

VISION ACCESS

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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.

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From the Editor

Welcome to the first issue of VISION ACCESS following CCLVI's annual convention in Pittsburgh. Reports of convention program presentations are a big part of this issue. If you were there, this will be a nice review. If you were unable to come to Pittsburgh, this issue will share some of what we learned with you. Before our convention, Robyn Wallen, a founder of the Working Group for the Partially Sighted listserv, wrote

about what the convention experience means to her. Many people will probably agree with Robyn. Here is what Robyn said:

"I was asked why I like to go to convention and it got me thinking.

"I do not go for the politics or the information as much as I go for a different reason. I know a lot of what we talk about in general sessions--although the last year brought any new surprises, and I have seen most of the adaptive equipment (although I am glad we are moving from a zillion and one CCTV models to things that are more useful like talking Rx and talking signs). But there is something there you cannot get anywhere else."

"That something came to me big time as I sat at church last night with all sighted people and thought about working with all sighted people and how, because of my software issues, everyday is a struggle for me socially and in so many other ways.

"What I love about convention is for that one week a year the world is ours. The world is geared to us. Everything is for people with low or no vision and we are the majority and not the minority. We are the culture of the week. There is large print and braille, talking signs, and strips on stairwells to let us know there are stairs. There are no grease boards or overheads. There is just us functioning in our own little society for that week.

"It is like a break in the big scheme of things where we are equal and we do not have to struggle to prove anything to anybody. It is a break for the mind and the spirit."

Thank you, Robyn. And thanks to everyone who contributed to this issue of VISION ACCESS.

Enjoy this issue and send your own contributions and suggestions to the editor.
JMK, 7/28/03

Organization News

President's Message

By Patricia M. Beattie, Alexandria, VA
pbeattie@nib.org

Vision Access readers are in for a treat! Our editor, Joyce Kleiber, has done a terrific job of reporting on all of the latest information in the field of low vision which was presented at the various educational sessions of CCLVI's 2003 convention in Pittsburgh. We know that these articles will make you begin planning now to join us next summer in Birmingham, Alabama where you also will be able to browse the latest in technologies and other products at the exhibit hall. Most of us find it as exciting as we felt when we were kids in the candy store! And it is so invigorating to be with hundreds of other folks who are living life with low vision - and willing to share ideas and experiences.

Once again, we owe a huge bouquet of virtual posies to our first vice president, Bernice Kandarian, who coordinated arrangements for all the convention program sessions. Helping out with great enthusiasm were Charlie Glaser and Barbara Kron with Game Night, Jane Kardas or her session on low vision services around the world, and all the experienced help of immediate past president Ken Stewart. A special thanks to Carlos Gourgey who conducted two peer support sessions and to Joyce Kleiber and all of the Project Insight volunteers from across the country who attended a workshop at our convention about this Project. They so willingly receive calls from those of you experiencing new or aggravated vision loss when you wish to talk about what that means in your life. Another past president, Coletta Davis, chaired both the opening night and post-banquet dances featuring the professional music of Gordon Kent.

Another big thank-you goes to Barbara Kron and the folks who put on the Sunday afternoon mixer that gets better every year.

Mike Godino cranked up his computer to develop our budget and resolutions on political issues and another past president, Michael Byington, helped us revise our constitution.

We missed seeing Janis Stanger, chair of our scholarship committee, but were pleased to see another past president, Carl Foley, and Fred Scheigert, founder and benefactor, respectively of our two scholarship funds.

We are pleased to welcome two new members elected to the board of directors:-- Angela Hadbavny and Jerry Weinger.

If you were among the convention attendees and wish you had a chapter in your local community, please be in touch with us at 1-800-733-2258. We know of interest in developing chapters in Seattle, Austin, Baltimore, and Memphis. Or if you are active in a state affiliate of ACB and would like some assistance in putting together a program session or support group for members with low vision, let us know how we might help. As you see from the reports of all of the wonderful speakers who all came to us without a stipend, we have many friends in the field of low vision with whom we could put you in touch. Our session on genetics was particularly fascinating for people who thought their condition was very rare - and found several others with the same diagnosis in the same crowded room! You may be surprised to learn how much more that researchers have learned about your specific condition - and that what you were told several years ago or when you were a child may not be true. I know that my grandchildren, Isaac, 6, and Phyllis, 4, will soon be asking whether their eyes also will get to be like mine. We still don't know. But for many of you, the information now is available. Enjoy this convention issue of Vision Access - and we look forward to seeing you at chapter meetings, new groups, in support groups, and at next year's convention.

Chapter Reports

California Council of Citizens with Low Vision

We are planning our fall state convention. Our chapter will meet at the Crowne Plaza LAX from October 16 to 18, 2003. Call 800-733-2258 for more details.

Delaware Valley Council

Our leadership team will meet in August to plan meetings for the coming season. For information call 215-835-5888.

Metropolitan Council (New York and Northern New Jersey)

We will meet in early September at 110 Williams Street in Lower Manhattan, just above a major subway interchange. Much of our agenda as usual will focus on advocacy issues. For more information call Ken Stewart, President at 845-986-2955, or email Isolde Keilhofer, Vice-President.

National Capitol Council:

National Capitol Citizens with Low Vision ended their spring 2003 season with two superb meetings.

In April, Dr. Phyllis Burson, Psychologist from Silver Spring, Maryland, presented ideas and led a discussion about "Vision Loss and Family Relationships." People responded so well to the practical tips and real experiences involved in parenting active toddlers and challenging teens that the meeting lasted one hour longer than planned.

People who asked the question "Can I be a good parent if I have low vision?" came away with a confident "Yes!"

In June this Chapter met at Rock Creek Park in Washington D.C. "Physical Fitness" was the theme. Members considered how to hike, cross-country ski and down hill ski safely despite low vision. At this park, people tried out a rope trail developed by a Boy Scout who earned his Eagle Scout Status with this project. A representative of the Fairfax County Recreation Center told how classes in aerobics and swimming have been made accessible to people with disabilities.

For information about this chapter email: ncclv@yahoo.com

From the CCLVI Office **The 800 Line Is for Members Too!**

We are continuing to work on CCLVI's membership roster. If your name or address is wrong on Vision Access or if you are receiving our magazine in a medium other than the one you prefer, please call the toll-free CCLVI line at 800 733-2258. Call us for other concerns, too. We like to hear from you.

Project Insight Update

We had a workshop for Project Insight volunteers at CCLVI's Convention in Pittsburgh. Each person attending this workshop told how he or she found support and resources to cope with vision loss. We hope to help others as we have been helped. As we listened to each one's story, we strengthened our awareness of how each individual reacts differently to vision loss. As we answer calls to Project Insight, we will be sensitive to these differences.

We considered ways to advertise Project Insight. One suggestion was that announcements about Project Insight be made on Radio Reading Services.

If you would like to volunteer for this Project, call us at 800-733-2258.

Convention Program Reports

Helping the Patient with Central Vision Loss **By Paul B. Freeman, OD, FAAO, Diplomate Low Vision, Chief of Low Vision Services, Allegheny General Hospital, Pittsburgh, PA**

According to statistics found in "Vision Problems in the U.S." (underwritten by National Eye Institute and Prevent Blindness America), there are about 3.4 million older Americans with vision impairments. Two major conditions that can lead to central vision loss are macular degeneration and diabetes. So, where do people go when they have been told "Nothing more can be done" about their vision loss? Doctors who emphasize low vision rehabilitation might be able to help. In the book, *The Art and Practice of Low Vision*, co-authored by Drs. Paul B. Freeman and Randall T. Jose, the following mission statement serves as an example of the mind set of the doctor who works with people who are visually impaired and who hopes to empower people to make a decision to use devices to enhance sight and the quality of their lives.

