive experience for me. Never before have I been so comfortable about not being able to see normally. It was so nice being in a situation in which I could just be myself and in which people were assisting me in various ways with no questions asked. Some of it felt like ‘pampering,’ because I am so accustomed to having to do things the hard way most of the time, without any assistance or sympathetic understanding from anyone with regard to my vision impairment. As one example, the restaurant where we had lunch while at this convention offered large print menus for those of us who were partially sighted and Braille menus for the blind. In the vendor room I got to try out CCTVs, some enlarging software, optical aids, and other devices. I had a great time!”

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From a teacher who works with 2 students with achromatopsia: “In my training to work with visually impaired students, I studied various approaches to assessment of needs, etc., and I became acquainted with a wide variety of low vision devices. But I suspect that educators tend to crowd the children with too much stuff, almost to the point where they are unable to understand their own natural coping skills. So I was intrigued to read the comments from networkers stating their honest feelings about how the ‘services’ could sometimes hinder the process, instead of helping. I back off from over-evaluation and over-analysis, especially with kids who are very bright and who seem to know exactly which low vision techniques and devices they need and when they need to use them.”

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“Regarding the term ‘legally blind’: I was informed by the State Services for the Blind in our state that, if I had chosen not to register my child as ‘legally blind,’ she would not be entitled to any services – no O&M instruction, no special education services, no special adaptations in her classroom or with her school materials. Since her visual acuity even in the dim lighting of a doctor’s examining room is considered ‘legally blind,’ I believe that it would be a disservice to her not to accept services that are made available to the ‘legally blind.’ I feel that these services promote her development and independence, rather than simply confirming her disability. When she was 3 years old, she refused to accept the term ‘legally blind.’ She would hear me on the phone advocating for her needs, and she would shout, ‘I am NOT blind! I can see!’ It took a while for her to understand that this term just meant that she was entitled to special services, since her eyes were different from other people’s eyes. By the time she was 5 years old, she realized that the term ‘legally blind’ got her a front row seat at concerts and theater events.”

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From a woman with achromatopsia who was a special education teacher for many years: “My parents got me involved with the Commission for the Blind when I was in my teens. One summer the Commission sent me to a college prep program, where I received training in independent living skills. My vision impairment was not as severe as that of most of the other students who attended, so the program was relatively easy for me. We stayed in dorms and took public transportation to and from the rehab center each day. When I graduated from high school, my college

tuition was paid for by the state, and it was arranged for me to receive Supplemental Security Income for living expenses while in college. I was required to apply for all financial aid I was eligible for. I was even provided with tinted contacts and other adaptive aids by the State Commission for the Blind and was put in touch with vision care specialists who were on the leading edge of the field. It was my understanding that the Commission wanted its clients to become financially independent, so they invested a lot in training me and giving me the tools I needed.”

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From a network dad: “When our son was 5 months old, his pediatric ophthalmologist registered him with the State Commission for the Blind. As a result of his having taken that action, many good things have occurred. For example, as an ‘official’ visually impaired child, our son automatically became eligible for a state program that provides special services until age 3. He is seen twice a month by a professional who specializes in helping visually impaired children in this age group. Also, they noticed a delay in his speech development, so he was referred to a speech therapist for monthly appointments. All of these services are paid for by the state. Also, since visual impairment is one of the specific learning disabilities under the ‘Individuals with Disabilities Education Act’ (IDEA) – commonly referred to as special education – the public school program in our town is required to work with us in developing an individual education plan for our son. This ensures that his future teachers will be educated about his eye condition and about the specific accommodations and special services he will need in school. Because of his registration in this program, he automatically becomes eligible to enroll in our town’s pre-school (slots which are usually subject to a lottery). This is yet another boost to his chances for future success in school. I can sympathize with network parents who do not want the label of ‘legally blind’ being applied to their children. But I just want to emphasize the fact that this label is a very useful one in getting the attention of persons (such as school administrators) who are in a position to provide the kinds of special help that a visually impaired child needs.”

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From an optometrist who works in a low vision clinic: “One of the challenges I have is convincing parents that ‘more’ is not necessarily ‘better.’ In my experience, when vision impaired children are shown options in optical aids and adaptive devices, they make better decisions than parents, teachers, or doctors.”

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From a woman with achromatopsia: “I participate in a low vision support group. The people in the group are great. We meet every month and talk about a wide range of subjects. We also go on scheduled excursions. Next week, for example, we will go rowing on the river through a special program that helps persons with disabilities access state parks. During the winter we went cross country skiing. It was a lot of fun. They sometimes schedule tandem bike rides. There is a variety of ages, personalities, and types of vision impairment within the group. Sometimes in our discussions we learn from one another about various benefits, discounts, accommodations, exemptions, services, etc., for persons with vision disabilities. And, it’s nice to learn about what others in the group are using in terms of adaptive aids. This is how I learned about the bold black large print key caps I use on my keyboard, which make it so much easier for me to find the keys I need. After a lifetime of searching for people who can empathize with the problems I have faced, having this support group is wonderful.”

Parenting Children and Teens with Achromatopsia

From the parents of a 21-month old boy: "Because of the rarity of this vision disorder and the fact that our son is too young to communicate about it verbally, we have had a difficult and frustrating time trying to help him. However, in the few months since we have been members of the Achromatopsia Network, we have learned so much that no one had ever explained to us before. We have ideas and references to use; and, probably most importantly, we now feel that, although our son will probably have a difficult road ahead of him, it is not an insurmountable one. And, now that we have a better understanding of achromatopsia ourselves, we are getting better at explaining his situation to others."

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From the mother of two children with achromatopsia: "There are times when it is very hard to witness the problems that our children have to deal with because of their vision. For me, sadness and tears surface again and again. While their courage amazes us, their moments of anguish are hard for us to bear. What helps most is being able to say these very things – often and to empathic listeners, who can validate such feelings and experiences. I would urge network members to write even more about the 'feelings' part of this disability."

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From the father of a 3-year old girl: "We recently moved to a house with a backyard facing east and with lots of trees and a big patio cover. It gets shade most of the day because of the patio roof and the trees. There is only one window on the south wall, and it has shutters that our daughter can easily close, if it is too bright for her. In the place where we lived last year, she never went out to play in the backyard, which faced west. She plays in the backyard a lot now."

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From a woman in her 30's: "I hope that the network parents will relax and trust that their children will naturally figure out ways around the obstacles in their lives (with appropriate help from their parents, of course – things like unconditional love, discipline, providing visual aids, and other parent stuff). So your kid may not be able to become a truck driver or an Olympic beach volleyball player or an appreciator of the colors in beautiful sunsets! I made it without even having very much help from my parents, and they'll make it too. I have a college degree and a job which pays the bills. I think that fully sighted people just can't imagine what it's like to have a lot less vision than they have. All they know about how to do things is the way that they do things. But it's a funny thing about human beings and that wonderfully created thing between the ears – we will find ways to adapt. Parents: do what you can for your children, but RELAX."

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"When our son (now in his late teens) was younger and we would comment about some TV programs being in black and white and others being in color, he would remark that all the programs looked the same to him. Then we began to watch black and white programs and movies purposefully to try to understand how he sees things, and we still do this. As a child, he always rooted for teams wearing dark jerseys. This past summer he has enjoyed rollerblading, mountain biking, and dirt biking. This is the closest he can get to driving. He is very careful about weather conditions and proper equipment (all the safety elements), but, even so, we are sure that his guardian angel is a busy one."

From a mom: “I benefit greatly from learning about the experiences and feelings of people who have this eye condition, since I will never understand what it is like to live with it. I just try to make my son’s life as comfortable as possible and do what I can to help him become as independent as possible as an adult.”

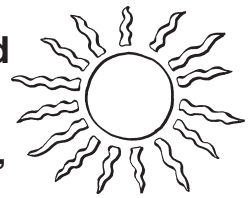
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From the mother of a teen with achromatopsia: “Our daughter recently got her first babysitting job – looking after a 4-year old boy. When the boy’s mother phoned about the job (having gotten our daughter’s name from a list of those who had completed a Red Cross babysitting course), I explained about her eye condition but also about how capable she is. We all met one another before the babysitting night. They were very impressed with our daughter and asked her back again. The mother said the boy liked her a lot and talked about her for days. Our daughter said he had asked about her dark glasses, so she had given him a brief explanation that he could understand, ending with ‘God just made me this way.’ Then the boy had said, ‘Oh, well, look! This is how God made me, and I really hate my hair!’ They played lots of games, including ‘hide and seek.’ She then had to tell him that they shouldn’t play that game anymore, because it was too hard for her to find him. He simply said, ‘Okay.’ It was great to see how good she felt after having handled all this so successfully.” *(Editor’s note: another teenager in the network has also reported on successful babysitting. She says she usually works for families in her neighborhood who already know her and are aware of her vision problem and that her babysitting jobs tend to be at night, when the kids are indoors or even in bed and when her vision is, of course, at its best.)*

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“Our 2-year old daughter’s ‘Hollywood’ appearance, with her cute hats and dark sunglasses, attracts lots of people, and we use this attention to develop her social skills. We are willing to talk to strangers when they express interest. Generally, I change the subject away from her eyes, when possible, and have her tell people her name, her age, and some little anecdote. When asked how she manages to keep her glasses on, I let her answer, ‘They help me see.’ So far, she enjoys this social interaction and has a positive regard for her ‘eye glass eyes,’ as she calls the tinted lenses. Once people get past the fact that a child so small is wearing sunglasses in the supermarket or outdoors on a rainy day, their focus usually turns to how advanced her verbal and interactive skills are. On the flip side, it does get a bit tiring to be approached so often about this. However, in my desire to set a good example, I try to be as cordial as possible – even when people glare at me and say, ‘Aren’t you going to take those dark glasses off her face while she’s inside, so she doesn’t hurt her eyes?’ A short and sweet ‘She needs them’ and some strong, direct eye contact usually do the trick.”

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“My daughter is doing fine in preschool. Achromatopsia has not held her back. In fact, she seems to have no fear of anything. She’s very athletic and active. She still gets lost (temporarily) often. I worry about the possibility of her injuring herself seriously. She’s fast and not very careful. We have had our share of emergency room visits. I also worry about her growing up too protected or neurotic. I’m trying so hard to treat her just like any other child, but it’s difficult.”

