

VISION ACCESS

Volume 9, Number 1

2002

Copyright 2001

by the Council of Citizens with Low Vision International.

VISION ACCESS is a journal by, for, and about people with low vision.

VISION ACCESS is published quarterly in three formats (cassette, large print, and computer disk) by the Council of Citizens with Low Vision International (CCLVI), a not-for-profit affiliate of the American Council of the Blind. Views expressed in VISION ACCESS are those of the individual contributors and do not necessarily reflect the views of the editor or of CCLVI. All rights revert to individual contributors upon publication.

VISION ACCESS welcomes submissions from people with low vision, from professionals such as ophthalmologists, optometrists, and low vision specialists, and from everyone with something substantive to contribute to the ongoing discussion of low vision and all of its ramifications. Submissions are best made on 3.5" disk in a format compatible with Microsoft Word. Submissions may also be made in clear typescript. All submissions should include a self-addressed stamped envelope. VISION ACCESS cannot assume responsibility for lost manuscripts. Submissions may be mailed to Joyce Kleiber, 6 Hillside Rd., Wayne, PA 19087.

VISION ACCESS is a free publication to all members of the Council of Citizens with Low Vision International. Subscription and membership inquiries can be made to Janis Stanger, CCLVI Membership, 1239 North American Beauty Drive, Salt Lake City, Utah, 84116. Call CCLVI toll free at 1-800-733-2258.

Editor: Joyce Kleiber

CCLVI OFFICERS:

Ken Stewart, President,
Carl Foley, 1st Vice President,
Janis Stanger, 2nd Vice President,
Barbara Kron, Secretary,
Bill Burgunder Jr., Treasurer,
Coletta Davis, Past President

CCLVI BOARD MEMBERS:

Patricia Beattie
Charles Glaser
Herb Guggenheim
Bernice Kandarian
Jane Kardas
Joyce Kleiber
Fred Scheigert
Mercedes Schott
Robyn Wallen

Contents	
From the Editor.....	2
Organization News	
President’s Message.....	3
Best Convention Ever!.....	5
Reports from CCLVI Chapters.....	6
Project Insight Update.....	10
Health and Vision Rehabilitation	
NEI Promotes Referrals to Low Vision Services.....	11
Eye Drops to Treat Childhood Eye Disorder Work As Well As Patching the Eye.....	12
Medicare Now Covers Glaucoma Detection Eye Exam.....	15
As Glaucoma Treatment Advances Vision Is Saved by Julie Bain.....	16
Eating for Eye Health—New Research Sharpens the Focus.....	20
Eli Lilly Offers \$12 Flat Fee Per Prescription for Millions of Needy Seniors & People With Disabilities Without Coverage.....	24
Some Notes from Optometrist Dr. Marc Gannon.....	25
Montgomery County Association for the Blind—An Agency with Heart, by Curt Woolford.....	26
The Theft of Useful Vision, By Bill Chapman.....	30
Features	
Member to Member, By Charles Gourney.....	39
Write Now! Starting a Personal Journal, By Mike Vogl.....	41
People	
Meet Joseph J. Neff—Shedding Light on Glaucoma, by Joseph Neff.....	45
Gifts and Bequests to CCLVI.....	50
Resources.....	50
CCLVI New, Renewal, and Donor Application.....	51

From the Editor

I am grateful to everyone who contributed articles and suggestions to this issue of VISION ACCESS.

You will find several articles about new developments in the treatment of glaucoma.

I invite you to respond to topics covered in articles in VISION ACCESS or to share your own questions and coping strategies with our readers.

In this issue our “Member to Member” column addresses the topic of dating and low vision—when and how to tell your date that your vision is not 20/20. What are your thoughts and feelings on this sensitive topic?

Bill Chapman, one of our contributors, has strong feelings about the use of blindfolds in rehabilitation programs. He resents that consumers are not taught to make full use of whatever vision they have. What did you experience in vision rehab? Were you required to use a blindfolded at any time? Were you encouraged to use your vision? Or were you trained as a person who is blind? How do you feel about this?

In contrast to the problems described by Bill Chapman, Curt Woolford writes about a training center that is a shining example—the Montgomery County Association for the Blind. This agency offers training that should be a standard for vision rehabilitation practice everywhere.

Mike Vogl writes about the benefits of “Journaling” for people with low vision? Do you journal? How has this practice helped you? What other ways have you found helpful in coping with your stress? Do you have a hobby? Would you like to share your interest in this hobby with us?

CCLVI is YOUR organization. VISION ACCESS is YOUR magazine. Let us hear from you!!

Organization News

President's Message

I am “putting thumbs to keyboard” (nowadays no one “puts pen to paper” any more) just after getting off a telephone conference call with almost half of our Board of Directors. The discussion topic was planning for our next convention’s program sessions. It was heartening to witness great enthusiasm among members of our Board. There were proposals for sessions presenting medical experts, surveying the latest in adaptive devices, airing controversial federal legislation on expanded Medicare coverage of rehab services, explanations of attitudes about maximizing the use of remaining vision, and exchanges of feelings and ideas about being visually impaired. Novel evening social events were also blossoming during the conference call.

Those Board members had stepped forward at our recent mid-year meeting in Houston to help put together the program that will be offered at the same venue from June 29th through July 3rd. It warrants note also that our mid-year Board of Directors meeting was very well attended in spite of the reality that the organization was unable to offer any financial assistance with hotel and travel expenses. Eleven of our fifteen Board members spent nine heavy-duty hours focusing on CCLVI’s highest priorities—membership services, balancing the budget, advocacy initiatives, as well as our upcoming convention.

Immediately after the Houston Board of Directors journey I flew off to Portland for a three-day meeting of the federal Access Board’s Advisory Committee on public rights of way. This body continues to meet frequently all around the country and it continues to present precious opportunities to educate key transportation decision-makers about the travel needs of pedestrian with low vision. This on going role is personally costly both in time and dollars (our organization has very limited funds for these activities, too), but can, I am convinced, yield great and long-term benefits for us all.

While in Portland I had the chance to meet that city’s very enlightened public transit ADA Compliance staffer. As we glided along beside each other during a field trip on their light rail system, I offered several observations—how the audible station calls could be more listenable, how to conspicuously mark stair treads, how to better time route announcements for a person waiting on a station platform. The staffer received each of my comment thoughtfully and noted them on her clipboard.

There are so many ways each of us can spread the word about the little things that can be done just a bit differently, and often at no additional cost, to make it easier for people with low vision to continue to function independently.

KLS 3/02

Best Convention Ever!

Where can you go this summer in Houston to enjoy a good horse race, learn about the latest research in genetic eye conditions, have a glass of wine and mingle with friends, or dance to the best music in town? Try the Council of Citizens with Low Vision International. This year’s convention program, mixer, dances, and Wednesday Game Night promise to be the best ever planned.

This year’s events begin Sunday morning. Join Patricia Beattie and her guests to learn more about genetic eye conditions, the role of the low vision therapist in the vision rehabilitation team, and learn about low vision services at the Houston Lighthouse. That afternoon, enjoy a sneak preview of what’s new inside and outside of the exhibit hall with Janis Stanger, Low Vision Advisor for Utah State Services for the Blind and Visually Impaired, Noelia Dillingham of Houston Lighthouse and vendors of technology which can be seen in the exhibit hall this year.

That evening, just before the opening session of the American Council of the Blind, ACB, Annual Convention, attend the best mixer CCLVI has ever hosted. But find some time in the day for a little

nap so you can stay up for the highlight of the day: dancing and listening to music the way you like it with Gordon Kent taking requests.

Sunday's activities are just a sampling of what will be available throughout the week. Of particular interest will be the program sessions scheduled for Monday afternoon. Patricia Beattie, of National Industries for the Blind, and member of the board of directors of CCLVI will lead a discussion on issues in rehabilitation for people with low vision. Later, she and others will participate in a panel discussion on different philosophical approaches to training for those who are blind and visually impaired. Particular emphasis will be placed on the impact these different approaches may have on individuals seeking training. The session will conclude with an update on proposed legislation to provide Medicare coverage of vision rehabilitation services.

New this year will be the Wednesday Game Night. Charles Glaser and Barbara Kron are busily planning the social event of the convention: an exciting night of horse racing, The Newlywed Game, team trivia, Name That Tune and the Dating Game. Anyone looking for a lot of laughs and great times will be there Wednesday night to cheer on their favorite horse, or root for their chosen jockey. Between races, laugh at the antics of our Dating Game contestants, and enjoy finding out how much our newlywed's actually know about each other. And of course there will be plenty of team trivia and Name that Tune with pianist, Janiece Petersen.

Friday night, after the banquet, top off your convention week with the CCLVI Texas Farewell Dance with Gordon Kent providing the best dance music in town.

CCLVI invites everyone to join with us this summer in Houston for some of the best programming and activities we have ever planned.

Reports from CCLVI Chapters

Delaware Valley Council

Dr. Larry Goldberg, attorney and medical doctor, spoke at the February 2002 meeting of the Delaware Valley Council of Citizens with Low Vision. His topic was the Americans with Disabilities Act (ADA). Here is a summary of his remarks.

The ADA is an offspring of rehabilitation and civil rights legislation. Important areas affected by the ADA are the workplace, education, and travel. The ADA from its beginning was not a strong piece of legislation. In employment, the application process for obtaining jobs has not changed with the ADA. It is hard to determine discrimination at the time a person applies for a job. Also the number of people with disabilities who have been hired since the passage of the ADA has not increased significantly. The ADA has had a strong impact in the area of accommodations that employers are now required to provide for their employees with disabilities.

Recent Court decisions have shown that it is more difficult for people to be classified as "disabled" and thus get protection under the ADA. Cases have been ruled in favor of employers. Two of these rulings involved public safety. In a third case, a person with a mental health disability was denied protection; the Court said this disability could be lessened through medical intervention. In another case a worker was denied protection because other protective options are available. These include workmen's' compensation, private disability insurance, Social Security Disability Insurance, or light duty on the job. Therefore her appeal to the ADA was deemed inappropriate.

With the ADA, people who are visually impaired find it easier to get accommodations to help them do their jobs. Prior to employment, they are more able to get the educational opportunities they want.