"We are eye care professionals helping those who are visually impaired to choose visual options to obtain a goal and maintain dignity. We recognize that this evaluation and management is part of the continuum of primary eye care. We bring to the

evaluation honesty, compassion, empathy, and certainty of direction. We do not prejudge the motivational needs and desires of our patients."

Sometimes patients have misconceptions about what this type of help means.

Examples are:

--"I will recover the same visual ability I had before my vision loss. I want to read like I've read before." This is like a person who has had knee replacement surgery saying "I want to run as fast as I've run before." --"I don't need other regular eye care." But patients with low vision have not been immunized against glaucoma, diabetes, cataracts, or against other compounding difficulties. To do a low vision exam, the doctor has to be aware of patients' goals-for example, to be able to read. Function rather than disease becomes the focus. Because psychosocial and sometimes vocational factors are involved, an interdisciplinary team approach to low vision rehabilitation is most effective. The team's purpose is to help the patient to maximize use of residual vision.

Central vision loss has cultural significance. Patients see a person but cannot see what that person looks like, or there may be limitations to activities such as reading, writing, and watching TV. Perception of what is in the environment can be confusing so that some people try to "pick sunbeams off the floor" or "trip over shadows." This confusion is different than the ability to get around because of good side vision.

Visual acuity measurements both at distance and at near (central vision) are important in low vision exams. A patient's visual acuity gives the doctor the platform needed to prescribe low vision devices. This testing describes what the patient sees rather than what the patient reads. However, all this testing is at a high contrast. Pictures with weak contrast, poor contrast on floors and stairs, lighting on a page, a white shirt reflecting glare on a computer screen, white potatoes on a white plate on a white tablecloth, all affect vision. Therefore, contrast sensitivity is an important variable to be tested in the low vision exam. Additionally, the low vision exam includes how far central vision loss extends into the peripheral visual field, testing for distortion, evaluating the pathology creating the vision loss, and must include a refraction to determine whether the patient is nearsighted, farsighted, has astigmatism, etc. Finally, results from the low vision exam can help families understand and appreciate the challenges of the person who has lost vision.

Once the evaluation is completed, it is my job as a doctor who emphasizes low vision to recommend appropriate treatment options. But ultimately it is the patient who must commit to the devices. Optical and electro-optical devices are the foundation for improving vision but one must understand the proper use, cosmetics, and limitations of these treatment options. Additionally, magnification, field, working distance, posture, and mobility requirements are all factors that go into deciding which device is best for a task and the patient's lifestyle. Non-optical systems also play a role in vision rehabilitation. These may include a stand for reading, large print, a black sheet of paper with a hole cut out in the center to help the patient keep his place in the text and to provide contrast, felt tip markers, large print playing cards, lights, and filters to modify light. Sometimes it is difficult for patients to find the best seeing spot to use both optical and non-optical devices. In those situations patients may be taught to eccentrically view objects using the blurred spot at the center of their vision as a reference point, looking to the left or to the right to see an individual's face, as an example. However, when reaching for an object while eccentrically viewing, some tend to over or undershoot the object. They are taught to deal with this discrepancy. People who are members of the Council of Citizens with Low Vision International can be ambassadors to others who experience the challenges of vision loss.

An Overview of the American Optometric Association (AOA) Low Vision Section and the American Academy of Optometry (AAO), Low Vision Section

By Kathleen F. Freeman, OD, FAAO, Diplomate Low Vision, Immediate Past Chair of Both Sections

The American Optometric Association (AOA) and its Low Vision Rehabilitation Section (LVRS) are involved in activities related to the care of people with visual impairment.

NEHEP

The AOA is a partner in the National Eye Institute's (NEI) National Eye Health Education Program (NEHEP). One of our LVRS Council members, Tracy Williams, O.D., of Illinois has been appointed to help develop NEHEP.

Under the leadership of Carl Kupfer, M.D. and the direction of Rosie Janiszewski, MS, CHES, the NEI NEHEP program was established several years ago. The following quote is from the NEHEP website (<http://www.nei.nih.gov/nehep/nehepov.htm>):

"The focus of the NEHEP is on public and professional education programs that encourage early detection and timely treatment of glaucoma and diabetic eye disease, and the appropriate treatment for low vision."

The initial research by the NEI identified these barriers to low vision care:

- Lack of awareness of services

- Lack of access to information

- Non-coverage of vision rehabilitation services and devices by third party payers

- Lack of qualified providers

The NEHEP intends to address two of these barriers to low vision care: lack of awareness of services and lack of information. Here is another quote from the NEHEP website listed above:

"This program aims to increase awareness of low vision and its impact on quality of life and is directed toward people with low vision, their family and friends, and the healthcare service professionals who care for them."

Part of NEHEP's plan includes a consumer media campaign directed at people with decreased visual function that interferes with their activities of daily living, and at people who are at risk for low vision. This program is also directed at people who work with older adults.

Another part of the plan is directed at professionals. This includes exhibits at professional meetings and posters for the exam room. Posters have an 800 number that patients can call for a referral to a low vision doctor. The poster will encourage patients to "ask your doctor" about low vision.

LMRP's for vision rehab under Medicare

Because many visually impaired people are Medicare recipients, and because Medicare has historically NOT covered low vision rehabilitation services, there has been an effort to address this "Medicare inequity" by establishing Vision Rehabilitation Local Medical Review Policies (LMRPs) for each carrier.

LMRPs outline how carriers will review claims to ensure that they meet Medicare coverage requirements. They detail what service will be covered, and under what circumstances.

To date, the Centers for Medicare and Medicaid Services (CMS) carriers in 18 states have established LMRP's specific to vision rehabilitation. These specify the use of rehabilitation codes for certain therapeutic activities, when vision impairment is the

diagnosis, and cover some of the therapy that is done in low vision rehabilitation. However, the examination and determination of the prescriptions or treatment plans are still non-covered services. In another 14 states, although there is no LMRP specific to vision rehabilitation, the rehabilitation codes are utilized in some cases when a specific visual impairment diagnosis is used. The remaining states do not yet have policies to address the coverage of vision rehabilitation.

Medicare Vision Rehabilitation Services Act

The AOA was involved in crafting the language of the Medicare Vision Rehabilitation Services Act, aka the Capuano/Kerry Bill. This bill, if enacted, would provide Medicare coverage for certain low vision rehabilitation services under the same framework as other medical therapies. In addition, it would permit coverage of services performed in the home by specific providers (i.e., O&M specialists, rehab teachers, and low vision therapists, all of which are defined in the bill) under the general supervision of an optometrist or ophthalmologist.

The bill has passed in the Senate as part of the Medicare prescription drug bill.

Student Educational Awareness Program

All optometrists are educated to provide low vision rehabilitation, but not all choose to offer it in their practices. Recognizing that an important time to encourage optometrists to become involved in this care is during their professional education, the AOA LVRS developed the Student Educational Awareness Program to compliment the classroom, lab and clinical training optometry students receive.

This program is intended to increase interest by optometry students to provide low vision rehabilitation care as part of their optometric practice. It is motivational in nature, focusing on the positive aspects of providing this type of care, emphasizing the need for such care, as well as describing the great satisfaction one gets by being a low vision rehabilitation optometrist. It has been very well received.

Continuing education for practicing optometrists

The AOA is one of the premier sources of professional continuing education for optometrists. Each June, during the annual Congress meeting, optometrists may take continuing education courses on low vision rehabilitation topics, ranging from basic to advanced.