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“When our son (age 4) was a baby, he would bury his face and cry through only the most necessary outdoor transports. Later, when he was a toddler, our attempts at enjoying the neighborhood pool and parks usually ended up being aborted. We

kept mostly indoors. Once he got some good sunglasses, he started exploring the outdoors. Although he still says, 'I hate the sun,' he plays outdoors almost every day now. He is adapting much better now to unfamiliar surroundings like when we go camping or hiking."



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"When my two children, both achromats, were toddlers, I felt it was best to just let them go. Of course, I made sure they were not in any real danger. They walked into quite a few things – picnic tables, etc. I felt that being overprotective would not serve any good purpose. I knew I wouldn't always be able to be there watching out for curbs, etc. So they got used to helping themselves. I'm sure they have had more scraped knees, bumps, and bruises than normally sighted kids. I did wait until they were a little older than the other neighborhood children to let them cross the street alone. Both are very independent now. We have had our share of tears, worry, and frustrations, but we just keep trying."

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"When my daughter was 9 months old, we took a trip to the beach, and that day I discovered how little she could see outdoors. We were sitting near a bunch of rocks, and each time she would drop one, she would feel for the rocks around her and then pick up the same one she had dropped, without ever looking down. I tried this with different rocks, dropping them in different locations, and she never failed to find them, but strictly by touch. I cried all the way home. I had known since her birth that something was not right about her eyes. I called the doctor. One appointment led to another appointment, another test, another medical center, etc. Finally I learned about an optometrist who was doing research with achromatopsia, I sought advice from her and had the ERG done, which helped to establish the diagnosis of achromatopsia. I was so relieved to have a diagnosis. But also there was a sad, empty feeling, being told that there was no cure and that we would have to work with this condition the best we could."

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"I believe our 6-year old son feels that he is special because of his eyes, and he is not ashamed of it. When asked about his 'red eyes' (due to the red contacts he wears), he simply states that he has red contacts on and goes on to say that he has 'special vision.' We call it 'night vision,' which is a positive sounding statement. He attempts to pronounce achromatopsia and explains that he doesn't have cones, and by then most listeners have had enough. If they haven't, he will go on. He is a 6-year old expert on his eye condition, and I think that this knowledge gives him strength. I also think that how parents react to the questions and remarks regarding their child's eyes and the lenses they wear will affect how the child reacts. Often curious people (especially adults) won't talk directly to him. They will talk to me, as if he were deaf or not even there. I'm tired of explaining it. I've lost my patience with people too many times in the last 6 years. What keeps me going is knowing that my reactions are being taken in by my son."

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From the mother of two children with achromatopsia: "When our second child was born, we were smarter and wiser. He did not have to go through the battery of testing that his older sister had endured. We knew what to do this time around. We have experienced the lost glasses, torn contacts, broken sunglasses, etc. We teach the children to be responsible for their own vision aids. They have to find any missing glasses, replace broken sunglasses, and keep their stuff organized.

They both wear hip purses for carrying all these things around with them. Their colorblindness results in questions every day. They remember which shirts go with which pants. Only once in a blue moon does a mismatch occur. I always accompany them on clothes shopping trips and help them select outfits. Both ask for help when using poster paints, watercolors, etc. Our daughter is great at sketching and using pencils and charcoal. We just do our best with whatever comes up and hope that things will go well. We shed tears sometimes, like the time our daughter asked if we believed in reincarnation. We asked why, and she said because, if she comes back, she hopes she has 'good' eyes. What the future holds is uncertain, but that is true for everyone here on earth. So 'one day at a time' is our motto."

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"Comments from other people continue to frustrate us. We get so sick of the 'Hey, Hollywood!' remarks. While it's true that having 2 boys with achromatopsia has been a challenge, our older son commented one day that it was a good thing his younger brother has achromatopsia too, or else 'It wouldn't be fair.'"

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From a mother of two children with achromatopsia: "At my lowest moments, when my parenting skills are sorely challenged by having to cope with two pairs of lost glasses, two extra tired kids, or both of them needing lots of narration at a show, etc., I feel so relieved that they have each other to fully understand about their special needs. I encourage them to express whatever feelings or concerns may come up in connection with their vision."

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"Our family recently relocated. Having to get our present community used to seeing our young son wearing dark glasses has been an interesting experience. We hadn't realized how well accepted and integrated he was in the community from which we moved. Now we are dealing with all these questions and comments about his glasses. When people tell him they like his glasses, he usually just says 'Thanks' and goes on with whatever he is doing. But we are noticing that quite frequently he takes his glasses off and runs around squinting, saying he doesn't need them. I suspect that the increase in comments has led to this behavior."

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"My daughter, age 4, is always saying she does not like the sun. When we go shopping, she loves the underground parking garage. She likes to stay up until 10:00 at night. It's amazing what she can see at night, compared with the daytime. It's so much fun to watch her run around and enjoy playing outdoors at night."

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"My 4-year old daughter wants to ride a bike and to roller skate. I've wondered if I should discourage her when she talks about owning a motorcycle someday or doing other things she might not be able to do. We're having a hard time dealing with starting school. She did fine in kindergarten, but thinking about her out on a playground where possibly no one would be aware of her limitations is scary. It's heartbreaking at times to watch her playing with other children and to have the others run off and for her to have no idea where they've gone. Sometimes we forget how difficult certain situations are for her and we lose patience. I want to protect her from how cruel people can be to those who are different."

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"It wasn't until my twins began to walk that I understood what it was going to be like for them to live with this condition. They were normal toddlers indoors; but, as soon as they would go outside, it was as if they were blind. They walked off

steps, walked into trees, etc. When they started to kindergarten, everything seemed to be OK until they had to start reading things written on the blackboard. We've made the best adaptations we can."

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"Our boys have been teased at times by neighborhood kids and at stores, etc., but we always try to smile and feel compassion for the ones who tease. Character weakness is so much more devastating to a life than is physical impairment."

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"I would like to lift the hopes and dreams of parents and children who may fear the future, concerned that achromatopsia will hinder opportunity for acceptance by peers or who are concerned that self-esteem will necessarily be low. Hard times and challenging situations will come. Our family faces new and unfamiliar situations from time to time. We focus on our daughter's strengths. Hidden strengths have unfolded in so many areas other than vision. She proves it to us daily. She is bright, giving, loving, and honest – and she has a very keen sense of humor (for which her father takes pride in having provided the gene). To all of the parents who have these special children, I say: 'Pray for guidance, always encourage your children, and always follow your gut about what's best for them.'"

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From a woman with achromatopsia: "I want all the parents in the network to know that their kids are going to be OK in life, but only if they keep letting them experience as much of the world as possible, letting them make mistakes, and making them accountable for themselves. Make your teens get jobs. Let them find out what they can expect when they are on their own. Let them find out how to cope. And, most importantly, let them tell you (when they are old enough) what works for them. Be aware that you, as normally sighted parents, can perceive the world only from a normally sighted perspective. Your kids have their own perception of the world, from their not-so-normally-sighted perspective. They will figure out how to adapt. Let them do so."

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"About two years ago I was in one of those 'parental pressure cookers.' My wife was off to a meeting, and I was home cleaning up from supper, herding our two little ones towards bed, doing pajamas, teeth brushing, cleaning up toys, trying to forget about the day's pressures at work. In the middle of all of this frazzle the phone rang. Great! I thought. Who's trying to sell me something this time!!! I picked up the phone, and, with a measure of exasperation and resignation, I almost barked, 'Yes?' The person on the other end very gently began speaking in a flow that soon brought me back to that precious place that only genuine concern can reawaken. 'You don't know me,' she said, 'but I have a daughter who has rod monochromacy. I learned recently that you have a young son with this condition, and I thought it just might be comforting to you to know that my child is doing well in school, has adapted very well, and is a healthy, happy young person. And, if you ever need to talk to anyone about your situation, I am here and very willing to listen and help if I can.' Hearing those words, all my tension broke loose, my heart opened, and I began crying with such sweet relief! I hadn't realized how much I was worried about my son and how much I had been straining to understand his condition and to try to make his life work for him. Suddenly I saw how demanding I was being on myself and what a lonely, burdensome path I was creating. The person on the phone



was encouraging and caring, a real balm to my sore heart. A week doesn't go by that I don't recall how strengthened and inspired I felt by that phonecall. She reminded me that I am not alone, I don't need to solve all my son's problems. There are people who, without even being asked to, care about us and our kids."

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From the parent of a young adult with achromatopsia: "During grade school, I would always arrange to meet with the teachers before school began, so that any large print materials that were needed would be available from day one, also seating up front arranged and lighting conditions modified, if possible. This way, the teachers were able to be prepared and would not have to make a big issue after school started about the subtle changes that are necessary for a student with achromatopsia."

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"Our daughter is fast becoming an independent third grader. She has a wide, very accepting circle of friends. She continues to have the support of an aide at school, but only on an 'as needed' basis, as this aide is also helping another student in the class much of the time. Our son, who is in kindergarten, is also receiving help from a teacher's aide. He has voiced much sadness and anger about not being able to drive when he grows up, as he is one of those boys who loves cars and trucks. His teacher is aware of this, and she continues to point out to him his many strengths and abilities, as my husband and I also do. These two children have a very close relationship and clearly derive support and comfort from each other's inherent understanding of all the trying and frustrating experiences. And my husband and I, while still sometimes overwhelmed by parenting two children with achromatopsia, feel so blessed. They wouldn't be the kids we adore if they didn't happen to have achromatopsia as part of who they are."