Our chapter is happy to report that some of our members supported a workshop held in Philadelphia in February to train audio describers who will work to make local theatre offerings accessible to theatergoers who are visually impaired.

Members of our chapter take every opportunity to speak to people in our community about low vision. In March Joyce Kleiber spoke to a group of patients at Ophthalmic Subspecialty Consultants.

Her topic was "Coping with Vision Loss." Members of this group also appreciated the chance to share their experiences with each other.

For more information about our chapter call us at 215-735-5888.

Florida Council of Citizens with Low Vision

The Florida Council of the Blind, along with the Florida Council of Citizens with Low Vision gladly invites all of you to share in our 2002 State convention. This will take place from Thursday, May 30, through Sunday, June 2 at the Double Tree Hotel Tampa - Westshore located at 4500 West Cypress Street; Tampa, FL 33607. Room rates are: single, double, triple and quad, \$65 per night and junior suites are available for \$69 per night. Phone (813) 879-4800 or (800) 355-0524 to make your room reservation, being sure to state that you are attending the convention of the Florida Council of the Blind. The cut off date is May 17, 2002. Remember, however, that your chance to make a reservation at these rates is based on room availability; so call soon!

On Thursday, May 30, for your enjoyment and by popular demand, there will be a tour of Busch Gardens. For those who are thrilled simply by shopping, Burdines, as well as other local merchants will be offering a discount to all convention attendees for the entire weekend. The hotel will provide complementary shuttle service to the mall.

On Friday, May 31, members will have the opportunity to participate in FCB's annual legislative seminar, the Library Users' Focus Group, our annual awards banquet and the welcome to Tampa party. On Saturday, June 1, the general session program will be devoted to how each of us can play a role in making the voting experience in our communities an accessible and positive one for all individuals who are blind and visually impaired. Kathy Dent, Supervisor of Elections for Sarasota County, will demonstrate their accessible voting system and will speak about the training program for poll workers in that county. Representatives from other counties will also speak. Melanie Brunson, Director of Advocacy and Governmental Affairs for the American Council of the Blind, will speak about the nation's accessible voting agenda.

Following that presentation, there will be two workshop choices. Choice one, "How to Learn about and Take Full Advantage of Municipal Programs and Services", will be hosted by Melanie Brunson and Gayle Krause. Choice two: ACB Immediate Past President, Paul Edwards, will host "Chapter Revival, Fitting the Bill, Making the Grade."

The afternoon will include an additional meeting with members of the Division of Blind Services. The annual business meeting for FCCLV will take place on Saturday June 1st, from 3-5 PM. Cocktail hour will begin at 6:30 PM followed by the banquet and dance.

Sunday programming gives you the opportunity to participate in the business of the organization and to elect the officers that will serve FCB for the next two years.

FCCLV is a very important part of the Florida Council of the Blind. The issues being addressed at the convention will help enlighten and educate all, and the social aspect will include some very fine Southern Hospitality.

For any additional information, please call our Project Insight Line at 1800 26 SIGHT (1 800 267-4448) and Bobbie will gladly help answer any questions.

Rosanna Lippen, FCCLV President

Metropolitan Council of Low Vision Individuals

Our Metro Chapter is looking for issues! We ask that any CCLVI member in the metropolitan New York, upstate New York, or New England area, a Chapter member or not, get back to us with your issues, your concerns.

Our Chapter has had some success in advocacy efforts. We want to learn more from people with low vision what "bugs" them about the actions or inactions of governmental agencies and other public organizations. We want to get involved and try to help out.

Recently our Chapter heard from a museum that we had contacted about the inaccessibility of an exhibit's informational displays. Previously, the agency that operates New York City's subways had been very responsive to Chapter input regarding the visibility of station elements.

Our Chapter can be reached via email at lsanborn@rr.nyc.com; by mail at MCLVI, Suite #1F, 357 West 55th Street, New York, NY 10019-4525; and by phone through the CCLVI toll free number, 800-733-2258.

Our Metro Chapter's bimonthly meetings are held from 6-8pm on Wednesday evenings at Alternate Solutions, 110 William Street, in the Financial District of Lower Manhattan, less than a block from many subway lines.

National Capital Citizens with Low Vision.

Our Chapter has had a great year with interesting speakers who generated stimulating discussions among our group members.

In September, Matt Ater from AccessAbility Inc., a company selling assistive technology, brought various CCTV's, electronic Braille and voice output notetakers, and the more conventional magnifiers and telescopes for our members to try out. He gave us some idea about the future of certain technologies.

Our own Laurie Gregorio, at our October meeting, told us about the consulting work that she does with the Smithsonian museums to help them make their exhibits and publications more accessible to people with low vision.

In November, Phillip Strong, an intern with American Council of the Blind, ACB, told the group about what ACB is doing concerning the issue of pedestrian safety.

We took a holiday break in December and had our usual holiday bash with the other local affiliates of ACB organized by our own Skip Sharpe.

At our January meeting, Herb Guggenheim led a support group on how to be an authentic person while dealing with various difficulties presented by having low vision.

Dr. Sulieman Alibhai, a low vision specialist, talked with the group in February about what he does in a low vision exam and answered a diverse range of questions from the future of assistive technology to possible directions for breakthroughs in medical research.

Here are our plans for future meetings. In March, Heather McDaniel, a visually impaired aerobics and water aerobics instructor and personal trainer will talk to the group about fitness in the workplace. In April, Janina Sajka from the American Foundation for the Blind will give us an update and demonstration of digital books and will also talk about what to do to get more accessible cell phones. In May, we will have a speaker from a local store that sells assistive technology, and she will also talk about ways to make office workstations more user friendly to those of us with low vision.

Anyone wanting to join our group should send their form and check to our treasurer, Bella S Guggenheim, 413 Torrington Place, Silver Spring, MD 20901

Email requests for information can be sent to Sarah Presley at ncclv@yahoo.com.

Project Insight Update

Bernice Kandarian answers CCLVI's 800 line, 800-733-2258. She refers callers to Project Insight volunteers who might be of help. We are looking for ways to reach out to more people who are challenged by vision loss. We are planning to print brochures about Project Insight. The title on these brochures is "You Have Lost Your Sight—Not Your Vision". We will ask our volunteers to strategically distribute these brochures in their communities. We hope more people will learn about Project Insight.

Project Insight is listed on the website of the National Eye Institute. Please make your suggestions to any of the members of our Project Insight Committee: Bernice Kandarian, Jane Kardas, Barbara Kron, and Joyce Kleiber. We want everyone to benefit from the information and support that has been so important to us in coming to terms with our own vision loss.

At this summer's CCLVI convention in Houston, we will offer a workshop for everyone who is interested in Project Insight. We look forward to hearing your ideas, experiences, and suggestions for how to reach more people through this project.

Health and Vision Rehabilitation

NEI Promotes Referrals to Low Vision Services

The National Eye Institute, NEI, assumed the leadership of a pilot project to determine effective strategies for increasing the number of referrals to vision rehabilitation services. NEI will be funding the design, conduct, and evaluation of this project. Elements of this pilot will incorporate findings from the NEI focus groups conducted last spring. (This focus group explored what ophthalmologists, optometrists, and eye care staff across the country know about low vision and its system of care.) A key element of the pilot project will be the promotion of the Lighthouse toll-free number. Last week, Cynthia Stuen of the Lighthouse and Rosemary Janisewski of NEI met with the leadership in the Low Vision Council. The Low Vision Council pledged "\$10,000 to the pilot project under the NEI leadership. It was agreed that the \$10,000 would be used for the cost of printing .

NEI is directing the project and assembling a committee with representatives from the National Eye Health Education Partnership Planning Committee and Partnership; Ed Bettinardi, representing the Low Vision Council; Bryan Gerritsen, representing Goal 2; and Cynthia Stuen, representing the Lighthouse.

Based on the results of the pilot project, the Low Vision Council expressed cautious interest in developing a national program.

The time frame for this project will be approximately one year, with implementation taking place sometime in the fall.

Eye Drops to Treat Childhood Eye Disorder Work As Well as Patching the Eye

News Release from National Eye Institute

Atropine eye drops given once a day to treat amblyopia, or lazy eye, the most common cause of visual impairment in children, work as well as the standard treatment of patching one eye. This research finding may lead to better compliance with treatment and improved quality of life in children with this eye disorder. These results appear in the March issue of Archives of Ophthalmology.

After six months of treatment, researchers found that the drug atropine, when placed in the unaffected eye once a day, works as well as eye patching and may encourage better compliance. Compliance is an important factor in the success of amblyopia therapy. Treatment should be started when the child is young, since amblyopia is more effectively treated in children under seven years of age. Timely and successful treatment for amblyopia in childhood can prevent lifelong visual impairment.

"These results are important because they provide an effective alternative treatment that helps prevent permanent vision impairment for children with amblyopia," said Paul A. Sieving, M.D., Ph.D., director of the National Eye Institute, one of the Federal government's National Institutes of Health and the agency that sponsored the study. "Amblyopia is currently treated by wearing an eye patch over one eye for weeks to months. Children usually do not like this treatment approach because of quality of life issues, such as irritation of the skin and teasing by other children. This new study found that atropine eye drops had a higher acceptance rate and better compliance by children and their parents than did patching. This may well become a new standard form of treatment for some forms of amblyopia.

Amblyopia, or lazy eye, is a condition of poor vision in an otherwise healthy eye because the brain has learned to favor the other eye. Although the eye with amblyopia looks normal, there is

interference with normal visual processing, that limits the development of a portion of the brain responsible for vision. The most common causes of amblyopia are misalignment of the eyes (crossed eyes) or significant differences in refractive error, such as farsightedness or nearsightedness, between the two eyes. Amblyopia usually begins in infancy or childhood. It is estimated that as many as three percent of children in the U.S. have some degree of vision impairment due to amblyopia.

Treatment for amblyopia is most effective when started in young children less than seven years old. Response to treatment in older children is much less effective. Most eye care professionals treat amblyopia by placing an opaque adhesive patch, or "eye bandage," on the skin to cover the unaffected eye. This forces the child to use the eye with amblyopia, which stimulates vision in the eye with amblyopia and helps the part of the brain that manages vision to develop more completely. However, many children do not like the appearance of the eye patch and the accompanying social and psychological stigma and will not fully cooperate, which can lead to treatment failure. Also, patching forces a child to use an eye that has poor vision, often making compliance difficult for active children. Unless it is successfully treated in early childhood, amblyopia usually persists into adulthood, and is the most common cause of monocular (one eye) visual impairment among children and young and middle-aged adults. Consequently, it is crucial for children to comply with treatment.