The American Academy of Optometry, AAO, is another organization which supports the profession of optometry by providing a forum for educational and research pursuits. At the annual meeting in December, there are educational courses offered for continuing education, as well as research papers and posters, in which low vision topics are well represented. The Low Vision Section of the Academy also has a Diplomate program, which allows clinicians to demonstrate advanced competence in understanding and providing low vision care.

Genetic Eye Conditions And Visual Impairment

**Based on a Presentation by Michael B. Gorin, MD, PhD, Professor,
Ophthalmology and Human Genetics, University of Pittsburgh Medical Center**

After members of the audience introduced themselves and stated the reasons for their vision loss, Dr. Gorin noted that most of the eye conditions that he deals with were represented here in his audience. He expressed gratitude to his patients. He said that

he learns so much from them and that he is happy to give something back today through his presentation.

A genetic disease results from an alteration in some gene. There are simple or monogenetic eye conditions. But even if a single gene is involved in a disease, there are a number of ways in which that disease can manifest itself. For example, retinitis pigmentosa, RP, a monogenetic condition, has many variations and degrees. It may be recessive or it may be dominant. In some cases vision loss is relatively minor. For example, Dr. Gorin has a patient with RP who is an Air Force pilot. There are different forms of optic nerve atrophy-autosomal dominant and Leber's hereditary neuropathy.

In contrast to monogenetic conditions, there are complex genetic disorders. Some of these are glaucoma, age related macular degeneration Stargardt's, and uveitis. In these conditions, several genes as well as environmental factors are possibly involved.

The higher oxygen environment contributes to the final result of retinopathy. Rubella is also an environmental condition. At present it's not known if there is a genetic component to rubella causing an eye problem. It is known that genetics plays a big role in infectious diseases. For instance, 10 percent of the population is genetically resistant to AIDS.

There are genetic diseases that are not eye specific. Retinal blastoma is one such condition. In this condition, tumors develop in the eye causing vision loss. However, these tumors can spread into the body and thus cause general diseases some of which may be life threatening.

Geneticists diagnose and identify the disorder. Knowing the precise condition can lead to a more accurate prognosis; it can be known whether the condition may be mild or severe. The precise label may also indicate that this condition may have other ramifications. Doctors can watch for these related conditions. For example, there is a kind of cataract resulting from a condition called aniridia; this condition can lead to tumors in the kidneys.

Geneticists try to understand the underlying cause of the condition and hopefully find a cure. That is a source of frustration because cures are often slow in coming. Progress is being made however. In some cases vision can be restored; in other cases the loss of vision can be prevented.

Genetic studies provide geneticists with DNA tests for the purpose of diagnosis. These tests are only recommended in cases in which the diagnosis can lead to a treatment. In many cases these conditions are not understood well enough to make the test valuable.

If a person manifests the condition, then the gene alteration is present. Yet, the DNA test still might not reveal the gene alteration because there are so many ways in which the gene might be altered. The standard test today might not pick that up. For example Leber's amaurosis is one of these. Here there are about 35 genes involved and DNA tests identify about 35 percent of the people who have this condition. This is frustrating because it would be nice to find a complete and simple set of genes that would yield a simple test.

At present some commonalities are beginning to emerge. For example: vitamin A is promoted as a treatment for RP. Now why should vitamin A be beneficial to all these various kinds of RP? Well, it probably isn't. In fact, vitamin A might even be toxic for people with certain kinds of Stargardt's disease.

It takes careful genetic analysis as well as a careful family history to reach a correct diagnosis. The ordinary ophthalmologist may not be trained to recognize the differences in eye conditions. For example, there are eye conditions that are just like Stargardt's and they are dominant. For most patients it takes a long time before they have the correct diagnosis. Many ophthalmologists will only see a handful of

certain conditions in a lifetime of their practice, and thus not be sufficiently experienced to differentiate these conditions.

People have been led down the wrong path either because they were misdiagnosed or their diagnosis lacked precision. For instance, if you are told that you have a genetic condition, you might ask, "Will I pass this on to my children?" Many lives have been ruined that way. People have been told, "You have RP, a genetic disease, therefore don't have children, good by." But things are not that simple. For example, a person might have x-linked RP, which means that their sons will not have the condition and their daughters will be carriers of the gene. X-linked RP is recessive. More and better tools that make it possible to diagnose these various subtypes will make it possible for people with these conditions to make more informed decisions about their lives.

If a person has a genetic condition that causes eye problems, it might be that that person has many good genes. None of us are genetically perfect. We might have genes for hypertension or dementia. People with genetic conditions that cause vision problems are entitled to live happy and productive lives. They still might contribute to society and they should not be discriminated against. There needs to be balance--know what your genetic alterations are, but these should not dictate your life choices.

Physicians are trained to tell you what's wrong and what should and what can be done. Genetic counselors have a role to play. They discuss with you what you might expect from this particular genetic condition. They educate, inform and empower. Then the patient can make a more informed decision about what to do with his or her life. Genetic counselors tend to be under utilized by ophthalmologists today.

It had been thought that late onset of a disease was caused by a gentle variation of the gene that causes juvenile disease. It turns out that this is probably not true, or, if it is true, it's true in a small number of cases. Ongoing studies of genetics are expected to give us faster and better methods of diagnosing these conditions.

Genetic studies are indicating that genetic factor may predispose a person to a particular condition. This may be true in retinopathy of prematurity; not all premature babies develop this condition.

It is not likely that massive gene therapy will be effective in treating vision loss. It's not likely that we'll get rid of genetic diseases. We shouldn't even try. What makes this impossible is that there are new mutations all the time causing new problems. That is what makes it possible for us to survive as a species. Genetic variation is essential. Something might be good under one circumstance and problematic in another. We shouldn't be thinking of good and bad mutations; we should focus on what they are and deal with their consequences. The real goal is to provide more individualized care for people. We try to find better ways to help people, to save vision and to give people better information so that they can plan their future and lessen their concerns.

Following his formal presentation, Dr. Gorin generously took time to answer questions from people in his audience.

Basic Genetic Terms Explained

Based on a Presentation by Kristal Platt, MS, Genetic Counselor, Boys' Town Medical Center, Omaha, NE

Genes are the body's recipe to direct production of proteins and chemicals. Genes are comparable to the recipe used, say, to make a batch of cookies. If the recipe calls for a teaspoon of salt and a cup of salt is added, the result will be different. If yeast is called for and the yeast is not added, then the final result is different. The genes specify the kinds of proteins that the body can produce. Genes might provide for too much of something, like in the case of too much salt, or, a gene might be missing and no yeast

might be added. There might even be a situation in which, like in cookies, no cookies are produced at all.

DNA is the code of the recipe. The DNA might be compared to the language that the body uses to communicate.

Chromosomes are packages of genes. Each person has 23 pairs of Chromosomes, 22 pairs of autosomes and one pair of sex chromosomes, xx in females and xy in males. Chromosomes are important, as in autosomes or for example in x-linked conditions.

Autosomal means a gene lies on one of the first 22 pairs of chromosomes. In an autosomal condition the sex of the individual doesn't matter.

X-linked means the gene lies on the X chromosome.

Dominant means it only takes one gene to cause a condition. A dominant condition is caused by one of the pairs of genes. In a dominant condition either the father or the mother can pass the condition to either a son or a daughter

Recessive means two genes, one from each parent, are required to cause a condition. In the case of X-linked conditions, the absence of a dominant gene can cause a condition.