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"I knew when our daughter was 2 months old that there was something wrong with her eyes. She was uncomfortable in the light, never tracked me as I moved about, and always wanted to be held. If I didn't hold her, I had to talk continually whenever I would move more than a few feet away, or she would cry. She was always most comfortable when she was in my arms; and, when the light became bright, she would recoil into my breast. When she began to crawl, she would stay beside me, holding onto my ankle with one hand and playing with her toys with her other hand. If I moved, she would re-attach herself. Her eyes exhibited nystagmus and would roll about or become crossed. The brighter the light, the more she squinted. At 9 months she learned how to open a washcloth and cover her face with it to shield her eyes from the light. She was 18 months old before the doctors diagnosed her and supported our concerns. Those first 18 months of her life were difficult for all of us. It has been amazing to see this child become so content, now that I have been able to get educated about this eye condition, to obtain the tinted lenses that help her, and to create the most comfortable environment for her. Now, at almost 3 years old, her own advocating skills have begun to emerge. At a recent visual functions exam she told the doctor, 'Hold those pictures closer, please. I can't see them that far away.' A high point of our holiday season was Christmas caroling with the neighborhood children one evening. Our daughter was able to keep up with the other kids, as they walked from doorstep to doorstep in the darkness. It was great to be just a parent of a 'typical' child for a change. And

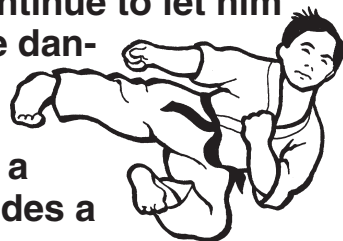
neighbors complimented her on her ‘beautiful eyes,’ which they had never had the opportunity to see before (because of the sunglasses she wears in the daytime).”

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From the mother of 3 children with achromatopsia: “On the subject of strangers’ comments about our children’s eyes: we’ve heard it all. ‘Is she tired?’ ‘Did he just wake up?’ The worst is: ‘Does he have a nervous tic?’ We try to deal with these comments in the most energy-efficient way possible (since we have much better things to use our time and energy for). However, there are some comments that just cannot be ignored and must be dealt with, especially if my children have heard a ‘put-down’ type of comment. If the comment is very rude or uninformed, we do not hesitate to ‘inform’ the offender in ways that (hopefully) will help to keep our children feeling positive about themselves. We’ve had so many people ask us if we know that our children’s eyes wiggle/ shake/ jiggle, etc. Sometimes we’d like to punch out the next person who says, ‘Did you know that her eyes go back and forth?’ So far, we have managed to maintain our composure.”

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“Our daughter with achromatopsia (age 8) got her first pair of rollerblades for her last birthday. I’m so proud of how determined she is to become proficient at skating. She takes off down the sidewalk, just like any other child would. Seeing her do things like that brings tears to my eyes sometimes. She has so few chances to enjoy life the same way other children around her do. She is really quite courageous. She is in Brownies and has been on several over-nights with her Brownie troop. The activities that they do are helping her build self-confidence. She enjoys many activities in settings where her eye condition doesn’t make much of a difference. I asked her if there was anything she would like to ask an adult achromat if she had the chance, and she said she wanted to know if you get teased less as you get older. She also has concerns about being able to have a job. We have always told her she could be just about anything she sets her heart on.”

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“Having 3 children with this eye condition can be very draining on me sometimes, although it has gotten a little better as they have gotten older. There are times when we need to go someplace new, and I find myself having to continually say things like, ‘Watch out for that curb . . . there’s a step there . . . and another one . . . Look out for that dangling branch,’ etc. I bless the really cloudy days, as our kids love to go outdoors on those days and burn off some energy.”

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“We know our son has many limitations, but my wife and I decided to concentrate on the things that he can do and not on the things that he can’t do. There are a surprising number of things that he can do. He played T-ball baseball (a non-competitive ball game for young children) when he was younger and also Farm League baseball (Farm League baseball uses pitching machines, so that there is no danger of being hit by the ball). He also has played youth soccer and loved it – he could see the ball easier because of its relative size and he loves to run. He’s very fast. Of course, he loves any kind of night game. We will continue to let him play organized sports until we feel that a particular sport may be dangerous for him. I strongly recommend martial arts for all young networkers. Our son has been in karate classes for 3 years, and it has been great for building his confidence. He loves it. He has a purple belt and will be testing for a brown belt in 6 months. He rides a



bike, rollerblades, and does a lot of other ‘normal’ boy stuff. We recently went to Hawaii, and he went snorkeling with his tinted prescription swim goggles on. He got to see a whole different world there in the ocean, and that made our whole trip. We know that he may not have seen everything we saw, but what he saw was exciting. In school he is very popular. His tinted lenses are part of his ‘persona,’ and he gets just as many compliments as rude comments about them. We know kids can be cruel, and so we prepare him for rude comments and teach him how to deal with them.”

.....
“Having adequately tinted lenses has changed our daughter’s life outdoors and in every way. She now does not consider herself blind at all (though previously she had thought of herself as blind when outdoors in the daytime), and she is much better in terms of self-esteem and social situations. Also, finally having a name for her eye condition has changed so many things for her. She now (at least sometimes) even feels ‘special,’ when others ask about her eye condition. She talks freely about it and about her abilities as well as her difficulties. I think that the struggles have helped her to grow as a person.”

.....
“Our daughter will take the back of my arm, if she ever feels unsure of herself in walking. This cuts down considerably on the ‘Watch out!’ kinds of sentences that we parents tend to use a lot for pointing out obstacles ahead, steps coming up, etc. When vacation days are cloudy or even rainy, it sure doesn’t stop us! Last week we went on an out-of-town excursion, and it started raining. We just ran from shop to shop, and the kids made a game of who could get to the car first. Other people complain about rainy, cloudy days, but we just tell them that God made these days for people like our daughter who has this eye condition.”

.....
“We have a field behind our house where we get to see lots of ‘lightning bugs.’ At the end of a hot summer day, we often sit on our porch admiring the beauty of the night. The little lights can be seen everywhere in the long grass. Our daughter who has achromatopsia loves lightning bugs. This year she managed to catch one in her hand and watch it light up. She would set it on her finger as if it were a ring and watch its light go on and off. Her grandmother told her that she had done exactly the same thing when she was young.”

.....
“Our favorite thing to do in the summer evenings is to swim. We live close to the airport, so we also like to go watch the planes land in the evening. And we go on rock and leaf collecting walks in the evening, bike rides, and chasing lightning bugs. We save many of our outdoor chores for twilight time or evening – playing with the dogs, cutting the grass, cleaning the pool, etc. We can see such a difference in our daughter at that time of day. She is more relaxed, and she is able to run free without her hat and sunglasses. We are planning to have her birthday party on a Saturday evening outside. We will have a Hawaiian Luau, with ‘tiki’ torches to supply low level lighting. We stocked up on sparklers from the 4th of July for the kids to enjoy along with the typical party games.”

.....
“Our 3-year-old daughter’s bedtime is so early that she mostly misses out on seeing the night sky. But recently, when we were on vacation, she enjoyed seeing the stars in the dark sky (city lights tend to ‘wash out’ the stars where we live).

More than once I've peeked into her room at 10 PM (3 hours past her bedtime) and found her peering out the window at the lights of cars going by, and she would point out things that she cannot see from her window during the day."

.....
"Ever since our daughter was just a few months old, it was clear to us that visual stimulation in bright environments for an extended period of time would always cause her fatigue, stress, and discomfort. I am careful to keep the lighting appropriate to her at home and to offer her a nap in a darkened room in the early afternoon. Even if she does not sleep, this 'dark time' helps. It is especially important that she has her time to rest and be peaceful after her preschool program, outdoor play, or any other time during which her eyes get stressed. Otherwise, she has symptoms that are similar to those which a person suffering from migraine might describe. As much as she loves the beach, I have found that, if we go there during the sunniest time of the day, it is guaranteed that she will suffer with a painful headache if we stay very long. Careful monitoring of her activities – alternating those that require more visual focus with those that require less – is an important key to her comfort."

.....
From a woman with achromatopsia in her 30's: "In a recent newsletter, someone asked adults with achromatopsia to comment about what they wished their parents and teachers had done differently when they were growing up. Based on my personal experience, I would say that parents should not pretend that a child with achromatopsia is normally sighted. Call a spade a spade and openly explore coping techniques together. Ask your child questions about his or her visual realities (if and when the child is open to talking about this). Make your home a fun place for your kid's friends, a place where they can participate in activities which your child enjoys and is good at. The challenge is to find out where the line is between giving us a break and pampering us. When in doubt, it's OK if we achromats find ourselves in situations where we have to work a little harder than everyone else. That's the stuff of life."

.....
"There is a rivalry developing between my 6-year-old son (a complete achromat) and his younger brother, who, because he is an incomplete achromat, can often do certain things better and much faster than his older brother. I wonder if other network parents have had to deal with this kind of problem."

.....
"Our daughter loves trees! I remember once when she was 18 months old and not yet wearing really dark tinted lenses outdoors – I took her to a park, where she was unable to move about independently until I placed her under a small grove of trees. She really came alive then and became independent (for obvious reasons), toddling from tree to tree, hugging and kissing each trunk, examining the gnarly roots of each one. Whenever she would reach the outer perimeter of the shade, she would stop abruptly, as if a stone wall was prohibiting her from stepping into the sunlight. We stayed in that grove for over an hour, and I luxuriated in observing the newfound independence of my child, as she reveled in her freedom from the confines of her momma's arms for the first time outdoors."



From a woman with achromatopsia in her 20's: "In a recent newsletter a network dad asked about what kinds of chores and summer jobs adults with achromatopsia did when they were teenagers. As a child, I was always in charge of emptying the dishwasher, and I also folded towels and clothing. My younger sister, who has normal vision, helped me out with matching the socks. There are lots of things kids with achromatopsia can do. One summer when I was in high school, my older sister (who also has achromatopsia) and I got the chance to be teaching aides at a summer school for visually impaired kids. It was great for us to be like role models for these kids who faced some of the same challenges we did. That was my first job experience besides baby-sitting, and I loved it."

.....
"I have noticed that my daughter, age 14, has begun to take more and more responsibility in terms of her special needs connected with her vision. It's wonderful to watch her making decisions on her own. Some of her choices may not be the best, but she is learning from her mistakes, and she is willing to do whatever it takes to make something work for her."