The atropine eye drop works by temporarily blurring vision in the unaffected eye, thereby forcing the eye with amblyopia to be used. This strengthens it and improves vision. The advantage of atropine treatment is that the parent simply places a drop in the child's eye once a day. With patching, the parent must monitor the child wearing the patch for six or more hours each day for many weeks or months.

In the Amblyopia Treatment Study, 215 children were randomly assigned to receive patching, and 204 were assigned to receive atropine eye drops. Researchers found that 79 percent of those receiving the eye patch were treated successfully, and that 74 percent of those receiving the atropine were treated successfully. This difference is clinically insignificant. Although researchers found that vision in the amblyopic eye improved faster in the patching group, the difference in the two groups at six months was small and not significant.

"The daily burden to administer treatment for amblyopia falls on the parent," said study chairman Michael Repka, M.D., professor of ophthalmology and pediatrics at the Wilmer Eye Institute of Johns Hopkins University School of Medicine in Baltimore. "This study shows that one drop a day of atropine works as well as patching the eye for some children with amblyopia. Since both patching and atropine work equally well, the choice of treatment can be made by the eye care professional in consultation with the parent."

The children who were treated in this study will continue to be followed until April 2003, allowing researchers to learn whether there is any longer term advantage to treating amblyopia with either patching or atropine.

The study was conducted by the Pediatric Eye Disease Investigator Group at 47 clinical sites throughout North America. The study was funded by the National Eye Institute and coordinated by the Jaeb Center for Health Research in Tampa, Florida and the Wilmer Eye Institute of Johns Hopkins University in Baltimore.

Medicare Now Covers Glaucoma Detection Eye Exam

News Release from National Eye Institute
New Coverage to Benefit At Risk Populations

Medicare now covers an annual dilated eye examination for all people at high risk for glaucoma. This important new preventive benefit will safeguard the vision of millions of Americans enrolled in the Medicare program.

This new coverage, effective January 1, 2002, is consistent with recommendations from the National Eye Institute, one of the Federal government's National Institutes of Health, as well as from eye care professional organizations and consumer groups.

Glaucoma, a leading cause of blindness, affects about three million Americans half of whom don't know they have this eye disease.

The new benefit defines high-risk Medicare beneficiaries as those with diabetes; those with a family history of glaucoma; and African Americans aged 50 and older. Glaucoma is five times more likely to occur in African Americans than in whites and about four times more likely to cause blindness in African Americans than in whites. "Preventive benefits, such as this new glaucoma coverage, help keep people enrolled in Medicare healthy and improve their quality of life," said HHS Secretary Tommy G. Thompson. "An eye exam now can prevent serious problems later, even blindness. It is important that we make taking care of our eyes a part of our overall health maintenance program."

"Glaucoma, and the risk of vision loss, remains unrecognized for millions of Americans," said Paul A. Sieving, M.D., Ph.D., director of the National Eye Institute. "The expanded Medicare coverage will help people keep their vision, especially those at high risk for eye disease. "Once vision is lost from glaucoma, it cannot be restored -- the damage is irreversible," said Dr. Sieving. "Studies have shown that the early detection and treatment of glaucoma, before it causes major vision loss, is the best way to control the disease."

The "air puff" test, which measures eye pressure, is one part of a glaucoma examination but this test by itself cannot detect glaucoma. Glaucoma is found most often during an eye examination through dilated pupils, which means drops are put into the eyes to enlarge the pupils. The eye care professional then can see more of the inside of the eye to check for signs of glaucoma."

For more information on glaucoma, write Glaucoma, 2020 Vision Place, Bethesda, MD 20892-3655 or visit www.nei.nih.gov.

As Glaucoma Treatment Advances, Vision Is Saved **by Julie Bain**

Reprinted with permission from The New York Times. Thanks to Charles Gourgey for directing VISION ACCESS to this article.

Roger Martin of Milford, Conn., watched his grandmother go blind from glaucoma. His mother lost most of her sight in her 40's from the same condition and had to give up the successful catering business that she loved. Four years ago, when Mr. Martin, then 51, found out that he too had open-angle glaucoma, the most common form of the disease in the United States, he was determined to have a better outcome. Three million Americans have glaucoma, and it is the second leading cause of blindness in the United States, after macular degeneration. But doctors' understanding of the disease has advanced in recent years, and so have the treatments, including eyedrops, laser procedures and surgery.

Dr. Robert Ritch, a professor and chief of glaucoma services at the New York Eye and Ear Infirmary, said that when he was training 25 years ago, "Professors then said, 'What do you want to go into glaucoma for? You just put drops in until they go blind.' That's all changed. With proper treatment, and if patients do their part, they should be able to see for the rest of their lives."

One of the biggest misperceptions about glaucoma is that the disease is simply elevated eye pressure. "Elevated intraocular pressure is not the disease," said Dr. Ritch, "but it is the most important risk factor."

Doctors have redefined glaucoma. "It's a progressive disorder of the optic nerve, characterized by a specific pattern of visual field damage and optic nerve damage that we can see with an ophthalmoscope," Dr. Ritch said. "This is caused by a number of different diseases that affect the eye."

In open-angle glaucoma, the fluid in the front of the eye drains too slowly or not at all, backing up like a clogged sink. This raises the pressure in the eye; the resulting stress on the optic nerve can kill nerve fibers and destroy vision. Peripheral vision is usually affected first.

Blacks are four times as likely as whites to have open-angle glaucoma and often begin developing it in their 40's. Also at high risk are people who have relatives with glaucoma, the elderly, those with high blood pressure and those who are quite nearsighted or farsighted. Other factors may include poor blood flow to the eye, diabetes, cardiovascular disease and sleep apnea, a breathing disorder also linked to high blood pressure, heart attacks and strokes.

People at risk for glaucoma should have yearly eye examinations once they turn 40, doctors say. Others should be tested every two to four years between the ages of 40 and 64, and every one to two years after that.

It is not clear whether glaucoma can be prevented. But Dr. Harry Quigley, director of glaucoma services at the Wilmer Eye Institute at Johns Hopkins, where he is a professor of ophthalmology, said aerobic exercise like walking had been shown to lower eye pressure temporarily in people at risk for the disease. But exercises that involve hanging upside down or standing on one's head can cause very high eye pressure, and people with glaucoma are warned to avoid them.

About 50 percent of Americans with glaucoma do not know they have it. Most forms of the disease have no symptoms until it is too late to reverse the damage, said Dr. Quigley, who is a founding member of the American Glaucoma Society. "It's rare for people to notice they've lost vision from glaucoma until they're blind in one eye," Dr. Quigley said. "Even doctors have discovered their own glaucoma that way. It's a very slow eating away of your vision."

A common misunderstanding is that elevated eye pressure equals glaucoma. That is not the case; some people have elevated pressure and yet no damage to the optic nerve. Moreover, some people with normal pressure do have glaucoma. For that reason, careful screenings are important. Doctors should look at the optic nerve and test its function, Dr. Quigley said.

"We can prevent vision loss in more than 90 percent of the people with glaucoma, but only if we've got our hands on them and they play the game," Dr. Quigley said.

Mr. Martin said: "My prognosis is very cheerful. I follow my doctor's directions religiously, and I have very little field-of-vision loss."

When he found out that he had the disease, he closed his Italian seafood restaurant in Milford and devoted himself to glaucoma awareness and education. He organized a national glaucoma screening program through Lions clubs and other organizations. The program has tested over 34,000 people in the last three and a half years.

Lowering pressure within the eye is still the main goal of open-angle glaucoma treatment. Prescription eyedrops are where most doctors begin. Beta blocker drugs, similar to those used to treat high blood pressure and some heart problems, were the standard pressure-lowering eyedrop for more than 20 years, but they often had negative side effects.

Newer drugs, including ones based on prostaglandins, are generally more effective at lowering pressure, and they tend to bring on fewer side effects. Different drugs work for different patients.

"I still start with medications," Dr. Ritch said. "If you look at the eye as a sink, you give medications to open the drain and turn down the faucets. If a couple of different types of eyedrops don't control the pressure, I go on to laser."

Laser treatment is now regarded as a kind of second medication for open-angle glaucoma. The laser is used to burn tiny openings in the drainage system in the front of the eye, to help drain fluid out and lower pressure. But the results are not permanent. "A study showed that laser and eyedrops come out at about the same rate of effectiveness after five years," Dr. Quigley said.

For some patients who have not had good results with eyedrops, or who have trouble remembering to use the drops every day, a good option is an operation called a trabeculectomy, which creates a new drainage system for the eye.

"When I was starting out," said Dr. Ritch, "surgery was the last resort. There were all kinds of complications, and the success rate was about 50 percent. But now the success rate from surgery is about 95 percent."

Several British studies in the mid-1990's found that glaucoma surgery was more effective than eyedrops, lowered the pressure more and preserved patients' vision better. But a major American study based at the University of Michigan and recently presented at a conference of the American

Academy of Ophthalmology found otherwise. In the American study, new glaucoma patients were treated either with eyedrops or trabeculectomy in both eyes. After five years, vision was the same whether patients had eyedrops or surgery. But the surgery group reported slightly more side effects.

Dr. Quigley said: "Conclusion: the British were not necessarily right when they said we should be doing a lot more surgery. But we should offer surgery to patients who can't or don't want to remember to take eyedrops. It's a reasonable choice."

New glaucoma treatments are being developed. A number of studies are looking for ways to protect the cells of the optic nerve. The immune system may have a role to play, and drugs similar to those used to treat multiple sclerosis, which also involves the immune system, may prove effective.

In a related approach, Dr. Michal Schwartz, a professor of neuroimmunology at the Weizmann Institute of Science in Rehovot, Israel, is developing a glaucoma vaccine, which researchers may begin testing in people in the next year or two. In rats, the vaccine works by stimulating the production of certain immune system cells that protect the optic nerve.