Mitochondrial genes are located outside of the nucleus of the cell. Conditions caused by a non-working mitochondrial gene are passed through the mother's egg. The chromosomes carry genetic material. These chromosomes are located in the nucleus of the cell. There is genetic material in the cell which is not carried in the nucleus. The mitochondria genes are like that. These genes are very active in the muscles, the kidneys, the heart, and guess what, in the eyes. One of these is associated with Leber's hereditary optic neuropathy. With very few exceptions all of the mitochondria genes come from the mother. That's because the egg cell carries the mitochondria and the sperm cell carries no such material. That means that the father cannot pass this condition to any of his children. Women, on the other hand, can pass the condition on to their offspring. The father can pass on an x-linked condition. His daughters may be carriers. Under certain circumstances they might even exhibit the condition.

Syndrome is a pattern of signs and symptoms. Ushers syndrome carries with it retinitis pigmentosa as well as hearing loss. Isolated eye conditions, like retinitis pigmentosa and Stargardt's disease affect one function, like vision. A syndrome, like Ushers disease affects more than one function.

The Value of Sports and Recreation for People with Visual Impairment and How to Get Involved Based on Presentations **By a Panel of Speakers**

Oral Miller, President, United States Association for Blind Athletes (USABA); Past President, American Blind Bowling Association, and Past Vice President, Ski for Light: Why are sports and recreation important for people who are visually impaired? Fun, social interaction, cardiovascular benefits, orientation and mobility, hand eye coordination-the same reasons that apply to people who are not visually impaired. It is estimated that people who have vision impairments require 10 to 30 percent more energy, effort and attention in performing the same functions as others.

It is important to look for opportunities to participate and to advocate that publicly supported programs be accessible. These programs often are not accessible. Therefore special programs for vision impaired people have been developed. Typically students in residential schools have had more opportunities than students in the main stream where there is not as much access in spite of efforts of Western Michigan

University to train teachers and coaches. Volunteers run many organizations that provide opportunities for people who are visually impaired; this may mean that such organizations have no permanent address. Therefore the best way to reach these organizations is through the American Council of the Blind's National Office which maintains an up to date resource list.

The American Blind Bowling Association (ABBA) is now 50 years old. This organization brought together 1800 bowlers who were visually impaired-the first largest national meeting of people with vision loss. In its hay day, this organization had 125 leagues and volunteers ran it. ABBA may use sighted spotters and guide rails. Over the years, ABBA has involved great numbers of people, whereas in regular sighted leagues, access varies.

Ski for Light began in 1975 with assistance from the Sons of Norway and Lions Clubs. Cross country skiing is the main activity of this organization, but some chapters have offered rafting, llama trekking in the Rocky Mountains, sailing, tandem cycling and canoeing. Cross-country skiing is an annual weeklong event open to 100 skiers who are visually impaired. Volunteer sighted instructor guides accompany each skier. The week is filled with learning opportunities, competition, social activities, and exposure to the customs of other countries. Ski for Light has developed the best teaching manual for cross-country skiing. Their national office is in Minneapolis and can be contacted through the ACB National Office.

The United States Association of Blind Athletes, USABA, was established in 1978. This organization promotes Olympic level sports including track and field events, judo, swimming goal ball, 5-a-side soccer, and others. USABA made its debut in the International Games for the Handicapped in Montreal after the Olympics. USABA has state chapters.

Marty Mathews, President, Western Pennsylvania Blind Outdoor Leisure Development (BOLD) Program, Pittsburgh, PA.

BOLD began in 1974. We offer opportunities for downhill skiing, cross country skiing, hiking, ice skating, roller skating, camping, swim parties, water ski outings, rowing with the 3 Rivers Rowing Association in both 2 person and 8 person boats, and social activities. The availability of volunteer drivers often determines the number and types of activities offered at a given season. The web address for BOLD is www.wpabold.org.

Sue Lichtenfels, Founder, SportsVision, Pittsburgh, PA

SportsVision offers subsidized programs for people with visual impairments. Payment of \$10 dues means that members can participate in 2 activities per month.

In 2001, SportsVision addressed the needs of children who have impaired vision. Through grants from Western Michigan University and USABA, a Sports Ed Camp was established. Children from Maryland, Ohio and Pennsylvania came to the first camp held in 2002. Recreational activities at this camp included track and field, wrestling, goal ball, beep baseball, swimming, and yoga.

Physical education teachers in the main stream are not prepared to address the needs of children with impaired sight. We must work to change this.

Enrique Perez, President, International Blind Sports Association, IBSA, Madrid, Spain

IBSA is a paralympic organization in which 110 countries are represented. This is the second largest organization of the blind in the world after the World Blind Union in which 150 countries are represented.

The goals of IBSA are to promote sports, foster friendship, and increase involvement, competition and recreation among people with impaired sight. IBSA defends the Olympic ideals--to promote universally accepted rules among all countries, to maintain international records, and to sanction official championships. There are 14 official sports with a subcommittee for each. Some of these sports are skiing, bowling, foot races, goal ball, judo, skating and many not yet officially accepted but on the way. IBSA has the capacity to govern sports championships and to promote these into Olympic games. IBSA implements resources to help people get involved. 1000 plus athletes from 70 plus countries are expected to attend the next paralympic games.

Through these events we hope to show the world that people who are blind have the capacity to perform in athletic events. IBSA is not an organization for just the elite, but a rehab process at all life stages at the grassroots level. Psychologically, people are helped to overcome mobility problems, raise self-esteem, and overcome barriers in life. Besides encouraging people who are blind, IBSA brings prestige to nations who support people with vision disabilities. IBSA demonstrates that visual impairment is no barrier not only in athletics but also in education, politics and community involvement. In sports, we aim for total integration of people who have impaired sight in the same events with fully sighted athletes. .

Low Vision Services **In India and in England**

Jagdish Chander, Professor of Political Science, University of Delhi, is a PhD candidate at Syracuse University in New York. He spoke about services for people with vision impairment in his native country, India. Here is a report of what he said.

The Civil Rights movement in the United States began in the 1930's and 40's, whereas in India, people who are minorities began advocating for their civil rights in the 1970's. A comparable time difference applies to the disability rights movement in both countries.

The 1990's in India were like the 1960's in the United States. In the 90's, Disability Rights groups began to form. These groups had discussions via satellite with comparable groups in the United States. In 1995 a law was passed regarding disability rights in India. Seven disabilities were described in this law. Low vision was one of these seven.

Jagdish said he became blind at age 6. A tumor in his optic nerve blocked blood circulation to his eyes. He lived with his parents, 11 siblings and a strong extended family in a village where there was no awareness of educational opportunities for people who were blind. For him there would be no future. His parents worried "Who is going to feed our blind son?"

Fortunately, Jagdish's father worked in Delhi as a security guard at a bank. In Delhi, his father learned of a residential school for children who were blind. Jagdish attended this school and later went on to earn a Masters degree at the University of Delhi and then to teach there as well. There were about 100 students who were blind at the University of Delhi. At the University, attitudes were more westernized and therefore people were more open to those who were blind and to the opportunities they required. Because of these opportunities in Delhi, Jagdish's educational level is greater than his siblings. In some way, his blindness has been a blessing. He has become a source of pride to his family.

Jagdish enjoys the United States but still appreciates the less individualistic, less materialistic culture of India.

Today, only 2 percent of people who are blind in India have access to education. There are 12 million people who are blind in India. 70 percent of these people live in rural areas with no access to information, no access to education.

There is a high incidence of cataracts in India. Surgery for this condition is readily available.

John Godber, Assistant Director of Service Development, Royal National Institute for the Blind said that in England, services for people with impaired sight are patchy. Counties have responsibility for social services. Services range from very good to not much. Counties may be stretched for resources and there may be long waiting lists. People may wait from 6 to 8 months for a visit from a rehabilitation counselor. Children receive attention first and the elderly are at a lower priority.