.....
From a new parent in the network: "I am so glad to have the chance to read the network newsletters and books. The familiarity of the stories networkers have shared is so comforting, since so much of what we have experienced with our son (because of his vision) has seemed very strange to most of our friends. He actually can fake the ability to tell colors fairly well, but I know he is just guessing. He copes so well that most people don't realize he has a problem. In fact, they sometimes don't believe us when we tell them. At times, we have chosen not to tell some people, if there really is no need for them to know."

.....
From a man in his 40's: "I have a need to believe that there are parents out there who really welcome their babies who have achromatopsia and who accept them as they are. In my own experience, having achromatopsia is not such a terrible condition, apart from some of the psychological involvements. What is sad, I think, is that some people who have normal vision and who are physically healthy in all other ways get trapped into a materialistic view of life that is much more 'monochromatic' (or 'black and white') than any achromat sees."

.....
"We can't decide whether to predict that our daughter (nearly 5) will choose a career in fashion design, dance, or art when she grows up. My husband and I believe it's healthy to keep a sense of humor, and we can't help laughing when we see her in the various outfits that she puts together. The things she chooses to wear do not match, of course, in terms of color, but they are always so interesting, because she chooses such unusual patterns. She is drawn to silver, gold, and copper and anything with sequins and glitter. We think she could make lots of money in the future, if she decides to become an artist and create 'abstract' paintings with such things as purple trees or orange grass! My husband is not amused when I tell him that I think I've come up with the perfect profession for her. With her love of music, dancing, and bright, shiny, sparkly clothes, I think she could be a night club dancer in a dimly lit club, where she could dance on a stage and wear beautiful clothes!"

.....
"When our son, now a teenager, was very young, he would play outside at times when it wasn't too bright, and he would ride his tricycle and his



pedal car. He loved to go out in the evening at twilight and in the dark – still does. In preschool they let him stay indoors, and he seemed happy enough. When they understood that he liked the shade, they would let him play in the darker parts of the school. He watches TV up close, sitting to the side. We keep the brightness level low for him, so that he doesn't have to squint and blink. We have had tinted film put on his bedroom window; and in one room, where there is a lot of sun, we had tinted glass installed in the windows and then had tinted film put over the tinted glass, so he doesn't need to draw the blinds. For one of the bedroom windows, which gets a lot of sun, we backed the curtains with a total light block backing. Today our son looks and acts like other teenagers. He goes to a school that is located in an old office building with small windows and subdued lighting. The classes are small. He sits at the front of the class. He uses a monocular to see the board and a magnifier to read small print – although it is surprising what he can read when he wants to, especially if it is the sleeve of a new rock CD. He uses a laptop computer and has become a computer whiz. Early on, we realized that he might be socially disadvantaged and that he would not excel in team sports and so needed to do or be something that other kids admired, for his own self-esteem. So we encouraged him to take guitar lessons. He is now a hotshot heavy metal guitar player, is in 2 bands, and has played in school concerts and local rock events. He is very popular with his peers. All in all, things are nowhere as bad for him or for us as we had feared they would be when he was little.”

.....
“We are ‘home schooling’ all 7 of our children, and this seems to work especially well for our 2 sons who have achromatopsia. They are both doing very well in their school work. My husband and I are assured that God, who is our designer and creator, has special plans for our boys who have achromatopsia. One of our daughters has Down's syndrome, and sometimes achromatopsia seems very minor by comparison. All of our children are wonderful blessings.”

.....
“My husband and I find that using the term ‘achromat’ to describe someone with achromatopsia can sometimes be amusing, because some people we talk with about our son confuse it with the word ‘acrobat’ and think we have a son who performs in the circus! I often wonder how he actually sees and wish that, at least for a while, I could see as he does, so I could know what it is like and be able to help him more. It would be very interesting if a special color language could be devised for achromats, to help them describe their visual world of texture, tone, luminance, shadow, and shades of light and dark, in the absence of color. I believe I can understand why achromats tend to love twinkly baubles and shiny metals. For them, Christmas decorations must be extra special. Even though they have little or no cone vision, the positive attributes of their condition can be accentuated, as is so often pointed out in the newsletter. They have good rod vision. In twilight hours our son likes to run around and play ballgames with his dad or his grandparents. He also likes to play hide-and-seek at that time. He likes bonfires and fireworks, except for rockets, which travel too fast for him to follow. Best of all, he loves sparklers. At Christmas time, he enjoys walking around to see all the decorations and the brightly decorated shop windows at night. He also enjoyed a candlelight Christmas service last year very much. He loves looking at stars and airplanes in dark skies. Compared



with our normally sighted daughter, he is much less bothered by the dark. Because I have some degree of night blindness, he leads me in the dark – which may one day be very helpful to me in such places as darkened theaters. In the future, I suspect that he will enjoy outdoor evening theater or concerts. I choose shady playgrounds for him away from roads, with lots of trees and fewer children. We plan to buy a TV with a bigger screen. On his desk there is a lamp with an incandescent bulb which is turned away from his work surface. All the rooms in our apartment have dimmer switches. We have sun blinds on the car windows. He is very concerned about what he wears and what goes well with what. Red, black, and navy are his favorite colors to wear; perhaps these dark colors are more relaxing to his eyes. He performed in the school nativity play last year; and, when they shone the theater spotlight on the shepherds and carpenters (indicating the bright, shining star), he put up his hands to shield his eyes. To the audience, this appeared to be very effective acting – but, for him, it was real!”

.....
From the mother of 2 girls with achromatopsia: “As a reasonable person and also as a nurse, I realize that my children will choose what is best for themselves. One of my daughters wants her glasses off almost always indoors, unless we are at the supermarket, where there are lots of strong fluorescents, or at the mall in the main aisles, where sunlight comes through the ceiling. Recently, on her first day of preschool, I let her choose whether she would wear her ‘indoor’ tinted lenses, and she chose not to. The teachers questioned this decision (I suppose because she was squinting some), but I assured them that she is able to decide about these things. There isn’t much strong sunlight coming into this classroom, and the overhead lighting is not obnoxious, so I think she is comfortable enough. My younger daughter, however, likes to have her glasses on most of the time. But I notice that she will take them off when she sees that her older sister has removed hers or if I offer to take them from her.”

.....
From the mother of 2 children with achromatopsia: “As our children mature, it is so reassuring to witness their foray into new activities and situations with no need of any kind of special supports. Our daughter is always eager to read the newsletter. It is marvelous to observe her positive outlook, as she strives to better understand the challenges that achromatopsia presents.”

.....
“My son, age 16, is a worry for me these days. He’s having a rough time in school, academically as well as socially. The problems lie mainly in the fact that he is in denial about being visually impaired. He won’t use any tools that would aid him in school, not even a magnifying glass. The school staff is being very supportive, learning all they can about achromatopsia, but he is ripping mad about all the attention and extra help he is getting. Achromatopsia, I think, is the ‘slippery disorder.’ It’s so hard to pin down, to know how best to help – especially with a kid who has put so much energy into concealing it for so many years. And a lot of the emphasis at school is on athletics, which is an area he cannot be successful in. He is often angry and sometimes gets painfully depressed, yet he’s such an incredible person!”

.....
From the mother of 2 children with achromatopsia: “Our son (age 13) joined his class basketball team this semester, and it has been the most self-affirming

thing that has happened to him. He is part of the team, and the kids are so accepting of him and what he is able to do. He is also going for his black belt in karate soon. Our daughter (age 9) is very open about all her struggles, and this openness seems to make it easier for her to deal with the problems that come up.”

.....
“Our son, who’s nearly 3, loves to read and watch TV. He’s a bright little boy – and very witty. He loves music and shows a talent for it. As for his vision, different doctors have expressed different ideas about what we ought to be doing for him, so we are letting our son guide the way. We try not to push him to wear any glasses he isn’t comfortable with.”

.....
“I want to tell you how awesome it has been for us to find the network. The amount of information we have gotten in the last few weeks has been unbelievable. It has given our family a whole new perspective. We feel that we are now able to put the final pieces into the puzzle of understanding how our son must cope with the challenge of living with this vision disorder. I don’t mind admitting that, even after 11 years of seeing doctors, our grasp of his visual impairment was still sketchy. The best part for me now is that, on those occasions when I have to explain achromatopsia to others, I am fully prepared to do so.”

.....
“My husband and I have been concerned about the problem of increased light sensitivity that our son, age 10, may develop as a result of routinely wearing the red contact lenses he was given recently at the low vision center. Up until now, he has always done fine without having to wear tinted lenses in all indoor settings, except for rooms having a lot of windows. We have tried to explain to him why it is important not to overuse these new lenses (which, for him, are darker than any he has worn before). This is not easy. We have to consider what his sight needs really are and also what his ‘laziness’ factor may be at different times. We don’t want him to become overly dependent on these new extra dark lenses.”

.....
“Thank you so much for all the information about options in tinted lenses. Some of the information really struck a chord in our lives. What a fine line we parents are treading, not wanting to deprive our children of anything that might help them but also not wanting to do anything that would further increase their sensitivity to light. We think of our son (age 2) as our guide, and we follow his instincts keenly. We are fortunate to have professionals who are willing to learn about his needs along with us.”

.....
“Our son is currently applying to several private high schools, and we are going through the process of telling people at these schools about his eye condition. It seems so easy now, thanks to all the information that has been shared in the books and newsletters. We know so much more now about what he needs. We find that he is being articulate and comfortable in talking about his vision with the interviewers. We are very proud of him. He now travels to school alone and is actively exploring the neighborhood by foot and by bus. He wants to travel by subway alone too, but his parents are not ready for this yet.”

.....
From a dad: “Our daughter, age 4, has a disposition that is almost magical. She is so happy-go-lucky around her friends, and she does very well in preschool. We agree with her teacher that she will probably be able to manage fine without a

special assistant in school (she starts kindergarten in the Fall). But, of course, we'll watch closely to ensure her successful integration at school. She is venturing outdoors a lot more on her own now, and sometimes she is the one who pushes for outdoor activities. Recently when we were planning to attend a children's theater production, we inquired about the possibility of close-up seating for her, and this was readily granted to us. We were even given backstage passes!"