Dr. Quigley said: "We want to do preventive medicine, so the ultimate aim is vaccine. She is highly regarded and an innovative scientist. We need to see more, but there's too much there to dismiss it."

Optic nerve regeneration is also being considered. Stem cells from nerves, which can develop into new nerve fibers, are being tested in animals to see whether they can repair damaged optic nerves.

In people, eventually, a way to achieve this may be to take cells from within a blind person's eye and treat them to turn them into progenitor cells that will grow nerve fibers and reconnect to cells in the brain, allowing the person to see again. The studies look promising, Dr. Quigley said, adding, "Before you and I retire, I expect somebody will have seen light again from a blind eye."

Eating for Eye Health

New Research Sharpens the Focus

Reprinted with permission from the Tufts University Health and Nutrition Letter. For further information, on the web go to www.healthletter.tufts.edu or tel: 1-800-274-7581. Reported to VISION ACCESS by Patricia Beattie.

Normally, the results of a single study don't lead researchers to make recommendations on whether people should change their habits. But a new study on macular degeneration, the leading cause of irreversible blindness in older Americans, has proven so promising that its authors are advising certain people to start taking high doses of vitamins C and E, beta-carotene, and zinc in hopes of slowing the advance of the disease.

In an enormous effort coordinated by the National Institutes of Health, researchers at 11 eye centers around the country tested various combinations of those nutrients on some 3,600 people ages 55 to 80 for 6 years. The study, called the Age-Related Eye Disease Study, or AREDs, found that certain people with macular degeneration who swallowed one particular combination reduced their odds of the disease worsening by 25 percent.

The AREDs results were compelling enough that the study's authors recommend that everyone over 55 have an eye exam to check for the presence of eye abnormalities that indicate risk for macular degeneration. Those whose doctors determine that they're in the intermediate stages of the disease should consider following the study regimen: 500 milligrams of vitamin C daily, 400 International Units of vitamin E, 15 milligrams of beta-carotene, 80 milligrams of zinc, and 2 milligrams of copper--the last of which is to prevent the high doses of zinc from interfering with copper absorption. (Smokers are advised not to take beta-carotene because earlier research has suggested that large doses of supplemental beta-carotene may be harmful to them.)

Vitamins C and E and beta-carotene, all antioxidant nutrients, are thought to play a role in protecting the body against the advance of macular degeneration by neutralizing destructive

substances called free radicals that can damage delicate tissue in the retina. As for zinc, more than a decade ago, a small study suggested that the mineral might also help prevent macular degeneration. Zinc is involved in metabolism in the retina.

To be sure, supplements are by no means a cure. But they provide a ray of hope for people who have macular degeneration, because they could slow its advance.

For prevention, research still points to foods.

The AREDS study didn't provide any word on whether taking supplements might help to prevent macular degeneration in people, say, with a family history of the disease. But there has been a great deal of evidence that eating produce-rich diets may pay off in the long run. For instance, studies point consistently to diets rich in dark leafy greens, like spinach, kale, and collard greens, as protective. The connection appears to be that certain substances in leafy vegetables and other produce, called lutein and zeaxanthin, are found in the portion of the eye subject to damage from age-related macular degeneration.

Indeed, a recent review by Tufts researchers of 30 years' worth of scientific evidence has linked "generous intakes" of lutein and zeaxanthin from foods like spinach and broccoli with as much as a 40 percent reduction in macular degeneration risk. A just-published study also bolsters the idea that eating more of those healthful foods may translate into real results in the eye. Researchers in Indiana who gave eye exams to 280 people found that higher intakes of lutein and zeaxanthin in the diet were linked with higher levels of macular pigment in the eyes. ("Macular pigment" is just another name for the highly concentrated deposits of lutein and zeaxanthin in the retina.)

That's important, because macular pigment is what's believed to protect against macular degeneration. Researchers think that it may help to absorb high-energy ultraviolet light before it can damage the retina. It may also be that lutein and zeaxanthin function as antioxidants--as do vitamins C and E and beta carotene--by deactivating destructive forms of oxygen that damage tissue in the retina.

New View of Cataracts

There is a lot of overlap on what looks promising for cataracts and macular degeneration. For instance, many studies of cataracts, cloudy spots in the eye lens that cause progressive loss of vision, also provide evidence that the antioxidant vitamins C and E, and perhaps beta-carotene, lutein, and zeaxanthin, may play a protective role.

In one recent trial, led by researchers at the Harvard-affiliated Brigham and Women's Hospital in Boston, people with early age-related cataracts who took daily doses of vitamins C and E and beta-carotene for 3 years showed a "small deceleration" in cataract progression. The doses involved were quite high: 750 milligrams of vitamin C, 600 International Units of vitamin E, and 18 milligrams of beta carotene. But as of yet, scientists aren't advising people to follow a similar regimen for cataract prevention. "It's premature to jump on those doses" as the answer, says Allen Taylor, PhD, who heads up the Nutrition and Vision Laboratory at Tufts. "The optimum levels are hardly defined."

Many other studies have linked produce-rich diets with lower cataract risk. The same Tufts review that linked leafy green vegetables with protection from macular degeneration also pointed to a 20 percent reduction in cataract risk. And a battery of research from the Nutrition and Vision Project (NVP), a joint effort by Tufts and Harvard investigators that looked at nutrient intake records and cataract formation in women in their 50s, 60s, and 70s, points to antioxidants in general, and vitamin C in particular.

It's a difficult task to tease out exactly which nutrients, in which amounts may be at work in protecting against cataracts. But still, "if you look at the totality of the data, there's general agreement that the antioxidants have benefit," says Dr. Taylor. "But it would have to be long-term, maybe 10 years or so." Since early cataract probably begins at about 45 years of age, people in their 30s should pay attention to their diets-eating plenty of fruits and vegetables. If that's not possible, supplements may be in order.

Glare. Most patients with degenerative retinal conditions usually require bright light to effect the proper amount of contrast to permit them to read at their optimum level. However, high amounts of light usually cause glare, hence, the problem. Gray tints simply darken the entire range of the spectrum. This is great if your vision is perfect and you are a fighter pilot who can't have any portion of the spectrum distorted. Not good, for the average low vision patient. As retinal cells are damaged typically the patient loses a portion or portions sensitivity to certain wavelengths of light. However, all wavelengths are present in sunlight, including those the patient is missing. The rays at these missing wavelengths cause a good portion of the glare the patient experiences, as they aren't absorbed by the cells that are missing and normally responsible for their absorption. Dark gray glasses reduce available light and decrease contrast and as a result decrease vision.

The corning filters are wavelength specific. They absorb the light in the wavelengths that the patient is missing, but permit the other wavelengths to pass through. By doing this they decrease glare and at the same time enhance the relative contrast of the material being viewed. They are definitely worth an evaluation.

Eli Lilly Offers Prescriptions at a Flat Fee of \$12 for Needy Seniors & People With Disabilities Who Are Without Coverage

March 2002 (Newstream) –Reported To VISION ACCESS by Robyn Wallen

Millions of low-income seniors and people with disabilities are caught in a gap between not qualifying for prescription drug coverage under Medicare -- yet not having the financial resources to pay for the medicines they need. The Pharmaceutical Company, Eli Lilly is announcing a new patient assistance program called, LillyAnswers(SM), to help the eligible Medicare beneficiaries gain access to critically needed prescription drugs. The centerpiece of the program is the LillyAnswers card, which allows eligible participants to pay a flat fee of \$12 for a 30-day supply of any Lilly retail drug-- exclusive of controlled substances as well as products not distributed by retail pharmacies. Potential annual savings is \$600 per medication under Lilly's \$12 fee. More than five million Americans are eligible for the program.

Seniors with an annual income below 18 thousand dollars per individual or 24 thousand dollars per household, with no prescription drug coverage, are eligible for the Lilly Answers program.

LillyAnswers will provide eligible Medicare beneficiaries access to Lilly's portfolio of retail products for illnesses such as osteoporosis, diabetes, depression, and schizophrenia -- chronic diseases that afflict nearly 18 million or one of every two seniors. These products include Evista(R) for osteoporosis, Humulin(R) and Humalog(R) for diabetes, Prozac(R) for depression, and Zyprexa(R) for schizophrenia.

Enrollment to the program is free and begins for eligible seniors on March 5, with participating pharmacies accepting the card beginning on April 1. The application process takes two to four weeks after submission of the application. Eligibility will be verified through copies of the applicant's most recent tax return and Medicare card.

The LillyAnswers assistance package also includes educational information for patients through the award-winning program One Care Street(TM). Participants in the program build a personalized information resource, complete with nutritional guidance, exercise recommendations, alternative treatments and medicines, and step-by-step health action guides to help manage their medical conditions.

LillyAnswers enrollment applications are available by calling the toll-free number: 1-877-RX-LILLY. For more information, visit www.lillyanswers.com.

Some Notes from Optometrist

Dr. Marc Gannon, Florida

Vitrectomy—anxious about. Remember minor surgery is on someone other than the Doctor! In actuality this isn't a simple procedure, but one that we have been doing for about 25 years, and the techniques and instruments available for doing it have improved greatly through the years. There is some risk but it has been greatly reduced and the benefits can be substantial.

Corning Lenses. The Corning lenses were developed over 15 years ago for patients with various pathologies that involved low vision. The first filters were the yellow and yellow-amber tints. The company is ever trying to meet the needs of patients with pathologies that affect other wavelengths within the range of the visible spectrum. They do have grays as well as greens and browns. They even have new ranges within some of the older colors, with slight to large shifts in the filtration. The 450 which was originally a yellow has now been recreated in the 450X and the 450 XG. These have very different therapeutic filtration characteristics. Even if you don't like the 450 you should still try some of the other variations. To try these you should put them on inside and then step outside to see how you do with them relative to resolution and glare sensitivity. If you are going to compare more than one while outside, close your eyes when you remove one pair and try on the other to avoid "bleaching" of the functional retinal cells.

**Montgomery County Association
For the Blind
An agency with heart
by Curt Woolford, President
The Woolford Group**

Summary

Montgomery County Association for the Blind is a well-managed and expertly staffed organization. It provides comprehensive services to blind and vision-impaired residents of Montgomery County Pennsylvania. Its staff is dedicated to helping consumers achieve high degrees of independence and to enhancing the quality of their lives.