In the '50 and 60's residential schools for children with visual disabilities were common. In the 70's, children were educated in the main stream. Here they are not as literate, have less access to information, and bullied more often by peers. The education of these children is the subject of debate in England.

80 percent of people with impaired sight in England are unemployed. Volunteers read local newspapers on tape. These are then broadcast on radio stations. The Internet is giving people access to more than local papers.

TRANSPORTATION, PRIORITY ONE

By Ken Stewart

Meeting transportation needs is the single most frequently mentioned problem among those who telephone the American Council of the Blind's National Office. So reported Melanie Brunson, ACB's Director of Advocacy & Governmental Affairs. She was reporting to the approximately one thousand assembled ACB members during the organization's July annual convention in Pittsburgh.

Ms. Brunson was speaking during the first plenary session of the week, a session tellingly titled, "Transportation Monday". Many CCLVI members were among the assemblage, participating in CCLVI's annual convention running concurrently with those of other ACB affiliates. In fact, CCLVI Board of Directors member Mike Godino shared the dais with Brunson and other presenters. He introduced one of the two speakers who described some of the technology now becoming available which gives automated travel information audibly. The morning's agenda also included a report from Alice Ritchhart, the Co-chair with Ron Brooks, of ACB's Transportation Task Force. The Monday morning convention assembly heard about something called Project ACTION too, that from Donna Smith. Project ACTION is sponsored by a not-for-profit organization which disperses a grant received every year from the Federal Transportation Administration. After Ms. Smith's presentation it was learned in personal conversation with her that in one local area for example, the Project's activity was a training outreach to persons with mobility disabilities paralleling the Orientation & Mobility training offered in standard vision rehab programs.

Two days earlier at the Pittsburgh Convention, the ACB Transportation Task Force held a well-attended workshop session during which thirty or forty people gathered in small sub-groups to exchange experiences with various categories of public transportation, ranging from the minimal paratransit offered in some rural areas to big-city mass transit. Unfortunately, the crowded schedule of events during Convention Week created time conflicts, and there was an overlap between that Task Force session and an ACB Environmental Access Committee meeting chaired by CCLVI President Pat Beattie.

Among other items on its agenda, The Environmental Access Committee discussed the travel technology with the cumbersome generic name, "Remote Infrared Audible Signage". It is more often referred to by the name of the one set of products being marketed in the U.S. thus far, "Talking Signs". Later in the week a Resolution came to the Convention floor endorsing a plan to use Washington, DC, as a model city to demonstrate various applications of RIAS's aiding the travel around the Capital by vision impaired people. The City of San Francisco is already applying the technology in several public buildings including its City Hall and a rail terminal. The traveler carries a small radio receiver which when activated, announces the information being constantly transmitted from specific spots like a Customer Service counter ("Customer Service" for example), a particular platform location ("Track Eight"), or a facility location ("Women's Rest Room"). Some, because of the need to carry a receiver, have criticized the technology. In response, Talking Signs has developed, and was showing at the Convention, a hands-free receiver which is worn like glasses. Others have expressed concerns over ACB endorsing the technology before there are multiple vendors in the marketplace. Still others worry that some municipal officials will seize the RIAS devices as a substitute for installation of accessible pedestrian signals which are eagerly sought nationwide by vision impaired advocacy groups. The APS of course, provides audio and tactual WALK/DO NOT WALK information to all pedestrians and requires no device on the person of the pedestrian.

Advocacy

Tiberi to Co-chair New Congressional Vision Caucus

WASHINGTON - (July 7, 2003) joining three of his colleagues from the House of Representatives, Rep. Pat Tiberi (R-OH) will co-chair the newly formed Congressional Vision Caucus.

"Over one million Americans are legally blind," noted Tiberi, "and it's estimated that by 2030, the number of blind or visually impaired people could double. We hope to bring this problem to the attention of our fellow Members, and let them know that many vision-related problems are preventable or treatable."

Tiberi serves on the national Board of Directors of Prevent Blindness America, the nation's leading volunteer eye health and safety organization dedicated to fighting blindness and saving sight. Joining him as co-chairs of the Congressional Vision Caucus are Reps. Gene Green (D-TX), Ileana Ros-Lehtinen (R-FL) and David Price (D-NC).

"Most eye diseases lack symptoms until vision is lost, most often permanently," said Tiberi. "That's why it's essential that people are aware of, and have access to, available services that include screening, treatment and rehabilitative care.

"As an example, thousands lose their sight each year because of diabetic eye disease. In Ohio, the estimated number of cases of Diabetic Retinopathy is over 216,000. With proper screening and care, up to 90% of diabetes-related blindness can be prevented. However, only 60% of those with diabetes receive annual dilated eye exams.

"We need to get the word out about the prevention and treatment of vision problems, and I believe this new caucus will prove valuable in doing just that."

AAPD and NOW Join Forcesto Co-Sponsor Women with Disabilities & Allies Forum

WASHINGTON, DC -- The American Association of People with Disabilities (AAPD) and the National Organization for Women (NOW) Foundation announce that they will hold a joint forum on disability and women's rights October 17-19, 2003.

Entitled Women with Disabilities & Allies Forum: Linking Arms for Equality & Justice for All, the three-day summit will address issues of mutual concern to the feminist and disability rights movement.

"Now more than ever, disability rights advocates must cultivate diverse allies in our common struggle for justice, dignity, and respect for human and civil rights. AAPD is delighted to join with the NOW Foundation to bring together leading activists and organizers this October for an historic opportunity to reinforce and reinvigorate our combined efforts to achieve equality, empowerment, and justice for all," said AAPD President and CEO Andrew J. Imparato.

"All women--including women with disabilities--share the dream of full equality, economic and personal independence, educational and employment opportunity, reproductive freedom and full participation in society," said NOW Foundation President Kim Gandy. "Women living with disabilities face multiple forms of discrimination, making it even harder to achieve their goals. Breaking down these barriers is a longstanding priority of the NOW Foundation."

The Women with Disabilities & Allies Forum: Linking Arms for Equality & Justice for All will begin Friday, October 17 at 5:00 p.m. and conclude Sunday, October 19 at 4:00 p.m. It will be held at the Hyatt Regency Hotel in Bethesda, Maryland.

AAPD and the NOW Foundation anticipate that this Forum will bring together a diverse group of women from across the country to discuss a broad range of issues and share ideas, and that it will celebrate AAPD's and NOW's common ground and help all women work toward creating a future that values and embraces them.

The forum will be kicked off Friday evening, October 17 with a welcome reception and entertainment. Saturday, October 18 and Sunday, October 19 will be combinations of plenary sessions, workshops and facilitated panel discussions.

Forum discussion topics will include women's economic empowerment, political activism and grassroots organizing, judicial nominees, Title IX, prenatal testing and abortion rights, health care, hate crimes, violence against women and inaccessibility of shelters, the future of civil rights, and how to bring together the disability rights movement and feminist movement issues.

The Forum's registration form will be available in late July on both the AAPD (www.aapd-dc.org) and the NOW Foundation websites (www.nowfoundation.org), and the early-bird registration deadline will be August 26. Please visit those websites for additional information and future announcements regarding the Women with Disabilities & Allies Forum: Linking Arms for Equality & Justice for All.

The American Association of People with Disabilities (AAPD), the country's largest cross-disability membership organization, promotes the economic and political empowerment of all 56 million children and adults with disabilities in the U.S. It was founded in 1995 to help unite the diverse community of people with disabilities, including their family, friends and supporters, and be a national voice for change in implementing the goals of the Americans with Disabilities Act (ADA). AAPD members have access to a full range of financial services through a federal credit union, a discounted mail order prescription program, and a quarterly AAPD newsletter. For

additional member benefits, or to learn more about AAPD's advocacy efforts and major program areas, visit www.aapd-dc.org.