.....
From the mother of a toddler: "My husband and I are becoming more comfortable with our son's vision impairment. We have encountered some inquisitive and annoying comments from strangers. None of the adults have been particularly rude yet, but we find ourselves always on guard about this. There have been a few rude children who have stared at our son and whispered among themselves. When that has happened, we have felt somewhat angry, uncomfortable, and defensive. Our son handles life as if his vision were normal. He's a tough kid, though he seems to know his limitations."

.....
"It's hard to know if our daughter's occasional negative behavior in school is related to her visual limitations and the fact that she doesn't have the same visual cues the other kids have or if she is just being difficult for other reasons. I have often wondered what she would be like if she didn't have achromatopsia and only had to deal with the same things that other kids deal with. In the past, when her vision teacher would come into her regular classroom, she would begin to act very differently. She would have temper tantrums or just stop paying attention to her school work. The specialist would then 'sweet talk' her or do her work with her or take her out of the classroom where they could be alone. Eventually she was pulling her out of class on a regular basis to do math or reading. Our daughter wouldn't do either of these subjects in class if she knew she would be getting special help later. So I insisted that the vision teacher come only once a month or else when the classroom teacher requested it. I told the specialist that, unless our daughter began to have problems that were directly related to her vision, there was no need for her ever to be pulled out of class for special assistance."

.....
"I have a daughter with achromatopsia, and she is the best gift I have ever received. I believe that she is a real asset to the world, with her bubbly, entertaining personality, her artistic and musical talents, her love of learning, and other fine qualities. She does very well, in spite of her visual impairment, although I realize that, when she is an adult, she will face new challenges. There are so many people who are healthy physically, with no genetic defects, but who are not happy or who don't seem to have much to offer the world."

.....
From a dad in Canada: "Most of the coping strategies described in the network materials are techniques our daughter, age 4, uses. It is clear that she perceives a 'different' world from ours – not a lesser world, just different. She perceives her world with greater difficulty than my wife and I perceive ours, and there is also the difficulty of constantly relating one world to the other. But I think this has had a positive effect on our wee daughter's character – and probably on ours too."



Discovering the Network

“I don’t think anyone can estimate the impact that this network is having on the lives of those of us who, until recently, felt isolated and misunderstood.”
.....

From a woman in her 40’s: “The newsletters are a means of communication such as I’ve never had before. None of my doctors ever told me about anyone else who had achromatopsia. Now I don’t feel so ‘different.’”
.....

From a network mom: “We met a wonderful family through the network. We first connected by phone and found that we had a lot in common. By the time we made the trip to their home (just a three hour drive away), I felt that there was already a permanent bond beyond words between us. It was so comforting for me to meet their two beautiful and gifted children, both of whom have achromatopsia. It helped me to realize even more fully the potential that our daughter has, despite her eye condition. It was also a comfort for me to realize that I am not alone in my fears, worries, and challenges and my need to advocate for my child. The highlight of our visit was watching our children interact with one another and enjoy themselves together. The two children in this family, ages 9 and 6, took our daughter, age 3, under their wing. When it was time to drive back home, we had to tear her away from them crying, ‘I love you.’ I am so thankful for having had the opportunity to meet this special family.”
.....

From a man in his 40’s: “I always used to wonder if I was the only one in the world who had this eye condition. So it was a very healing experience for me to find out, through the network, that there are others who have it and that it is a recognized eye condition. I suspect that some persons with achromatopsia may be reticent about getting ‘out of the woodwork and into the network,’ because they may have a certain fear of possibly feeling even worse about their situation, once they start networking. So I really appreciate the reassuring process that has been so evident in the newsletters.”
.....

From a young woman who had just discovered our network via our Web site: “What a surprise it was to find out that there are others like me! I am very excited to think that one day I may be able to talk with someone who knows what it’s like to live with achromatopsia.”
.....

From a man in his 20’s: “Reading the recent newsletter reminded me of what a gift it is to be part of this fellowship. The network is an invaluable service. From speaking with my own parents, I know that they and I desired this sort of support during my younger years. Thank you for ‘bridging’ us all.”
.....

From a woman in her 30’s: “I recently got together with a member of our network, who came to my city for a visit (we had previously ‘met’ by phone as a result of the networking lists we had been sent). This was a ‘first’ for both of us – the chance to be with someone else who has achromatopsia – and it was great! This encounter has encouraged me in my struggle with this visual anomaly.”
.....

“Thanks for the network and the newsletter. When the newsletter comes in the mail, I make the world stop and leave me alone until I have read it at least twice. My mother enjoys it too. She would so have loved to have had a support like this

when I was growing up and she and my dad were so alone with this strangely sighted child who couldn't understand colors and who loved the dark."

.....
From a dad: "Our son is doing well in kindergarten. He never complains or even comments about his eye condition. At times he wears a Mickey Mouse baseball cap in class, and he sits near the front of the class, when he wants to. A lot of his happy orientation comes, I'm sure, from the confidence that my wife and I developed – a confidence that has been so much strengthened by our connection with others in the network and the information you keep channeling to us. I don't even want to imagine what it would be like, if I couldn't take for granted this network of families who are all living with this common 'challenge.'"

.....
"I've learned so much about myself in the last year and a half since I've been a member of the network, and a lot of it has happened because of what has been shared through the newsletters. It's like discovering civilization after having been stranded on a desert island all my life. I want to write about these 'inner workings' I've discovered, and I know that there's no audience who can really understand the things I want to say as the one that reads the network newsletter."

.....
From the mother of two adults with achromatopsia: "I hope my children will decide to share their experiences with others in the network. They are probably afraid to begin, because their experiences could fill volumes. My son reads the newsletter with great satisfaction, because the material evokes in him the feeling of, 'Ah! Someone understands what it's like! Someone knows!'"

.....
"Because I didn't look blind and for a long time doctors couldn't find a diagnosis, I always felt I had to appear and behave as though I were fully sighted. It wasn't until I learned about your network that I understood that I wasn't alone in this, as I had always believed myself to be."

.....
From a man in his 40's: "The newsletters are so nice. They reassure me of my humanity. They give me a little angelic comfort that I am not some monster who has created this bizarre and hellish sub-chamber of experience that I have lived my life within. I know now that there are other people with the same condition; and so, when I listen to their voices out of the same 'cave,' so to speak, I feel comforted and validated. I know that all this time I've been 'OK' after all."

.....
"It seems clear that this network is made up of people who choose not to be isolated and separate from others. But there are also probably a lot of achromats out there 'in the bushes' (so to speak) who aren't ever going to contact the network. Ten years ago I wouldn't have been interested in this network, because I thought I was doing just fine and had nothing to gain by networking. But now, at this phase of my life, I'm recognizing that I need help from wherever I can get it.

I really appreciate the network and the newsletter and all the contacts I've made."

.....
From a woman in her 30's: "Thanks so much for the way the newsletter has unified us and let us know that we're all in this together. I love the words of camaraderie and commiseration which are made possible. I wish there had been such a newsletter when I was a kid."



From a man in his 20's: "I feel that the newsletter is potentially life-changing for some of us who have achromatopsia. It has been a real blessing to me."

.....
From a woman in her early 30's: "It's cool talking with people in the network, because it's as if I know them already, just through the common experiences we all share. We discuss issues like dating – for instance, how do you find the person that you would like to meet (instead of just waiting for someone who decides to come over to you) when you're not able to see people well unless you're close up to them? We talk about subjects like these and lots more."

.....
From a man in his 20's: "In the weeks since I read Oliver Sacks' book, *The Island of the Colorblind*, and then made contact with the network, I've found that my view of life has been turned completely upside down. I've spent most of my life trying to downplay the significance of my visual impairment. I had pushed it way back and had even become skittish whenever I had to talk about it with anyone. To me it had always been just a liability that had brought pain and punishment in my school years and had made me conspicuous as an adult. Now I feel as if I've stumbled upon a room full of people who understand my experiences (as I do theirs). Dr. Sacks' book and the network have given a 'voice' to my own experiences, something I've never had before. The lives and experiences of other achromats that I've read about so far have been chillingly recognizable as my very own. When I first heard the word 'achromatopsia,' I repeated it over and over again like a mantra. Having a single word that encapsulates all of the monotonous, sterile sounding phrases like 'lack of color perception' and 'hypersensitivity to light' (I've heard and said those words so many times!) was a relief to me. And knowing that there was a network of people with these same kinds of experiences filled me with a great sense of peace. I had never even thought it would be possible to meet someone like myself! Quite honestly, all of this is really very emotional for me, and I get choked up trying to form complete sentences. Lack of practice and experience, I guess. Thus, a usually literate and articulate person has been reduced to a blithering idiot, as far as the subject of achromatopsia is concerned."

.....
"I have just discovered the website for The Achromatopsia Network as a result of having read *The Island of the Colorblind*. Suddenly the world is a more comfortable place. I am 51 years old, and have never communicated with anyone else who experiences the world as I do. I am hungry for that kind of communication."

.....
From a woman in her 20's: "Before finding the network, the only time I ever met another achromat was many years ago when I was participating in an outdoor activities program for visually impaired young people. It was a wonderful experience for me. We were playing a tag game out in a field, and this other person with achromatopsia and I were crouched down near some bushes getting ready to make a run for it. But we were both stymied by an object in the near distance. We could not decide whether it was a tree or a person, so we sat there waiting for any sign of movement from the object. We finally decided that it was too still and must be a tree, so we ventured out and then had a good laugh together. It was indeed a tree. It was so neat to find someone who understood what it's like to see this way. Other visually impaired persons can never really understand these

experiences in the same way, partly because the others tend to see color and so can more easily tell a tree from a person in the distance.”

.....
From the mother of a young adult with achromatopia: “It has been wonderful for my daughter to find that there are other people living with the same eye condition she has. When she was growing up, I always told her she could do anything she wanted to do with her life and supported her in every way that I could. But the network offers her something I could not give her, and that is the chance to meet others who have vision impairment. I did not deliberately keep her from meeting other visually impaired persons. The fact is that she always wanted so much to be like everybody else, and she found it very difficult to face up to her vision problem. She is a different person now since reading the network books and newsletters – much more confident and able to come to terms with her condition. You have no idea how much this has helped her.”

.....
“I have begun corresponding with two other members of the network. I would never have believed that I could feel so close to people I had never met, but I feel this way toward those whose stories I read about in the newsletters.”