Overview

Montgomery County Association for the Blind (MCAB) is a private, non-profit organization, and member agency of the Pennsylvania Association for the Blind.

Founded in 1945, MCAB is the only organization in Montgomery County, Pennsylvania, providing comprehensive services to blind and vision-impaired residents. MCAB's mission is to enhance the quality of life of people coping with blindness or vision impairments through education, support, and advocacy, and to strive to prevent blindness through education and screening programs.

"If you've experienced blindness or vision loss and don't know where to turn next, MCAB is 'one stop shopping' for the knowledge, support, training, recreation and path to a quality life," says Doug Yingling, Executive Director.

Services

MCAB provides a wide variety of services tailored to each person's individual needs. Services include orientation and mobility training, home rehabilitation, employment readiness training, social services, support and recreation groups, computer training, and transportation. MCAB also conducts vision screenings, community education programs, and a summer day camp for children with vision impairments.

Employees

Executive Director Doug Yingling came to MCAB over 12 years ago. Under his leadership, the organization has grown considerably to be the successful association it is today. “We have long-term staff members who provide stability to the organization and to the consumer. There is very little turnover,” explains Yingling.

MCAB has 20 employees, including an orientation and mobility instructor, social workers, a computer training specialist, a program director, a prevention specialist, an employment placement trainer, as well as administrative personnel.

Michele Jaffe, Social Worker, enjoys working for MCAB because the agency is so dedicated to people’s feelings. “It is a remarkably sensitive place,” she explains. “There is dedication to insuring that each person’s experience is given proper attention. The staff helps consumers to feel empowered.”

An agency with heart

Lynne Maleeff, Assistant director of the employment program, came to MCAB as a client. She was told that MCAB was the agency with a heart. “People here really care about enriching the lives of visually impaired people. The staff cares deeply,” says Maleeff. When asked what has contributed to the success of MCAB, Maleeff responded without hesitation: “Caring, concern—above and beyond.”

After spending a day on site, it was very clear that MCAB is, indeed, an agency with heart. There was an atmosphere of caring, cooperation, professionalism, and dedication to excellence. With an average tenure of over 10 years, the staff is well trained in providing a variety of essential services to people who are blind and vision impaired. The facility is a well-maintained, well-lit, modern office—a delightful departure from the stereotypical blindness center.

Well managed and well funded, MCAB invests the resources necessary to acquire grants to support essential consumer programs and begin new ones. There is initiative from the Board of Directors, the Executive Director, and staff, to continually move MCAB to the next level, improving current services, and offering new ones.

“We go the extra mile, we take that extra step,” says Deena Laver, Transport coordinator. The transportation services that MCAB provide are no less than remarkable. MCAB will pick consumers up at their door, take them to their doctor, wait, and return them home. Comprehensive transportation services are also provided for consumer job interviews.

MCAB stands out

As an organization committed to growth and new programs, MCAB stands out from other blindness organizations. “Our association has experienced steady growth over the past 10 years. We have worked hard to get new funding. Initial growth spawns further growth,” says Yingling.

MCAB offers individual, customized services, explains Elaine Beard-Hendricks, Certified Orientation and Mobility Specialist. “Our philosophy is to train consumers, through our vision efficiency program, to use the vision they have wisely and efficiently. We never blindfold our consumers. This can be very traumatic to someone suffering vision loss,” says Hendricks.

MCAB mobility training occurs over a year and a half. This is a significant advantage to consumers who can easily become overwhelmed with intensive, agency-based rehab. Considerable training is offered on-site at consumers’ homes. The staff is well educated and trained in the latest rehab techniques, and strives to return people to independent lives. The agency puts no restrictions on a consumer’s goals. A goal could be as simple as getting the paper, or as complex as traveling to Philadelphia. It can involve 20 hours of training or 100.

MCAB also stands out with their Access Technology Program. Technology is playing an increasingly significant role in the lives of the blind and visually impaired. Jule Ann Leiberman, Director, explains that they offer one-on-one training for adolescents through senior citizens. “The expertise and enthusiasm of my training staff enables consumers through access technology,” says Leiberman. Consumers learn an important set of tools that can improve the quality of their lives.

The recreation program stands out as well. "MCAB is dedicated to removing the limitations that may have been imposed upon the blind and vision impaired," explains Jim Hunt, Program Director. MCAB reduces imposed limitations by providing opportunities and training in recreational activities that build confidence. Consumers are taught recreational skills not typically considered within the reach of the blind or visually impaired. These include rock climbing, bowling, and golf.

Words of wisdom for the newly blind or vision impaired

The slower you go, the faster you get things done.

-Michelle Jaffe, MCAB Social Worker

"If you've lost your vision, pretend that you've just been reborn. Sit down and take stock of your past life and then decide which pieces will fit into the new. Set goals and take incremental steps to accomplish them. Then embark on your new journey. It's different, but it's a new and full life," says Yingling.

As the newly blind or vision impaired individual prepares to embark on a new life, it is important for them to get involved in a support group. "Don't do it alone," says Maleeff. "There are so many avenues that are full of hope and inspiration. There is nothing that you can't do—you just need to learn to do it a new way."

A support group is essential for dealing effectively with the great turmoil of feelings that accompany vision loss. These feelings include considerable grief and fear, explains Mary Brucker, Social Worker. Over time, given a desire to learn how to manage home and work, a consumer can learn to do things differently through adaptation. "You can have a full and happy life. In time the overwhelming feelings subside. Social services will help you work through these feelings," says Brucker.

Conclusion

Montgomery County Association for the Blind is truly an agency with heart. Through expert leadership and a dedicated staff, MCAB provides customized services to its consumers. Taking the initiative to procure continued funding, MCAB has been able to offer a wide variety of services and support to the blind and visually impaired.

Montgomery County is fortunate to have such a vibrant and proactive blindness association.

Contacting MCAB

Montgomery County Association for the Blind

212 North Main Street

North Wales, PA 19454

phone: 215-661-9800

fax: 215-661-9888

e-mail: mcab@mcab.org

web: <http://www.mcab.org>

About Curt Woolford

Curt Woolford is a visually impaired small business owner. He is founder and president of The Woolford Group, an organization providing dynamic communications services to small and medium-sized businesses. Services include copywriting, editorial, marketing communications, and market planning. The Woolford Group also provides general communications support for small businesses.

Mr. Woolford has over 20 years business experience, with increasing responsibility and achievements in marketing communications and organizational development. He started The Woolford Group with funding from Blindness and Visual Services. He received access technology training from Julie Anne Lieberman (now with MCAB) at the DELCO Blind/Sight Center, Chester, Pennsylvania.

For more on The Woolford Group, visit <http://woolfordgroup.com/>.

The Theft of Useful Vision

By Bill G. Chapman, Ed. D.

In this country, the earliest rehabilitation programs dealt with the needs of people who were totally blind or deaf. Not long after the colonists felt secure from hostile Indians and starvation, they turned their attention to those who needed help.

These early programs were primarily custodial, providing the essentials of safety, food and shelter. As the centuries rolled by, these programs were improved. New technologies and methodologies developed, so that those who were totally blind could live more productive lives.

When a blind teacher of the blind in France named Louis Braille (1809-1852) developed a means of communication based on a tactile block of six dots, rehab programs for the blind took a giant step forward. When Helen Keller (1880-1968) came along and her story became known, rehab for people who were blind took a mighty leap ahead. The white cane was developed and methods were devised to teach people who were blind to use it.

People who were blind never had it so good. These programs were magnificent; the instructors were dedicated and students were trained and equipped to live productively in a world dominated by print. These programs were great and they still are.

While these programs were being developed, society was changing. By the 1920s many communities began to require children to attend school for twelve years. By the 1940s this was common practice throughout the nation. Once these mandatory education laws were enforced, educators began to identify a new type of disability. There were people who were not blind, but who could not see to read ordinary print. Before mandatory attendance laws, these students simply dropped out of school. They went back to the farm and plowed a straight furrow despite their less than normal sight. People in society began to realize that visual disability comes in many forms. Finally people with partial sight were identified as a unique population who needed special help.

As is the case with most social issues, the government became involved. At the time, the political question was: At what point does a person's poor vision warrant assistance from public coffers? A person with a visual acuity of 20/200 cannot read print in the usual way. SO 20/200 became the standard for measuring visual disability. Those with a visual acuity of 20/200 or worse were labeled "blind." These people had mobility vision. They could walk wherever they wished without a white cane. They could see the sunsets. They could play football and other sports, yet they were classified "blind."

The difference in the ability of people with partial sight compared to those who were totally blind was obvious, so a way of distinguishing between the two groups was needed. The term, "blind," came to be used to designate the people who were totally blind and those with minimal light perception. Those with partial sight were said to be "legally" blind.

The distribution of people who are totally blind and those who are partially sighted is interesting. Today among the people classified blind and legally blind, 6% are totally blind, 19%¹ are said to have minimal light perception (MLP) and 75% fall into the group called legally blind or partially sighted. These figures² surprise many people because before about 1970, the bulk of the money spent on rehabilitating the visually impaired was spent on people who were totally blind. Do not misunderstand. I do not resent this, nor do I place any blame on those who are totally blind for this inequity. I simply point to this as one of the reasons why rehabilitation of people with partial sight has lagged so far behind rehab of people who are totally blind.

The next step in this story is where things began to go wrong for people with partial sight. Here we have millions of people who are classified "legally blind." They need help but what should we do for them? The answer was right there staring decision-makers in the face. We had rehab centers for people who are blind. These people were classified "blind" so they were sent off to rehab centers for the BLIND where they could learn to live like blind people. They went down the tube into a mold designed to meet the needs of people who are totally blind.

People with partial sight were taught Braille, the communication skill used by people who are blind. Braille is larger than print so many of those with partial sight could see the dots with their eyes. To assure that they did not cheat and read with their eyes, they were given blindfolds. They were given blindfolds to learn how to use a white cane because it was one of the "skills a person who is blind should know."