The NOW Foundation is a 501(c)(3) organization established in 1986 to enhance the status of women in the United States and worldwide through education, advocacy and litigation. The NOW Foundation is affiliated with the National Organization for Women, the largest women's rights organization in the U.S. In its educational and advocacy efforts, the Foundation works to inform the general public, as well as policymakers, about the need for fair and equal treatment of women. The litigation efforts of the Foundation seek to protect reproductive health options for women, as well as focusing on other concerns, such as employment issues, pregnancy discrimination, sexual harassment, lesbian and gay rights, civil

rights and ending violence against women.

4th National Congress of Pedestrian Advocates

Mark Your Calendar! America Walks will convene the 4th National Congress of Pedestrian Advocates on May 6-8, 2004 in the Washington D.C. suburb of Silver Spring, MD. This is YOUR Congress, so here's your chance to make it work for you: Send Your Ideas! We're working on the program now and need your ideas. What information does your group need to be a more effective pedestrian advocate? What would you like to know how to do better? Explain the elements of good pedestrian design? Find new members? Conduct interesting walks? Engage elected officials? Write grants? Promote pedestrian-friendly street standards? Tap corporate giving programs? Connect with the disability community, public health officers, different ethnicities, seniors?

Send your ideas to info@americawalks.org.

Watch for Call for Papers! We will soon be submitting a call for papers or presentations. So watch your e-mail and get your thoughts together. Thanks for all you do to make America more walkable.

Andy Hamilton
Chair, 4th Congress Steering Committee
Vice-President, WalkSanDiego
info@americawalks.org

Roundabouts and Pedestrians

With Low Vision

By Joyce Kleiber

Are there roundabouts in your city? Do you know what a roundabout is? I've never seen one. But I am hearing more and more about them-especially as they may complicate life for pedestrians who are visually impaired. There are an estimated 40,000 modern roundabouts worldwide and more than 250 already in the United States, and more are being planned and proposed.

A roundabout is an alternative to traditional intersections which are controlled by stop signs or traffic signals. A roundabout is a circulatory roadway around a central island; roundabouts have four sets of entrance and exit lanes. Vehicles slow their speed when entering a roundabout. A splitter island lies between the sets of entry and

exit lanes. Pedestrians can wait on these splitter islands for gaps in the flow of traffic before attempting to cross these entry and exit lanes. But how can we who do not see well determine when it is safe to cross these lanes of traffic? We can't rely on our hearing because of the continuous traffic noise in these roundabouts.

Roundabouts are becoming increasingly popular where new roads are being constructed and where existing roads are being redesigned. Drivers are happy to keep moving rather than stopping for a red light to let other lanes of traffic and pedestrians cross the intersection. Roundabouts have been described as "the safest, most efficient and attractive form of traffic control in the world." The risk of pedestrians being involved in a serious collision is low because of reduced speeds at roundabouts. The probability of a crash resulting in a fatality is three times greater at a controlled intersection and about eight times higher at an uncontrolled intersection than at a roundabout.

Roundabouts are more inexpensive and easier to maintain than controlled intersections.

But what about the safety of pedestrians who have trouble seeing when a gap in the flow of traffic gives a window of opportunity to safely cross those entry and exit lanes?

At the 82nd annual meeting of the Transportation Research Board at Kansas State University last January, engineers suggested possible solutions to the problems roundabouts pose for pedestrians with low vision.

Some of these solutions included the following design modifications-consistency in location of crosswalks and splitter islands, the use of bollards, pedestrian barriers and even landscaping to indicate location of crosswalks, minimizing crossing distances by making crosswalks as straight as possible, textural differences between the street and sidewalk, curb ramps with returned edges aligned with crosswalk direction, sufficiently steep curb ramp slopes to be detected under foot, raising or otherwise marking the crosswalk edges to provide a boundary. It is being suggested that Accessible Pedestrian Signals equipped with locator tone may be needed to provide safety and that roundabouts may not be the appropriate intersection design in areas where there are high populations of pedestrians.

Some engineers have begun to recognize that the safety of pedestrians who are visually impaired is a concern. It will be interesting to see what steps they will take to protect pedestrians who have low vision. What can we learn from the experiences of other countries where roundabouts have been used since the 1960's?

NEW CONSUMER-LED COALITION LAUNCHES TO IMPROVE AMERICANS' ACCESS TO ASSISTIVE DEVICES

Washington, D.C. - On June 17, 2003, more than 65 organizations launched the consumer-led ITEM Coalition (Independence Through Enhancement of Medicare and Medicaid), at an event attended by Representative James R. Langevin (D-RI), the only wheelchair user in Congress, to highlight the need for greater coverage of assistive devices for people of all ages with disabilities and chronic conditions.

Henry Claypool of AIMMM (Advancing Independence: Modernizing Medicare and Medicaid), one of the ITEM Coalition's founders, stated, "At a time when Congress is poised to make important additions like prescription drugs to Medicare's benefit package, it is alarming that Congress is siphoning resources from the durable medical equipment benefit to increase payments to other providers. That's robbing Peter to pay Paul."

The Coalition will work to raise awareness and build support for policies that will improve access to the assistive devices, technologies and related services that people of all ages with disabilities and chronic conditions need to be as healthy, independent and functional as possible.

Lee Page of the Paralyzed Veterans of America, another founding member of the Coalition, said, "If Medicare is going to save billions of dollars on assistive devices over the next decade, they should use those resources to modernize the Medicare benefit to satisfy unmet needs, including hearing aids, advanced wheelchairs, vision aids and other assistive devices."

Representative Langevin spoke of the importance of assistive devices in his own life and career, stating, "As assistive technologies have made it possible for me to serve in Congress, I know firsthand that access to such devices goes a long way in making it possible for people with disabilities to fully participate in society."

Initially, the Coalition will work to preserve and enhance Medicare and Medicaid's coverage policies, with the aim of later addressing related coverage issues under the policies of other federal and private payers. "The entire purpose of Medicare and Medicaid was to allow older adults and people with disabilities greater independence. Access to new technologies and services must be available to fulfill this promise," said Robert M. Hayes, president of the Medicare Rights Center, a founding member.

The ITEM Coalition's initial activities have included submitting comments to the Department of Defense on proposed changes to the TRICARE regulations which significantly enhance coverage of assistive devices, and testifying before the Interagency Working Group on Assistive Technology Mobility Devices, established by President George W. Bush by Executive Memorandum.

"We urge policymakers to recognize the breadth of assistive devices, technologies and related services that aid individuals with disabilities and chronic conditions," stated Paul W. Schroeder of American Foundation for the Blind, another founding member. "These items range from mobility devices to hearing aids to grab bars (for one's bathroom) to closed circuit televisions to prosthetic limbs and orthopedic braces. They can be as simple as hand held magnifiers and canes and as high-tech as speech synthesizers and other communication devices."

The Coalition is consumer-led and comprises a diverse set of over 65 disability associations, aging organizations, consumer groups, labor organizations, voluntary health associations, and non-profit provider associations. Members include American Association of People with Disabilities, Center for Medicare Advocacy, Inc., Self Help for Hard of Hearing People, Christopher Reeve Paralysis Foundation, Brain Injury Association of America, The Arc of the United States, United Cerebral Palsy Associations, and the American Academy of Physical Medicine and Rehabilitation.