.....
From a man in his 40’s who lives in Italy: “I think that, for many of us achromats, having the chance to share what we feel with others who can understand is a basic, vital need. I recently visited my parents; and, since they do not understand English, I read the newsletters aloud to them, translating them into Italian (this included, of course, the comments I myself had contributed). I hadn’t planned to do that; and yet I found that, in doing so, it was probably the first time in my life I managed to communicate certain significant things to them. I feel that it made an important difference for all three of us and that it will continue to do so.”

.....
From a mom: “Thank you for granting my request to be put in touch with one of the adult achromats in the network. I wrote to her, and she sent me a most insightful letter in response. It was optimistic and yet honest in describing her struggles. I plan on sharing this letter with our daughter (now age 3) someday when she is in need of the support of someone who has ‘walked in her shoes,’ so to speak.”

.....
From a new member: “My husband began searching the Internet in 1995, trying to find any information at all about my eye condition. A few months ago, late at night, he tried again and found the network Web pages. He read them and wept. When I woke up the next morning, he showed the information to me, and I wept as I read it. Now all of the aloneness is gone.”

.....
“My husband says that the biggest change he has noticed since I found the network is that previously, whenever I would refer to something having to do with my vision, I would say ‘I’ and now I say ‘we.’”

.....
“I am still in shock that I finally found something about my visual condition! I am 34 years old and, until now, I thought that I must surely be the only one in the world with this disorder. I connected to The Achromatopsia Network Web pages this evening, and I continued reading until there was nothing left to read. The tears rolled down my cheeks as I read the ‘Responses from Networkers’ from the



sample newsletter that was presented on the Web pages. I have gone through what these people have gone through and have felt what they were feeling! This is such an extraordinary experience that I just can't seem to put it into words. Thanks for helping me learn that I'm not alone."

.....
"Reading through the network books and newsletters has been extremely emotional for me. To read some of the comments from other networkers has been like reading my own diary. Even my mother feels as if she is reading her own life story. Over the last 21 years I have gone to numerous specialists, and we have spent a fortune on these visits, yet it wasn't until we found Oliver Sacks' book, which then led us to find The Achromatopsia Network, that we were finally able to learn much about my eye condition. It is such a relief and a comfort to know that there is a term for what I have and to learn that I am not alone. I feel now that finally I might be able to come to terms with this condition. Also I have hope that now I might actually get somewhere with the specialists. Now that all this is written down in black and white, they might take me seriously. They might even make my contact lenses as dark as I want them to be. I am thankful to everyone who has contributed the comments and experiences shared in these publications."

.....
"I cannot adequately express how invaluable (and sometimes moving) the experiences related in the newsletters have been to our family. It is amazing how certain types of seemingly inexplicable behavior that our daughter has exhibited can be explained simply by understanding how she experiences the ambient lighting conditions. The network materials have been enormously rewarding and have affected how my wife and I relate to her. The sum of the experience and information presented in these publications is absolutely amazing."

.....
From a man in his 20's: "I am incredibly happy today, because I received the parcel of network materials. It was a strange feeling for me, reading about people who have so much in common with me and who are coping with the same kinds of difficulties I encounter – even though I had the advantage of growing up with a sister who has the same vision disorder. I had thought she and I were alone among the other people of the world. To follow a metaphor that was used by Oliver Sacks, it was as if we were on a little island in the middle of the ocean. Now I find that the island has become a bit more inhabited."

.....
From a new member: "I received all the books and newsletters last Saturday and immediately cancelled all other plans for the afternoon. I read for 5 hours! In anticipation of reading all this material, I envisioned the experience as being like the scene from the movie, *The Dark Crystal*, in which two people meet, touch hands, and are locked in an exchange of their youthful memories. They had a name for it. It has been that and more. To be honest, it was really too much to absorb at one time. For days my attention has been diverted, thinking of all the things I have read that I would like to respond to. I was especially touched when reading about a dad who had observed his daughter's sheer enjoyment and freedom while playing outdoors at night. I remember that freedom. It was almost as if the weight of the world took a vacation. I also remember standing in the center of town in the evening, reading all the store signs up and down the



streets and peering into the store windows. This was the place where, at high noon, I could barely see anything on the other side of the street. I grew up in the 50's and 60's. My father's understanding of my vision disorder was so clouded by what he was told – as well as what he was not told – by the medical professionals. I believe that, if he had been helped to really understand my condition, he would have felt toward it the way some of the dads in the network seem to feel, instead of feeling despair. I believe that one of the most important things that any of us need in this world is validation. The network materials have given me a validation I never knew I could have. The day I found out that this network existed, it was as if the world stopped for at least half an hour.”

.....
“This year has been so full of pleasant surprises, ever since I discovered the Network. My optimism grows with each new discovery and each response I read in the newsletter that resonates with my own experience.”

.....
“Another parent in the network and I have made it our goal to stay in touch, since our boys are the same age. This way they will always have a friend who has the same eye condition. That might make it easier for them as they grow up.”

.....
From a network dad in The Netherlands, reporting on a meeting which took place in his home as a result of having been able to make various contacts through the network: “We were 17 people altogether, 8 of whom were achromats. Besides our daughter, there were 2 other children with achromatopsia. The rest were adults between the ages of 30 and 70. I found it absolutely amazing to witness this meeting. They almost jumped at each other, asking all sorts of questions, from how and when achromatopsia had been diagnosed to details about tinted lenses and everything you could imagine in between. Most had never met another achromat before. Two or three of these people had never even had the word ‘achromatopsia’ to apply to their condition until recently. It makes a huge difference to have a name for your condition, for many reasons, including being able to research it in libraries or on the World Wide Web. So, at the beginning of the meeting, there was total chaos, with everybody talking, people arriving. Then I proposed giving the afternoon some kind of structure, so that no one would miss anyone's story and no one would have to repeat their story several times. We sat in a circle, people introduced themselves, and everyone got to ask questions. This took 4 hours. For me, it was truly overwhelming to hear what these people had to say. Like all humans, achromats have very different personalities, and so they can look at their condition in various different ways. We heard some very encouraging stories from people who had been extremely successful in their professional and private lives, and we also heard from others who had experienced much frustration and depression with regard to their visual condition and their social experiences. For example, almost everybody invited to this meeting accepted the invitation and was very enthusiastic, but some said they did not feel they could attend such a meeting, at least not yet. One man replied that he has fought against his fate all his life and presently does not feel that he can meet with others having this condition. We exchanged addresses and lots of information regarding various resources for the visually impaired, as well as information about all kinds of visual aids.”



Networkers Comment on a Variety of Subjects

“More and more, I am realizing that there really is no ‘right way’ to deal with achromatopsia. This fact comes through so clearly in all of the information that has been shared by networkers in the newsletters.”

.....
From a man with achromatopsia: “I am so used to my vision, and it’s been so stable all my life that I tend to think of myself as having normal vision and most of the rest of the population as having ‘super-normal’ vision.”

.....
From a woman in her 40’s: “As a child I attended regular schools. I could not read the blackboard, so I followed the lessons mostly by ear. When I went to the university, I studied linguistics and psychology. The way I was educated made me very ‘self-managing.’ I did all of my school work without any special aids. I also made my own clothes, and, for several years, I biked. However, I often demanded too much of myself, which led to much tiredness and chronic pains in my back and my neck. During these last few years I have become increasingly aware of how functioning with bad eyesight requires lots of energy. For this reason I am now working only 20 hours per week.”

.....
From a woman in her 30’s: “It doesn’t hurt to have 20/200 vision, but it does hurt when the supermarket clerk accuses you of being too ‘proud’ to wear glasses or when relatives pester you about sitting close to the TV (‘It’s bad for you!’). Or when you’re made to do a self-portrait in high school art class (‘Why did you make your face purple?’). And so many folks will try to turn on more lights for us – for kids especially, because it’s assumed that they don’t know what’s best for them.”

.....
“I wonder how the lack of visual stimuli affects us. Up until I was 10 years old, I had a habit of rocking – mostly rocking in the car and rocking against the wall at school. I was also a nail biter, though I’ve managed to stop. And I also remember as a child being preoccupied with the way things smelled. I still love smells, especially the smell of leather – but not perfumes or anything that masks natural aromas. I wonder if our brain is actually made to receive a given amount of stimuli so that, if it doesn’t get its ‘allotment,’ the body compensates in other ways. In other words, if our eyes can’t give the brain the sensory input it can potentially receive (such as color perception), maybe it ‘fills in the gaps,’ with increased motor activity or increased attention to other sensory experiences. If so, then I guess propriety eventually takes over, and socially unacceptable habits get stifled.”

.....
“Here’s my Top 10 List of ‘Most Boring Things’: Sunsets, crayons, rainbows, the Candyland game, 12-inch TV’s, sunbathing, fabric stores, the Dakota Badlands, 3-D Magic Eye pictures, and overhead projections.”

.....
From a woman in her late 50’s: “When I was born, my parents – like most people at that time – knew little about genetics. They didn’t know that my vision problems were caused by defective genes that I had inherited. People didn’t get genetic counseling, and most people didn’t ponder possibilities like choosing not to have biological children because of concerns about passing on a defective gene or the abortion of a fetus found to have a serious defect. Had all this been possible back then and had it also been possible for my parents to know before I

was born that I was going to have this vision disorder, then they might have decided that I shouldn't be born and that my sister, who did not have achromatopsia or any other physical defect, should be born. My sister was a beautiful, healthy child, and she had a fairly normal childhood, but in middle age she succumbed to various physical and emotional problems, and she died at an early age after much illness. By contrast, I experienced many problems in childhood related to my vision impairment, but my adult years have not been like my sister's at all. I feel that I have had and continue to have a very fulfilling life. I have observed these same kinds of contrasts in the lives of other people too. There just doesn't seem to be a strong correlation between the presence or absence of a physical impairment and the value and fullness of one's life."

.....
From a man in his 50's: "Many other networkers besides myself can attest to the fact that having achromatopsia is not a devastating catastrophe. We can lead very rich and full lives, even though we may not drive cars, fly planes, or pursue vocations where good visual acuity and normal color vision are necessary. I have complete achromatopsia, and I have to say that, in spite of my visual handicap and all the practical and social problems I encounter, I feel that I live a very rich and interesting life."