A hundred years ago, eye care professionals and others began to develop special technology and aids to assist those with partial sight. This was the beginning of VISION rehabilitation where people with partial sight were taught and equipped to function SIGHTED, using their residual vision. For example, in 1926 Dr. William Feinbloom developed telescopic glasses. Since January 1971, I have used these telescopic glasses to drive 700,000 miles despite the fact that I am legally blind. Today, with VISION rehab rather than BLIND rehab, most of those with partial sight can be trained and equipped to function as SIGHTED. Almost all of the people with a visual acuity of 20/800 or better can be helped dramatically when they receive VISION rehabilitation. Even those on the severe side of visual impairment (20/800 and worse) can be trained to use the vision they have to function far better than they ever will under the restraints of BLIND rehab alone. For example: I personally tested a man with brain damage who could read with a closed circuit TV (CCTV) reading machine using his residual vision. His visual acuity was 1/700 or 20/14,000.

VISION rehab had its beginnings in doctor's offices where dedicated men and women, now called Low Vision Specialists, painstakingly trained and equipped people with partial sight, legally blind, to function SIGHTED. Most of these doctors were optometrists but a few were ophthalmologists.

During the 1970s and 80s VISION rehab took off like a rocket. When people who had received VISION rehab were around people with partial sight who had gone through BLIND rehab, differences in their performance were painfully obvious. Example: In 1977, a counselor in the Texas Commission for the Blind asked me to come to Houston to evaluate one of his clients in the use of a CCTV. The counselor was stunned when he learned that I had the same retinal disease and the same visual acuity as his client. As he put it, "My client is nearly helpless; but with the same disease and the same visual acuity, you drove 550 miles by yourself to evaluate him. Something is wrong."

VISION rehab has literally encircled the world. It is being used in most progressive countries. Nevertheless, not everyone is convinced. A group³ of people still insists on teaching Braille and the white cane, using blindfolds to block out useful vision. It pains me to admit that in my own state of Texas, the Commission for the Blind has apparently aligned itself with this group who insist on training methods that lost their validity thirty years ago--if they ever had value. This change in TCB policy was made several years ago but I have just become aware of it.

I do not understand the philosophy of this group. I can only believe there is a hidden agenda driving this policy. They say their only interest is the client's welfare. I have exchanged e-mail with Mr. Terry Murphy, Executive Director of the Texas Commission for the Blind (TCB). I have talked to Ms. Juanita Barker, Regional Director of the TCB in Lubbock, TX. I have talked with Ms. Barbara Madrigal, Deputy Director for Programs with TCB, who is in charge of a program they call "The Texas Confidence Builders Initiative." The program in a nutshell proposes to build confidence in clients by teaching them Braille and use of the white cane, using a blindfold if they have partial sight. The philosophy is that if clients learn Braille with a blindfold, they will have confidence they can survive if they lose all vision later. This is the rebirth of a philosophy that existed 30 years ago. I thought it was dead.

Let me tell you about the experience of Carl Foley, my friend for 25 years and current Board Member of the Council of Citizens with Low Vision International (CCLVI). Carl reports that in 1972 he went into BLIND rehab at Hines, a VA facility in Chicago. Before his arrival, Hines used the blindfold on everyone. When Carl arrived, Hines was switching to a dual training program, separating those who were totally blind from those with partial sight. Carl, being partially sighted, wore the blindfold only one day a week. On those days he was taught Braille and the white cane. He admits that learning Braille raised his confidence. Carl said:

I learned that I could survive if I went totally blind. However, use of the blindfold for instruction with the white cane had the opposite effect. Letting me use my vision and giving me a CCTV and other low vision aids is how they really helped me. Then my association with other successful low vision people, like you, gave me the confidence to be a success.

If Carl had been taught that people with his diagnosis NEVER lose all their vision, he would not have needed Braille to give him confidence.

There is no way I could have said it better than Carl. With BLIND rehab Carl was convinced that he could SURVIVE. With VISION rehab he had confidence that he could achieve SUCCESS and he did. All the years we were fellow-distributors for Visualtek, later called VTEK,--a company that produced and marketed CCTVs, Carl was one of the top three producers for the company. He was a leader at VTEK and he has gone on to become one of the prime leaders and movers in CCLVI.

What is wrong with blindfolds and the TCB Confidence Builders Initiative? When TCB staff members describe their program, it sounds great if you are not fully familiar with this field. Nonetheless, the program is fatally flawed and an abomination of horrors for people with partial sight. Consider these flaws, and remember that I am talking about people with partial sight only, not those who are totally blind.

1. All clients who go to Criss Cole Rehab Center for the blind in Austin are required to sign a contract (my word, not theirs) to conform to rules of behavior during training with the stipulation that those who break the rules will be dismissed. Alcohol, drugs, and sex are forbidden. And mixed in with these conditions of training is the fact that blindfolds will be used. I have a reliable report that two veterans who were visually impaired read these conditions and refused to submit to the use of blindfolds. So their efforts to get training were short circuited before their applications could be submitted.

2. The fact that all clients regardless of diagnosis must use blindfolds totally ignores the scientific fact that many eye diseases will NEVER blind a person to the extent that they will need Braille or a white cane. Of course, there are diseases that lead to total blindness, but not all do and TCB treats them all the same. This is not a direct quote, but the information comes directly from the Director of the program. One's diagnosis is not a consideration when it comes to the use of blindfolds at Criss Cole Rehab Center.

3. All clients go down the same tube. All receive the same training regardless of their individual needs and requirements. I suppose this is less costly and far less trouble for the staff. These could be the main reasons for these policies..

4. As explained in the paragraphs above, this program teaches those with partial sight survival rather than success.

5. People with partial sight should be trained apart from those who are totally blind. The ideal would be to have different facilities, but there are budget constraints. This may never happen, but the two groups must be separated and treated differently as was done at the Hines VA Center thirty years ago. The training objectives are different for people who are totally blind and for people who are the partially sighted.

6. In a facility for BLIND rehab, the person who is blind is the role model. He or she is the one all clients are urged to emulate whether this is taught directly or implied by example. When people who have partial sight are given BLIND rehab they are conditioned to think of themselves as blind; after all, the people who are supposed to know taught them Braille. Their minds are not expanded to realize that they can function more independently by using their residual vision and low vision aids. Another example: In 1973 I visited a mid Atlantic state BLIND rehab center. A client there had in his pocket magnifying spectacles to use for reading. He had brought them with him when he came to the facility. I watched him for three days. Not once did he take his glasses out of his pocket nor did staff members encourage him to use them. I watched him struggle with tasks that would have been simple if he had used his glasses. He was being trained to be blind, not sighted.

How do we divide clients into those who will receive BLIND or VISION rehab? "This," as the English say, "is a sticky wicket." I will admit that there are shades of gray here when it would be

easier if there were fixed parameters. I will give standards that I personally believe should be followed.

1. Clients with no light perception should be given BLIND rehab.

2..Clients with Minimal Light Perception (MLP) should be given BLIND rehab. Only a qualified Low Vision Specialist should make the diagnosis of MLP. 4

3..The partially sighted: Two different groups exist.

A. Those with a disease like macular degeneration that will NEVER destroy all vision should be given only VISION rehab.

B. People with a disease that carries the probability of destroying all vision: This is the gray area I mentioned. People with diabetic retinopathy and retinitis pigmentosa (RP) certainly face the potential of total blindness, but the probability is that this will come later in life. An orientation course in Braille might give them the confidence that they can cope even if they lose all vision later; but I am convinced that these people should receive VISION rehab first. Later, give them BLIND rehab when and if they need it. In the meantime, teach them vision skills to maximize what they can see and do until they actually need BLIND rehab. A part of the sticky wicket here is the RP patient. Often before peripheral vision is gone, they experience night blindness. If they are to avoid being shut in at night, they need mobility training.

The funny, strange, inconsistent and ridiculous thing about this "mess in Texas" is that the State of Texas licenses people who are partially sighted to drive with telescopic glasses. At the same time the Criss Cole Rehabilitation Center puts blindfolds on these people and teaches them Braille. We sometimes say it is better to laugh than cry. This is too serious to laugh, so I am crying.

1 Note that charts used in testing visual acuity and the way they are used by eye care professionals are so flawed that most people classified MLP (the 19% group) actually have a testable visual acuity and an unknown percentage of them should be in the 75% group. Example: An eye test chart has letter sizes of 400, 200, 100, 80, 75,70, etc. When a person comes in with a TRUE visual acuity of 20/210, the doctor shows him the 200-size letter. He cannot read it, so the doctor gives him the next sized letter on his chart, the 400 size. The doctor then reports this person's visual acuity as 20/400 instead of 20/210.

2 Different writers use different percentages. While working for the Department of Health, Education and Welfare, The Social and Rehabilitation Service, Region III, Philadelphia, I talked to the head of Rehabilitation Services about the percentages above. He confirmed that these figures were consistent with his knowledge and experience.

3 When I began writing this article, I talked to four people who are knowledgeable about vision impairment and blindness. When I mentioned my concerns about blindfolds being used, each of the four said the same thing. "That sounds like the NFB, the National Federation for the Blind, not to be confused with the American Foundation for the Bind established by Helen Keller. I am not familiar with the policies of the NFB, but if this does reflect their policies, it is clear that I do not agree with them.

4Most people, including those who work in rehabilitation, do not realize it but many optometrists, and even ophthalmologists do not know how to test the visual acuity of people who are worse than 20/80. This statement opens a bucket of worms and I do not have space here to cite examples, but it is true. See Endnote No. 1

above for an explanation of part of the problem.

Features

Member to Member

Visually Impaired and Dating

By Charles Gourney, Ph.D., MT-BC

Among people who are visually impaired or who have any kind of disability, a particularly sensitive topic is social life and dating. This is an area loaded with ambivalence. We want to be accepted like everyone else, but may suspect that our options are limited because our physical limitations make us

less acceptable to others. Often today people seem to be shopping for perfection, and this can make us feel very uneasy. So the question has come up: Should we mention our visual limitation to the person we are dating? Is it better to be "found out" sooner or later? Here are some of the comments that were shared on this topic by members of WGPS listserv for people with low vision:

One person brought up the question of admitting to dates that she has a vision difficulty. Obviously, she sees very well for a person with low vision, but still not well enough to drive, read textbooks, etc. So what does she say to guys? Should she tell them before they ask her out, when they ask her out the first time, on the third date.... You get the point. Here are some responses to these questions.