"I applaud the efforts of the over 65 member organizations represented here, who have banded together to pool their resources and work in collaboration in the effort to modernize public health programs. I am confident their dedication will dramatically improve the lives of millions of people with disabilities," stated Langevin.

At the launch event, the Coalition also announced the formation of their website at www.itemcoalition.org.

Usability and Visual Impairment **Reported by Carla McCollaum**

People who work in the usability field are beginning to realize how little interaction they've had with the visual impairment world. A consequence of this lack of interaction is that many people who are concerned with visual impairment issues are unaware of

how the field of usability could help improve the lives of individuals with visual impairments.

The "Usability for Visually Impaired People" (UVIP) mailing list has been established to facilitate communication between people who are interested in usability and people who are concerned with visual impairment issues. Some of the goals include:

- Helping each group understand the other group better,
- Identify problems and explore possible solutions based on the knowledge, experience and background of each of the groups,
- Share new information as it is discovered,
- Explore ways to include people with visual impairments in usability testing,
- Discuss approaches to improve efficiency and accuracy of visually impaired people when using computer interfaces,
- Look at ways that people with visual impairments can handle asynchronous interactions, e.g. multiple instant messages.

If you would like to subscribe to this mailing list, just send an empty note to:
uvip-subscribe@yahoogroups.com
(The mailing list is also available in daily digest format.)

From Our Members
Member to Member
By Carlos Gourgey, Ph.D.

Low vision comes with many losses. One of the greatest is loss of the ability to drive. We live in an automobile culture, and so not being able to drive can make us feel like we have no place, like we don't belong. Being dependent on others who may resent taking responsibility for our transportation is distasteful. It is not a happy choice: participating in life by constantly relying on others or not participating at all.

Not surprisingly, this became a hot topic in our electronic discussion group. One member summarizes the challenge:

Giving up driving was by far my biggest adjustment in life, but it was the lesser of two evils. The worse evil is hitting somebody because your vision was not good enough for you to be driving in the first place. I had drove for years while I was partially sighted until one day I almost hit an old woman who was jaywalking. That was the final blow to me because it took something like that for me to stop driving. I was so determined not to drive after that close call that I mailed my driver's license in to the state vehicle division.

Then I had my hardest adjustment facing me, that of losing a major portion of my independence and freedom, and having to rely on others to be driven some place I wanted to go. My limited sight had limited my life's choices considerably, which caused me to flounder like a lost child. Adjustments, there are always adjustments to make in life, and some really hit home as I am ultra sensitive to any negative responses, to the point where I'll not ask that person to take me anywhere.

Adjusting to the loss of independence is a major struggle. We must grieve it as we grieve any loss. In addition to the loss itself there are social consequences. Being dependent on others changes our relationship to them.

Another member tells us how she copes with it:

I think asking for rides is the hardest thing to do because you do feel like you are imposing and because you also have pride issues and simply feel like you would like to have some control over the whole situation. I am the WORST person on earth for asking for rides and have been low vision all my life. Why? Because I have known people who were so good at asking they had no respect for the person whom they were asking and would actually make the person feel obligated to drive miles out of their way and in situations they might not have felt comfortable with.

I too hate it when someone is resentful if I swallow my pride and ask for a ride because honesty is the best policy. I say if you cannot drive me or do not want to just tell me. Otherwise the resentment just builds up and destroys the relationship. I am like the rest of the world and hate the word NO but I can live with it.

Like I said I am the world's worst in asking for rides and would spend a king's ransom in cab fare before I put someone out.

A third member expresses very similar feelings:

I can tell you that the VERY WORSE thing about losing your sight is also losing the ability to drive and to be independent. Although I've now been legally blind and not driving for nearly 9 months now, I still get very upset when I have to ask someone to take me somewhere. If they show the slightest resentment I will never ask them again for help. My husband knows I'm this way so is very good about being honest. If he really doesn't want to take me I don't go or find another ride. If he's ok taking me, he'll tell me that and then not be resentful about it. I was EXTREMELY active in social justice work before I went blind but have had to cut back extensively because I hate to ask for too much assistance and because I am really trying to get my own head together.

Aside from the issue of personal relationships, there are also concerns about safety. As strongly as we may yearn for the independence of those who drive, the group seemed to agree that safety must come first. The husband of one member suffered significant vision loss, and was wondering whether driving with a bioptic might be an option. The group expressed some strong reservations about the use of bioptics for this purpose.

It is sad but true: driving is a hard thing to give up, but what your husband needs to understand is that even if he feels like self-destructing he is a lethal weapon when he gets into that car and he is not only risking his own life but the lives of all the other people on the road including men, women, and children.

How would one feel using a bioptic if they missed a small child crossing a street because they had no peripheral vision and hit him or her? I am not putting anyone down who does use them because I understand how strong the desire to drive and be independent is, but to me doctors and the department of motor vehicles have an obligation to think of the risks and benefits before giving a license to someone using bioptics. I think it is irresponsible to put both the drivers' lives and the lives of others at risk. I will just wait for the miracle implant when I can drive or the electric car.

Another member agrees:

Bioptic driving is a subject of tremendous controversy, even within the visually impaired community. Regulations also vary greatly from one state to another. Personally, I just don't see how it could be a good idea. How can you drive if you have no peripheral vision? You would be a menace both to self and to others.

The greatest challenge in experiencing any loss is becoming able to accept it. This always takes time, and also the willingness to feel the grief. Hopefully this group can help with support, but there is no replacement for the tough hard work that each one of us has to do.

In conclusion, no one was able to solve the problem of nondrivers' dependency, but we did find that most of us are dealing with the very same issues. Tonight on the local news I heard the story of an 86-year-old man who killed a child after he lost control of his car. Many are calling for stricter driving standards for the elderly. Perhaps when large numbers of people realize they will not always have the option of driving, society will begin thinking seriously about alternatives.

What Does It Mean To Be Legally Blind?

By Valerie Ries-Lerman

I've always wondered what others who are visually impaired feel about having partial vision. Do they think that people understand? Does the public have any idea of how low vision affects our work, our social interactions, our home life? What do others think about how well we were prepared to deal with the issues that eventually and inevitably arise?

Personally, I was woefully unprepared to face the "real" world. In the 60's it seemed that everyone had other things on their mind rather than attempting to understand the world in which I lived. Of course there were some attempts of sorts to help me face my challenges. I can remember being asked by a beachgoer mellowing on the Santa Monica sands "Why are you wearing those Coke bottles?" My parents casually stated one day near my eighteenth birthday that since I was "legally blind", I was entitled to the Social Security check that they handed me. The relief that my father felt was almost palpable. I should explain: it must have been very difficult for my parents to have a disabled child--especially one born prematurely and slated as "one who was not going to amount to much".

Of course, I always felt "different". At the age of 5 my teeth were growing in a little crooked and on top of other little problems, that seemed to add up to so much. I remember thinking "My parents will possibly abandon me any day now". The closest we

ever got to discussing my vision problem was when we talked about whether I should ride a bike.

It's funny, despite being in a classroom for the visually impaired, I never saw a CCTV. There was never any discussion of career possibilities. I could see print held close enough, but no one alerted me to the fact that I'd be seen as odd due to the angle and direction I needed to look at things because my retina was off center. Should I carry a cane? How did my vision differ from someone with 20/20? It seems rather odd, in retrospect, that in the twelve years of what was considered to be an education for a legally blind child, we never discussed these things.

Now I have a job, a husband, and a college degree. But I still ask myself some of the same questions. How do I describe my vision? What do I say to the teenager who protests, "Why are you carrying that cane? You're not blind!" How do I explain to co-workers that partial vision means not only that I see less than they, but that I see differently? Having good mobility skills does not mean that I can drive, or that I can recognize an acquaintance I pass on the street. Where something might be readily apparent to someone with normal vision, a person with low vision uses other senses to put the picture together into a cohesive whole.