.....
From a woman in her 30's: "I feel that God has put us in a position to see things differently for a reason. We appreciate the forms and textures of nature, rather than colors. We tend to accept other people who are also 'different.' I think we are more inclined to try to understand other people, because understanding is something that we ourselves have wanted all our lives."

.....
From a woman in her 30's: "I don't think having achromatopsia is such a big deal. Yes, it has affected my life, but so has being a woman, being from a strong middle class family, being able to go to a good college having a full professional life, and being a wife and mother. If any one of these factors had not been a part of my life, I would be a different person. I will never know whether having achromatopsia, being colorblind, etc., has had more of an impact on my life than my sex, my class, or my chosen profession. In many situations, my vision impairment is totally irrelevant."

.....
"One of my pet peeves is when someone says, 'I know that you can't see this, but . . .', when that person really hasn't got a clue about what I can or cannot see. Or there is the 'Gee, Marge, she sees it this way . . .' routine, in which someone goes on to give a totally inaccurate description of the way I must see things."

.....
From a woman in her 30's: "Achromatopsia is the window through which God lets me view the world, and I've come to accept it. It's given me insight and sensitivity that I might not otherwise have – and also a degree of dependence, which forces me to share in the lives of others. For example, I need others to drive for me. It's okay to need help from others, and I think we have a lot to give in return."

.....
"What a difference good communication makes in this world! I am a writer, and I feel that my writing contains more sensitivity, understanding, and psychological, emotional, and spiritual insights than most; because, as a visually impaired

person, I have had to come to terms with my inner self and how it relates to others. Many people take so much for granted, see so little beyond the surface, and become so self-sufficient that they miss many of the really important things in life. We achromats are full-fledged, fully capable members of a world in which seeing well is not a prerequisite for seeing what's important."

.....
From a young adult with achromatopsia: "I have found it very helpful to develop my abilities and my talents. Instead of concentrating on what I can't do, I can show people all that I can do. For example, I enjoy creative writing and performing."

.....
From a man with achromatopsia: "This vision disorder can certainly be quite unpleasant and restricting. But there are far worse disabilities in this world."

.....
From a woman in her 40's: "I learned about the network from reading Oliver Sacks' book, *The Island of the Colorblind*. I believe that the most important thing I learned from the book was that complete achromatopsia is caused by a recessive gene. I always thought that to be the case, but none of the specialists I had dealt with had ever come across a case like mine before, so they knew nothing about it. I had begun to think that I was suffering from some 'freak' condition, or else it would surely have appeared in some of their medical textbooks. I became convinced that I was the only person in the world with this defect. It was just by chance that, I came upon the TV documentary about Dr. Sacks and the subject of colorblindness. At first I was not very interested in the program, because I thought it would be about the red-green colorblindness that is so common, especially among males. Then, as I watched the program, I saw the Norwegian scientist, Knut Nordby, who has complete achromatopsia, and everything fell into place for me. Then I obtained Dr. Sacks' book, and my personal search of well over 30 years came to an end."

.....
From a man in his late 20's: "Recently I saw a bumper sticker that said, 'God Is Colorblind.' This bumper sticker reminds me that God created me and all achromats in His image. I feel that our experience is spiritually unique."

.....
From a woman in the U.K.: "I was absolutely delighted to get to watch *The Island of the Colorblind* on BBC-TV. I am 72 years old and this was the first time in my life that I had ever even heard of anyone else who knows about the total colorblindness and extreme sensitivity to light that those people on the island – and, indeed, I myself – have. It made me feel that at last I belong somewhere. All my life I have been struggling to lead an ordinary life, but it has certainly taken its toll on me. Because of my age, you can imagine what things were like for me as I was growing up. For education I was sent to a school for the partially sighted, where I was taught virtually nothing. Nobody knew anything about my eye condition. I felt quite isolated and extremely frustrated, as it was so difficult for people to understand what I could or could not see. My life was a kind of hell. Dark glasses were not advised, because the doctors said that they might weaken my eyes! Consequently, I was constantly walking into things and being laughed at by the other children. My parents just accepted what they were told by the eye specialists. I have always had very little confidence in myself, and my nervous system has been affected. I have suffered from depression. But, having said all that, I want to say that Dr. Sacks' book has lightened my spirits, and I admire him greatly for

taking such an interest in unusual conditions like this and putting it over in such a clever way.”

.....
From a man with achromatopsia in his 20's: "I consider my discovery of the network to be yet another amazing experience in what has been so far a pretty full and interesting life. Every revelation presents new challenges, and coming to terms with my sight is the single greatest challenge I've ever faced. But I just know that, by meeting this challenge, I will reap the greatest rewards. In some ways I feel as though I'm just beginning my life now."

.....
From the mother of a teen with achromatopsia: "Recently I learned about a flower that blooms at night. The flowers are white, and I think it's in the morning glory family. How perfect! My daughter would be able to see flowers like that with her night vision! (*Editor's note: the Evening Primrose is one example of such a flower.*) We always kid her about the big crows and grackles that are so common where we live. This is one ugly group of birds, but I like to tell people that God made them for our daughter to see easily, and that's what they're good for!"

.....
From a woman in her 40's: "I enjoyed reading about the networker who says that she sometimes gives a friendly nod to trash cans when jogging. I've done that many times myself, so I can truly identify with her. How well I recall that abashed feeling I would get when the inanimate object of my polite attention didn't wave back. Nowadays I just smile at everything, figuring that, if it's a pole, it won't matter – and, if it's a stranger, they'll just think I'm friendly."

.....
From a man in his 30's: "Since I have learned more about my eye condition, I have become more pro-active in seeking out better solutions. Knowing what the problem is actually makes all the difference, doesn't it?"

.....
"In one of the newsletters, a parent asked for input from networkers about colleges and universities that have good services for vision impaired students and good public transportation resources. These were the same criteria with which I was concerned at different times in my life, when I was considering where to go to college or where to look for employment. However, it turned out that all of the other aspects of who I am (i.e., my characteristics other than vision impairment) always mattered at least as much as my special needs as an achromat, in terms of how much I enjoyed living in a particular location. For instance, the city where I lived while I was in college had very poor public transportation, and yet that was one of the happiest times of my life, because I so loved certain qualities of that city, and I loved the beautiful and very old college campus. Later I moved to a city which offered much better options for non-drivers, and the university in that city, where I took graduate courses, had a wonderful disabled students program. But it was an ugly campus, and I greatly disliked the climate and other aspects of that city. Once I spent a year working in a big, sprawly city which had terrible transportation, but I loved my job and I loved my inexpensive little apartment, which was surrounded by beautiful trees. I found a friendliness prevalent in that city which I have never experienced anywhere else. My time in that city was a very happy time for me, but I could never recommend that location to other achromats in terms of the criteria being considered. I visited New York City once and recognized the

advantages there for non-drivers, but I knew that I could not be happy living there, because I personally need to be around open space, trees, foliage, and lots of sky. This is such an individual matter.”

.....
From a woman in her 40's: “I just got the recent newsletter in the mail and am thrilled with it, as always. It brings me into a frame of mind in which I can think deeply again about who I am as an achromat and what challenges I face – most of which I normally just deal with in the course of the day without ever wondering if there is something there which might be pondered and then shared with the network. My sister got me thinking years ago about the various ways that my vision impairment influences my ways of doing things. For example, do I do certain things the way I do them because I am visually impaired or because I'm a klutz or slow or shy or disinterested, etc? I appreciate the opportunity, through the network, to explore this perspective – not because it lets me ‘off the hook’ but because it leads to greater understanding of myself. After all, how can I expect others to understand me if I don't understand myself?”

.....
From a woman with achromatopsia in her 30's: “I found a book entitled, *From Homer to Helen Keller*, by Richard Slayton French, that provides a historical overview of social responses to the blind. This book was written in the 1930's, which gives it a rather dated flavor, but the author's strong and dedicated (if opinionated) voice gives it a timeless appeal. I guess that, in a way, I am looking for stellar role models in terms of individuals who have succeeded in spite of having serious visual handicaps.”

.....
From a woman whose brother and sister also have achromatopsia: “My sister has the poorest visual acuity of the three of us, and I am the one with the most photophobia. None of us went to special schools, but we did have the benefit of private schools, which meant smaller classes. Everyone in our family has a great sense of humor regarding our eyesight. Dad's favorite story is about when he once asked my sister if she could see the clown who was on top of the elephant in a parade, and my sister asked, ‘What elephant?’”

.....
From a man with achromatopsia in the U.K.: “I am so thankful for the network and for all the help and information I have received. For many years I have truly been in the dark about the true nature of my vision disability. I am 31 and have spent all my life trying to overcome the problems that I have had to face because of my vision. My parents have been terrific. They refused to have me go through the special education system, because they felt that it might limit my ability to adapt and to come to terms with my difficulties. So I went through conventional education programs at both primary and secondary levels and, in my 20's, continued on to further education in Scotland. It was not easy for me, having to keep up with classroom work and integrating with my peers. And I suffered some very intimidating and cruel treatment because of having to wear dark glasses throughout the year. As an achromat in Scotland you don't often get to use the excuse that you are wearing sunglasses because of the sun. Nevertheless, I was blessed with a good group of friends who treated me with understanding and respect. Sometimes my closest friends – and, indeed, even my family – forget about my vision limitations, and this can sometimes result in all of us seeing the funny side of

things. I was not exactly a success in decorating the places where I lived. I had no idea that my pink ceiling, purple carpet, and yellow curtains would cause so much trouble! (So much for my career possibilities in interior design.) And then there was the collection of Hawaiian shirts I used to have! My wife now, mercifully, helps out with my clothes shopping. I lead an active life, though I do have limitations in terms of participation in sports. Ten pin bowling is my best sport – partly because the target doesn't move. I also enjoy playing a number of musical instruments, although I can't read or write music. I was never able to keep up in music class or to read sheet music and play an instrument at the same time. But I developed a good ear for music and I now play in a Celtic folk/rock band."