* * * * *

The person who wondered when she should tell her dates she had a vision problem brought back memories for me. I am a high partial, and many people don't notice I have a vision impairment. I remember in my late teens and early twenties agonizing over when, how, and if I should tell my dates I had a vision problem. I was very insecure about my vision impairment then and often tried to hide it as much as possible. It is wonderful that you have organized a support group for people with low vision. I wish I had access to a low vision support group when I was growing up. Perhaps I wouldn't have felt so insecure about my vision impairment.

* * * * *

I haven't been on the dating scene for a long time. But if I started dating again, I would look for an opportunity to mention my vision impairment at least by the second or third date. For example if we went to a movie I would mention that I need to sit near the front of the theater because my distance vision isn't good. I wouldn't go into a lot of detail at first, unless he asked some questions, and I felt comfortable talking about my vision impairment in more detail with him.

* * * * *

Personally it took me years to learn this but I am finding more and more that if I am up front about my vision problem right away people tend to be more accepting. I carry my cane now and if I am asked I answer the questions they have; then I just drop the subject and let things go where they may. I find if I do not make a big deal out of my vision other people do not either. I waited many years to learn this lesson. At least this way when I do something weird like walk into a wall or misread a sign people do not think I am a nut, they know what the problem is.

* * * * *

About the dating issue, I think honesty is by far the best policy: by not being pretentious in any way, by not hiding from your true self, and by saying to the world, "This is the way I am. Understand it and love it, or go on your way." This way you will be totally upfront and you will attract those to you who are interested in your heart, not in what you look like. The others have no worth to you.

* * * * *

Although I do agree, as long as you are honest, why is it necessary to begin a meeting with someone new by saying something like, "Are you sure you want to go out with me?" I didn't mention it, but I'm legally blind. I did not use a cane then, I did not need it. And, also, I was seventeen and self-conscious about my sight and tried to hide it when possible.

* * * * *

When I was high partial, I was barely legally blind. People could know me for quite a while and not know. They might think I needed glasses for reading, but that's about it. You have to remember that the public does not think of blind or any variation of blind unless they are told. That is, unless it is obvious. My ex-husband, being very British, would say something like, [she] is a bit short sighted - whatever that means (grin).

* * * * *

I must admit this topic rather confuses me. Unless one's condition is progressive, I think it would be pretty hard to hide one's visual impairment from another person who (hopefully) is really paying attention to you. It's true I meet a lot of clueless people on the street who can't figure out that I'm visually impaired even when I'm carrying my cane. But in a dating situation, if my partner didn't notice

it, I think I'd look for another partner. (Unless of course the reason was that she is visually impaired herself! <smile>)

* * * * *

(Comments from readers are welcome; please send them to [Editor Vision Access etc.] Anyone with internet access who wishes to join our group may do so by visiting <http://groups.yahoo.com/group/wgps/>. Please introduce yourself when you join so that we may welcome you properly!)

Write Now! Starting a Personal Journal **By Mike Vogl, Elm Grove, Wisconsin**

Have you ever thought of keeping a diary? Have you ever begun writing in a diary and found it daunting or too time consuming, and then given it up?

I would like to outline some benefits of writing a diary, which I prefer to call a journal, and give tips on how to start, and encourage all--especially people with low vision--to begin.

First, to dispel a common misunderstanding about keeping a diary or journal, your entries do not have to be daily! A daily "must do" becomes a chore and is soon given up. Journal keeping, although a task, should be a rewarding one. Having your notebook handy and writing when time and the spirit dictate, or when you have an event or thought you wish to remember, is the way to go. Of course, the more often you write, the better. Beginners sometimes find writing at regular intervals helps establish a pattern of writing.

A journal, beside a day-to-day record of events, can also be a recording of thoughts, ideas, reactions and feelings. We keep journals for a variety of reasons. Some are:

1. To record travels such as vacation or business trips, to remember where we went and what we did.
2. Phenology, which is the recording of natural happenings such as weather patterns, the date of the first robin of spring, the date our tulips bloom, the first day the crickets started chirping, etc.
3. Memories of family events, especially of the progress of children, their first words, first steps, funny things they say, achievements, etc.
4. To resolve worries and problems, to solidify opinions, to express feelings, to ease tensions, to lessen depression and loneliness. This is probably what most people perceive as the main reason for journaling.
5. To keep memories of things we've heard or read that are meaningful or strike a note with us.
6. Writers who want to be published keep journals to capture experiences that might later spark ideas for articles or books or poems. Diaries are to writers as sketchpads are to painters.

These reasons in themselves indicate many of the benefits of keeping a journal. I suspect all or many of the above reasons motivate most journal keepers.

While I was a journalism student, a professor devoted a class to explaining the value of journal keeping. Besides being an excellent way to practice writing, journaling hones observational skills and gets thinking. A journal can be an incubator for future writing projects.

The professor, being an unusually empathetic teacher, took me aside and told me, as a person with low vision, that keeping a journal was doubly important for me. "There is a Chinese proverb," he said, "that says, 'I hear and I forget, I see and I remember, I write and I understand.' Because that second element of 'seeing' is reduced for you, writing about experiences soon after they occur, including as many details as you can, will help you remember them."

It is an important lesson, not just for journalists, but for all with low vision. Since we lack the lasting imprints vision can make, writing helps us remember. "All life is an accumulation of memories," Leo Buscaglia said. Rereading journals and enjoying memories is to live twice. What we do, or did not do, is who we are. Writing allows us to fulfill the need we all have to establish a thread in our lives. Benjamin Franklin said, "The thing most like living one's life over again seems to be a

recollection of that life, and to make that recollection as durable as possible is by putting it down in writing.”

Keeping a journal can be important for us who have low vision for another reason. We often struggle with complex negative feelings related to our impairment. Journaling about these feelings can lead to understanding and perhaps acceptance.

Journal keeping allows, in future review, the rediscovery of those surprising moments of past days that give a boost to feeling alive. Recording your thoughts, of course, is no guarantee that you will live better in the future, but it will convince you that you can survive the twists and turns of life by doing your best in making decisions. There is no need to try to overcompensate for past mistakes, for then we might miss the miraculous part of life, which is, as our journals will show us, that life happens amid the patchwork of happy and sad moments, the difficult and easy, the adventure and the routine.

How does one start journaling? Today there are options other than writing your journal in a notebook. Composing on the computer and saving your writings on disks is one way. Having a voice readback program is wonderful for those of us with low vision. Voice tape-recording your journals is another option.

I personally use ring binder notebooks with loose-leaf pages. I can write as large as I need for easy rereading. Or if I compose on a computer, I include a printout in the binder. This also allows me to paste in photos or clippings and quotations; after all a journal can contain more than just one's own words.

Beginners sometimes wonder, “How do I start? What do I say?” One positive way is to think of something from the past day, or week, that you are grateful for, e.g. a phone call from a friend, the feel of warmth from the sun on your face. etc. Or you can start off each log with some of the things you did since your last entry. Or write about your feelings at the moment. Or discuss an item in the news. Or list things you have accomplished, or list things you would like to accomplish during the next day, month, year. Start with a remark you heard on the Oprah show or from the sermon at church. Write about your family. If you have children, write about them. Someday you will be able to share these memories with your adult children and this will be a most enduring gift for them.

Or write about your own childhood memories, past vacations, holiday traditions. Start a dialogue with yourself, or compose a letter you won't send to a friend, your child, a teacher, or a deceased loved one. Writing about problems or crises you face sometimes can help solve the problem or decrease the worry. After a crisis is over, ask yourself, “What did I learn from this experience? How has it made me grow?”

“Brainstorming” (writing all possible solutions to a problem without passing judgment on them) and later going over them, can spark an answer.

It is important not to edit your journals as you write them. Let your thoughts and words flow. The process really matters more than the finished product.

A journal is a safe place to try your hand at poetry. Compose prayers. Save quotations and jokes you've heard, or a line from a song. Write about those who influence you most, about when you are happiest, or which of your talents you're proudest of, or what you did today you are pleased with-- things that will help you write and learn about yourself.

I hope these suggestions will encourage you to begin keeping a journal. At the end of a year, you will get great satisfaction out of seeing where you've been and how far you've come. Even if there were no great adventures or illuminations, you will find that life is full and the journey is as important as arriving.

Recording our dreams or changes we wish to make in our lives can be a first step to making these dreams or changes a reality. A journal makes us realize that we all have our own story--and that it is worthwhile! When you are having tough times, it can be therapeutic to go back over your logs and see how you survived and made progress in the past. Everyone has inner wisdom which often gets lost in everyday pressures, but often becomes evident in reflective writing. Journal keeping lets us tap into this inner wisdom. As Catherine Drinker Bowen says, “Writing is not apart from living. Writing is a kind of double living.”

My wish for you in journal keeping is that the good memories outnumber the bad, and that you seek and find many things in your life for which to be grateful, for a life of gratitude is a life of happiness.

Write on!

People

Meet Joseph J. Neff

Shedding Light on Glaucoma

Reprinted with Permission from Rotarian Magazine

I have always been very healthy and active in all areas of my life. I am the proud father of four children (and now grandfather of 10), a registered professional mechanical engineer, a licensed private investigator, a licensed commercial pilot and a Rotarian. I have traveled the world, walk four miles a day and enjoy tennis.

In mid 1994, at age 59, I started to have problems with my vision. There was no pain, only some fuzziness and blurriness early in the morning and late at night. I simply thought that I needed a change in the prescription of my glasses. When I went to the ophthalmologist to be evaluated, I was stunned by the diagnosis: advanced glaucoma. I was even more shocked because I had dutifully gone in for my annual eye exams, including the eye pressure test for glaucoma, since the age of 30.

Glaucoma is known as a "silent" eye disease because you often do not experience any pain or symptoms until the damage is done. It is the third largest cause of blindness in the world, according to Sight Savers International in England. More than 5 million people are blind from the disease, with more than 100 million suspected cases, most of them in the developing world. Glaucoma is a leading cause of preventable and irreversible blindness in the United States, especially among high-risk groups such as African-Americans, those over 60 and diabetics.

The ophthalmologist informed me that the disease had destroyed most of my optic nerve, leaving 20/25 central vision but less than a 10 degree field of tunnel vision. In short, he told me, I was "legally blind" in both eyes. (The definition of "legal blindness" is worse than 20/200 with glasses or vision with less than 20 degrees field of view.)

At first, I experienced fear-then anger. Then came the question, "Why me?" To my knowledge, I was not in a high-risk group for glaucoma. One specialist told me that I would be totally blind in six months to two years. My immediate reaction was to learn everything that I could about my condition, and to do anything I could to save my remaining vision.

Through my research, I learned that treatment may prevent additional vision loss, but it can't regain lost vision. For now, there is no "cure" for optic nerves damaged by glaucoma, but there is prevention. My form of glaucoma, called "normal pressure" or "low tension," is experienced by 45 percent of all those who have glaucoma. This condition is particularly dangerous because there are no early warning signals. Those who do not receive treatment experience a gradual loss of side vision (tunnel vision) until they go totally blind.

Until recently, many ophthalmologists believed that the intraocular pressure test (often called the "puff of air" test) would detect glaucoma, but this is true in only about 55 percent of the cases. For the other 45 percent-like me-the intraocular pressure is normal. The damage can be detected by administering visual field tests.

I aggressively treated the disease both through surgery and medication (daily eye drops). However, the surgeries to reduce intraocular pressure caused even more damage. One procedure on my left eye (my "worst" eye) resulted in a cataract because of the sudden increase in intraocular pressure. A second surgery on the same eye caused the total loss of intraocular pressure, which resulted in a folded retina and permanent double vision, as well as the eyelid drooping over the iris. A lens replacement eliminated the cataract, and a portion of the top eyelid was surgically removed to prevent the drooping that blocked vision. Further surgical corrections and steroid injections into my left eye returned vision to 20/60. In addition, the muscles of my right eye were surgically

repositioned in an effort to compensate for the double vision. I also wear special prism glasses that partially compensate for this problem. (I should mention that only 5 percent of all patients experience the complications that I did. The other 95 percent usually have successful surgery.)

Since 1994, I have suffered some additional vision loss, but the brain has an uncanny ability to adapt, so fortunately I can still perform most activities with my remaining vision. Today, I have sufficient vision left to lead an active life. Unfortunately, my employer at the time feared the risk of liability if I continued my position as vice president and chief engineer at a California corporation, so I was forced to retire in February 1995. I then teamed up with my wife, Judie, to launch our own company. We are technical consultants who determine product failure causes on trucks, buses and motor homes.

I feel that the support of family and friends, along with perseverance and self-determination, plays a key role in adapting to disabilities. My wife has continuously challenged me to do whatever I feel I can do, even if there are some risks. For example, I had an opportunity in April 2000 to be a passenger on the aircraft carrier Enterprise, courtesy of the U.S. Navy VIP program. And while I can no longer catch a baseball or toss a football, I still visit and play with my 10 grandchildren who live in three states. I also feel it is important to stay active physically. My wife and I walk four miles (about 6.5 kilometers) daily in a neighborhood park and play a modified form of tennis. I also still ski downhill and cross country in the winter. Since my condition was diagnosed, we have traveled to 15 countries, including Kenya, Tanzania, Australia, New Zealand and Fiji. We love hiking and I continue my hobby of photography.

In addition, I am active in other areas of my life. If you have a positive outlook, a disability does not have to limit your activities. I currently volunteer as a member of the speaker's bureau of the Glaucoma Research Foundation based in San Francisco. I feel it is important to speak to senior-citizen groups about the importance of early detection and treatment of glaucoma. I also inform them of organizations that will arrange a free comprehensive eye exam by a volunteer ophthalmologist.

I have been a member of the Rotary Club of Brownsburg, Ind., USA, for four years and serve as the chairman of our Vocational Service Committee. I have spoken to three Rotary clubs on the importance of the early detection and treatment of glaucoma. I continue my volunteer effort to counsel eighth-grade and high-school students on technology careers. And for the last 20 years, I have volunteered as a member of the Society of Automotive Engineers, reviewing about 50 technical papers each year prior to publication.

I have learned that glaucoma is most likely caused by abnormal genes that were present in a parent or grandparent. You may be more prone to glaucoma if you have had a severe eye injury, but that is not the usual cause. You cannot develop glaucoma by reading in poor light, by wearing contact lenses or by having an improper diet.

According to the Glaucoma Research Foundation, as many as 1.5 million Americans are losing their sight because their condition has not been diagnosed. Since glaucoma is genetically based, certain groups are at higher risk for contracting the disease. Glaucoma is the number-one cause of blindness in African-Americans. This group is five times more likely to develop the disease and four times more likely to go blind. It is unfortunate that the group that is often least able to afford the costs of early detection and medical care is the group with the highest genetic risk.

For those in high-risk groups, glaucoma tests should begin at age 35 to 40, and continue every two years. Since age increases the risk of glaucoma, those over 60 should have an annual glaucoma exam. The exam is painless, takes minimal time and should include an eye pressure test and dilation of the pupil to examine the optic nerve.

I am very pleased that RI President Frank J. Devlyn has made the health issue of avoidable blindness a priority this year. As Rotarians, we can Create Awareness And Take Action by educating the public-and ourselves-on the prevention of blindness through early detection and proper treatment. Rotary clubs can also sponsor medical clinics that offer free glaucoma screenings and provide medication for the elderly and disadvantaged. People in the United States who have Medicare (government subsidized healthcare) must pay 20 percent of their own doctor costs and 100 percent of their prescription costs. This may be prohibitive for those without savings or a steady income. For

example, my medication (three types of eye drops and an oral experimental drug) and special prism glasses cost \$2,500 each year. Rotarians can also provide jobs and training for those who have disabilities related to degenerative eye disease and other conditions.

Despite my limited vision, I can still read-and in fact, I eagerly read two daily newspapers and 60 weekly and monthly technical, business, and general-interest publications. I have tried my hand as a freelance writer on a number of subjects, including this one (the prevention of glaucoma). So as you can see, having a disability does not mean you have to limit your life. It only means that you have to learn to adapt accordingly to accomplish many of the same goals.

So how can you help? Ask your family, friends and co-workers: "Have you had a glaucoma exam recently?" Create awareness at your workplace by distributing information and encouraging employees to visit an ophthalmologist on a routine basis. Work through your Rotary club to provide free glaucoma screenings and medications to the disadvantaged in your community.

Because my condition was not caught in time, total vision loss is likely. Today, I have only about five degrees of central vision. I have taken steps to learn Braille and become familiar with computers that assist the vision-impaired. But for now, I can still ride my motorcycle (on country roads), read to my grandchildren and travel the world. (We want to go hiking in France for our next vacation.)

With early detection and today's medications and surgical techniques, blindness is not inevitable for people with glaucoma. With proper medical attention, you can stop or slow the deterioration. Many medical researchers have recently confirmed that surgery and medication will reduce the intraocular eye pressure and delay vision loss for those with "normal pressure" glaucoma.

When I learned that I had glaucoma, I immediately informed my family and urged them to get tested. All my brothers and sisters were screened for glaucoma. And in the process, we learned that my oldest sister suffers from the same condition. Thanks to early detection, her vision loss is not as severe as mine.

There are many important questions in life. But one of the most important may be: "Have you had a glaucoma exam today?" It may make the difference between a lifetime of sight-and a lifetime of darkness. You can make that difference.

Gifts and Bequests to CCLVI

Financial support for all of CCLVI's programs to assist people experiencing vision loss is always needed and gratefully accepted. If you would like to remember CCLVI in your will, you can do so by including a statement reading, "I give, devise and bequeath unto the Council of Citizens with Low Vision International, a not-for-profit charitable organization, the sum of _____dollars, or (real property, personal property), to be used for its worthy purposes on behalf of people experiencing vision loss." If your wishes are more complex, you may have your attorney communicate with our Washington office. A friend or a relative may wish to know about these opportunities also.

Gifts can be made at any time and are fully tax deductible. (Tax I.D. 1317540).

Resources

American Academy of Ophthalmology,(415) 561-8500

American Foundation for the Blind

11 Penn Plaza, Suite 300

New York, NY 10001

Tel: 212-502-7614

Fax: 212-502-7770

www.afb.org

Email: Lgreco@afb.net

www.afb.org

CCLVI Chapters

Delaware Valley Council, 215-735-5888.

Florida Council of Citizens with Low Vision (1 800 267-4448)
Metropolitan Council of Low Vision Individuals lsanborn@rr.nyc.com; by mail at MCLVI, Suite #1F,
357 West 55th Street, New York, NY 10019-4525; and by phone through the CCLVI toll free number,
800-733-2258.

National Capitol Council of Citizens with Low Vision, ncclv@yahoo.com.
Lighthouse International, (800) 829-0500
LillyAnswers
1-877-RX-LILLY.
www.lillyanswers.com.

Montgomery County Association for the Blind
212 North Main Street
North Wales, PA 19454
phone: 215-661-9800
fax: 215-661-9888
e-mail: mcab@mcab.org
web: <http://www.mcab.org>

National Eye Institute
2020 Vision Place, Bethesda, MD 20892-3655,
301-496-5248,
877-LOW VISION,
or visit www.nei.hih.gov

WGPS
<http://groups.yahoo.com/group/wgps/>

The Woolford Group,
<http://woolfordgroup.com/>

CLVI NEW, RENEWAL, AND DONOR APPLICATION
(Tax I.D. 1317540)

Name _____
Address _____
City, State, Zip _____
Home Phone _____ WorkPhone _____

Circle one: I am a

Low Vision, Blind, Normally Sighted Person.

Circle one: I would like VISION ACCESS in
Large Print, Tape, 3.5" Disk.

___ \$10.00 Individual or Family (U.S.)
___ \$25.00 Agencies, Organizations, Clinics, & Health Care
Professionals
___ \$150.00 Life Membership (May be paid in 3 \$50.00 installments)

Donation To:

\$___ Carl E. Foley Continuing Education Fund
\$___ Fred Scheigert Scholarship Fund
\$___ VISION ACCESS Publication Expense
\$___ 800 Help Line Expense

Mail this application and check or money order to,

Bill Burgunder, Jr.
CCLVI Treasurer,
3252 Faronia Street
Pittsburgh, PA 15204