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A woman with achromatopsia writes: "Judging from what has been shared in the newsletters, it is clear that networkers have a wide range of experiences and preferences in terms of how they deal with their light sensitivity. I wonder if this is because we have different numbers of functioning cones in our retinas or if it is due to differences in environmental and personality factors? I find it interesting that parents who have more than one child with achromatopsia mention how their children deal with it in different ways. I wonder if that is because one child is more visually impaired than the other or because of other individual characteristics. My sister and I both have achromatopsia, but our visual differences seem almost as disparate as our personalities. We inherited achromatopsia in the same way, but it didn't manifest in the same way. Also, our feelings regarding our vision are different. She was raised on our grandparents' farm, surrounded by the extended family, and she grew up feeling loved and accepted, but her school was intolerant of her special needs. By contrast, I, having been born quite a few-years after she was born, was put in day care and later was a 'latch key kid,' and I attended a school with a good special education program. I struggled socially, but I have wonderful memories of teachers who helped me in so many ways. Looking back, I can see how all of these factors affected our different ways of looking at things."

.....

"Some of the happiest memories of my life are memories of having fun outdoors at twilight time or at night time in the spring and summer. I fondly remember participating in folk dancing on an expansive lawn on a summer's night, meeting with college friends in a beer garden where there was great music (and other experiences of dining alfresco in the evening), night walks with my husband in places far from city lights, where we could see so many stars, relaxing around a campfire with friends in the Sierras, accompanying my son and his friends on a special Halloween tour of a Storybook theme park at night time, and many other good memories. I long for a lifestyle and a location that would allow me to focus on enjoying the good vision that I have in relatively dark settings, especially in the out of doors."

.....

From a woman with achromatopsia in her 20's: "I don't believe we should put limitations on ourselves. Last year I was apprehensive about starting a course in sailing, but I found that I had very few problems with it. There have just been a few times when I've had to explain to people I've sailed with that I am extremely sensitive to light and have poor eyesight. I have just finished being the liaison officer for the Cutty Sark tall ships race in Dublin, and I plan to take part in a 4-month



long race in the year 2000, which will involve sailing to the Canary Islands, Barbados, Florida, and other destinations. I have canoed in the Florida Everglades, rowed for 6 years, and gone jet skiing. I find that, the more I do, the more I am able to do. This past year has been amazing for me in coming to terms with my vision. I now have a positive attitude and actually do not mind having to explain why the irises of my eyes are black (because of my dark contacts) or why I am so light sensitive and colorblind. So far, I have found that people are usually fascinated to learn about this, but in a nice way. Just two years ago I was so self-conscious about being visually impaired and being 'different.' Now I rarely think about either – and, when I do, it is no longer in a negative way. There are three main reasons for my change in attitude toward my vision impairment: (1) my discovery of the network and other people like me, (2) finally getting my lenses as dark as I wanted, and (3) achieving some things I never would have even contemplated 2 years ago. For example, I got my year-long teaching contract renewed this year, as well as being offered a contract by another school. I also went volunteering in Bosnia, teaching refugee children in summer school, and then I toured around Croatia afterwards. Now I feel I can do just about anything. I do not believe we should let anyone tell us otherwise.”

.....
“When I go on vacations, I like to take lots of pictures of scenic views that I wish I could see more clearly. Then, when I get home, I have enlarged prints made. That way I get to enjoy my favorite scenic views in a special way after the vacation.”
(Editor’s note: some of us with achromatopsia also like to have enlarged prints made of family photos and any other photos that have special meaning for us.)
.....

From a network dad: “I get a kick out of seeing my 6-year old son (the one with blue cone monochromacy) racing his 9-year old brother into a theater. The older one is usually ahead as they go down the hall toward the theater, but when they actually enter the darkened theater, the younger one runs straight down toward the front rows. His older brother (the one without BCM) typically stumbles and falls, bumps into somebody, or gets lost if he tries to keep up with his brother.”
.....

From a woman with achromatopsia: “In the book, *The Island of the Colorblind*, I very much enjoyed reading Oliver Sacks’ sympathetic reaction to Knut Nordby, although it also made me feel sad in a way. I must say that I do not experience the visual world as richly textured as Dr. Sacks conjectures, but I do think I enjoy it from a different, albeit less detailed, perspective. We live in a culture that is very visually oriented, but there are many different ways and various other senses with which to experience the world.”

Reminder: Network members continue to share their experiences and thoughts in connection with all of the subjects considered in this book, as well as other subjects, and their comments continue to be included in mailings I send out to those who subscribe to the Achromatopsia Network Journal. Also, there is a substantial amount of helpful information regarding matters of interest to network members in the book, *Understanding and Coping with Achromatopsia* (updated in 2004). For information about ordering this book and other publications, write to any of the addresses listed on the bottom of the following page.

The Achromatopsia Network

The Achromatopsia Network is a support network and information network for individuals and families affected by achromatopsia, a vision disorder affecting 1 person in 33,000 in most parts of the world. Before this network developed, very few people knew about achromatopsia. Even eye doctors and other professionals serving the visually impaired, because they rarely (if ever) encounter someone with achromatopsia, have had very little knowledge of how achromats see or how to assist them with their special needs. Before this network existed, very few individuals and families affected by achromatopsia had the opportunity to meet others similarly affected. Also before this network developed, it was very difficult to obtain any information about this rare vision disorder, and such information as could be found (in the professional literature of vision care specialists and vision scientists) was of little use to persons affected by achromatopsia. Little was known about how achromats cope with the challenge of living with very poor visual acuity, total (or nearly total) colorblindness, and the most extreme light sensitivity that can be experienced by the eyes.

The goals for this network and for network publications are:

1. To gather and share information about achromatopsia, from a variety of perspectives, and about resources for meeting the special needs of achromats
2. To promote awareness, education, and understanding about achromatopsia, especially among professionals who work with the visually impaired
3. To help individuals and families who are affected by achromatopsia to connect with one another

Books and other publications created for the network present information about many subjects – light sensitivity, tinted lenses, orientation and mobility, special needs in school, vocational options, diagnosis, adaptive methods and devices, research, social and psychological aspects, products and services for the visually impaired, and more. The network Journal also serves as a forum for networkers to share their experiences, thoughts, and suggestions. See p. 165 for more information about the publications that are available.

There is no funding for this network except for what people send in when ordering books and subscriptions or when making a donation. Donations are essential in order to maintain this work.

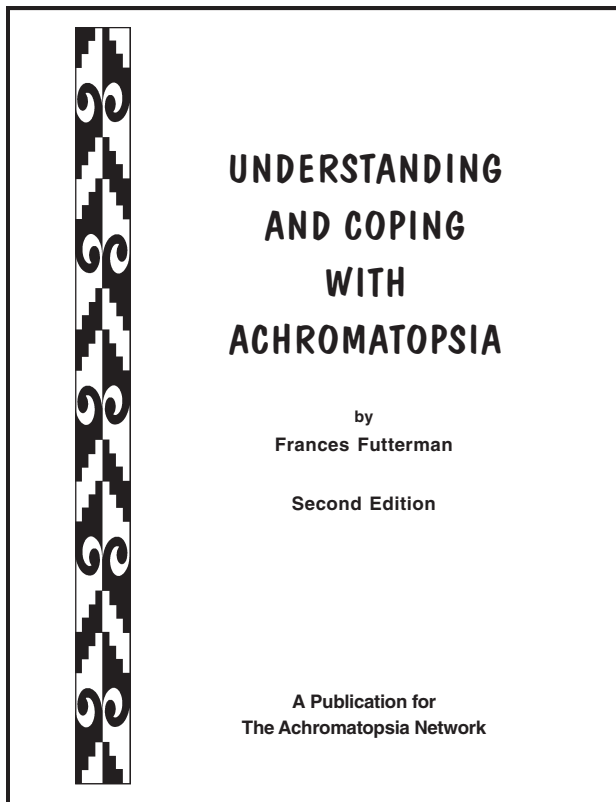
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Or visit our network's website at <http://www.achromat.org/>

Frances Futterman, who serves as facilitator for the Achromatopsia Network and editor and reporter for publications, has complete achromatopsia. Her background has been in the field of special education for visually impaired students and rehabilitation teaching and counseling for visually impaired adults.

Publications for the Achromatopsia Network



Understanding and Coping with Achromatopsia This 160-page spiral-bound book brings together a substantial amount of useful and interesting information that has been gathered and published for members of the Achromatopsia Network from 1994 (when the network began) through 2004. It presents information about the vision of persons with achromatopsia, symptoms, diagnosis, inheritance factors, options in tinted lenses, adapted environments, orientation and mobility, special needs in school, social and psychological aspects, adapted lifestyles, services for the visually impaired, coping strategies, colorblindness, vocational choices, optical devices, sports experiences of networkers, achromatopsia research, and more. This book, first published in 1998, was substantially revised in 2004.

Living with Achromatopsia What is it like to have achromatopsia? To go through life with little or no color vision, poor visual acuity, and the most severe sensitivity to light that can be experienced? This 165-page spiral-bound book, first published in 1999 and then revised in 2004, offers information and insight. It consists entirely of comments from persons who have firsthand knowledge about achromatopsia. Adults and teens with achromatopsia and parents with children who have achromatopsia tell what it is like to live with this challenging vision disorder and how it can affect experiences at school, at work, and in other kinds of activities. These comments have been gathered through various means of communication with network members, mostly by way of correspondence through letters or e-mail. Much of the material in this book appeared previously in the “Comments from Networkers” sections of the Achromatopsia Network Journal.

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Also available:

The Island of the Colorblind, by Oliver Sacks (published by Alfred Knopf, 1997). This book has done much to increase public awareness of achromatopsia. Hardback copies of this book are no longer available in bookstores, but they can be obtained through this network at a very low price (U.S. orders only).

A Network Membership Kit may be ordered by any person qualified for membership in the network who orders *Understanding and Coping with Achromatopsia* or one of the Special Offers which include this book. The Network Membership Kit includes the *Handbook of Information for Members of the Achromatopsia Network* plus a membership form, details about membership, several back issues of the Achromatopsia Network Journal, and other items.