What is probably obvious is that we ought to try to help others understand visual impairment wherever and whenever we can. It seems though that if low vision is outside of a person's normal awareness or understanding, he or she would rather not really be bothered. I guess at times it's too much of a stretch to expect that people would alter their perceptions (or lack thereof) in order to look at things differently from what they comfortably misunderstand. For me to always take that first step towards education is sometimes difficult.

Do you find it easy to reach out to people and bridge those gaps of understanding? Each of us has unique and interesting experiences to bring to the table. I would like to explore what we share as legally blind individuals in our homes, in our workplaces, and in our communities. We have a unique set of concerns that are different from those who have no vision. Our concerns are by no means any less challenging. Editor's Note: Send your responses to Valerie care of Joyce Kleiber, Editor, 6 Hillside Road, Wayne, PA 19087, or email: jmkleiber@hotmail.com

Science and Health

Study of Living Eye in Real Time Now Possible With Optics Technology

A new optics technology is providing scientists with real-time microscopic images of the living retina, and may allow doctors to focus in on earlier diagnosis and treatment of diseases such as diabetes and glaucoma.

University of Houston, UH, researchers are using a technology called adaptive optics to peer inside the eyes of human subjects and for the first time get clear, sharp images of features such as blood flow in the eye's retina. Until now, clear images of the living retina were not possible because the eye's own structure interferes with the imaging process. "Everyone suffers from natural irregularities in the cornea and lens of the eye, and even in people with normal, 20/20 vision, these defects prevent the eye from focusing light from the world into a nice sharp image on the retina," says Austin Roorda, assistant professor of optometry at the University of Houston.

"Eye doctors have to look through these same defects when they examine a patient's retina, and the image they see is not very clear, limiting the amount of information they can get." A clear view of the retina is key to the early diagnosis of

diseases such as glaucoma, which produces changes in the nerves in the eye, and diabetes, which affects blood flow in the retina. Using adaptive optics, researchers accurately measure the defects in the cornea and the lens and compensate for them to produce detailed microscopic images and video of human retinas. In his lab, Roorda and his colleagues have built a scanning laser ophthalmoscope, the only device of its kind that incorporates adaptive optics.

"We get a much clearer picture of the retina than any other technology can produce, with the added advantage that the data we get is in real time," Roorda says. Roorda's scanning laser ophthalmoscope won't be in clinics any time soon, but he says it's a prototype for the next generation of such devices. He and colleagues at four other institutions, led by the University of Rochester, recently received a \$10 million, five-year grant from the National Institutes of Health to build more adaptive optics devices. During the past year, Roorda and his UH team have seen capillaries the smallest blood vessels in the retina and the white blood cells flowing through them. Tracking the movement of white blood cells helps them measure the rate of blood flow, as well as monitor their specific behavior. The UH researchers are working with a physician at the Texas Medical Center and plan to look at patients with diabetes, for example, to examine their blood flow dynamics. In diabetics, it is thought that white blood cells tend to be sticky and may move differently through the capillaries than they do in normal retinas. Roorda's team also plans to look at glaucoma patients, whose retinal nerves have been changed by the disease, and people with changes or losses in their cone photoreceptors. Source: University of Houston science news Medscape TechMed 3(1), 2003. (c) 2003 Medscape Excerpts- the Health Library at PCBVI

Overweight, Inactivity Increase Risk for Progression of Macular Degeneration Reported to VISION ACCESS By Dawn Wilcox, Health Library

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NEW YORK (Reuters Health) Jun 23, 2003.

In patients with early or intermediate stages of age related macular degeneration (AMD), being overweight or obese appears to increase the risk for disease progression, while physical activity may decrease that risk, investigators at Harvard Medical School report. In their report in the Archives of Ophthalmology for June, Dr. Johanna M. Seddon and colleagues point out that previous epidemiological studies looked at the onset or diagnosis of AMD, but not progression. Therefore, they conducted their prospective cohort study to evaluate the relationship between obesity, physical activity, cigarette smoking and cardiovascular disease (CVD) and development of geographic atrophy and exudative neovascular disease. The 261 subjects were at least 60 years old when they enrolled between 1989 and 1998. Average follow-up time was 4.6 years, with 22% followed for 7 years or longer. During the course of the study, 101 patients progressed to advanced AMD, as documented by standardized ophthalmologic examination and fundus photography. The risk for progression was more than doubled by having a body mass index > 25 compared with leaner counterparts, after adjusting for age, gender, carotenoid intake, initial AMD grade and education. Higher waist circumference and higher waist/hip ratio measures of abdominal adiposity were also significantly associated with progression. There was a relative risk of progression of approximately 0.75 associated with vigorous activity "enough to work up a sweat" 3 times per week compared with no activity. Although there was also a trend toward increased risk with smoking, the relationship did not reach statistical significance.

Hypertension and history of CVD were not related to progression. "Results provide new information regarding modifiable factors for individuals with the early or intermediate stages of this disease," Dr. Seddon's group concludes.
Arch Ophthalmol 2003;121:785792. <http://www.medscape.com/viewarticle/457674>

Assistive Technology

Enhanced Vision Improves JORDY Functionality

Improved Reading Capability, Vivid Color Display and Sharper Images Greatly Assist People with Low Vision

Enhanced Vision unveiled a number of significant enhancements to its popular JORDY device. These improvements are effective immediately and are included on all JORDYs.

The JORDY is a head worn, portable, lightweight device that is battery operated and has been designed for people with active lifestyles, enabling them to read, write and enjoy TV, movies and hobbies again.

Specifically, at higher magnification the JORDY's depth of focus has been enhanced to be from 1 inch to infinity. This enhancement allows a user to bring material closer for easier reading on the go.

Sharper letter definition, especially in high contrast negative mode, is also one of the features that have been improved in addition to overall image coloring. The JORDY now features display colors that are truer to life.

JORDY starts at \$2,795.00 (alone) or \$3,095.00 (complete system which includes desktop video magnification capability). Upgrades are also available for existing customers. For more information please contact the Company at 1-888-811-3161 or visit their website: <http://www.enhancedvision.com/jordy.php>

Extreme Reader Takes Optical Character Reader Technology into the 21st Century

Guerilla Technologies, Inc (GTI), a Stuart, Florida-based technology company, has developed a new optical character reader (OCR) and scanner system in a PC based platform that allows the visually impaired and blind to read. Sales, training and support for the system are offered locally in California by Wisdom Solutions of Santa Ana, CA.

Extreme Reader is what GTI calls "a revolutionary personal reading system for people who are blind or have low vision". The product addresses the void in new innovation in the OCR market and the lack of upgradeability in competitive and older versions of this technology. Extreme Reader is a multi-function OCR system offering users a choice of options: 1. Scanning and reading documents 2. Reading books/text documents from CD or 3.5" disk 3. Reading MP3 file format for loading on portable players (PDA's).

Individuals using the system can easily scan documents with one touch scan, read, pause and stop keys or can utilize the Daisy format CD drive to listen to books on CD. GTI expects that users of Extreme Reader will access the growing libraries of scanned books that exist on websites such as Bookshare.org. Bookshare.org is a non-profit site created by Benetech, (Palo Alto, CA based organization) as a method to legally offer

books to the visually impaired or blind. Bookshare members grow the available library by scanning and downloading texts to the site. Membership in Bookshare is a one-time fee of \$25.00 and an annual fee of \$50.00 to download an unlimited number of books.

Voice reading quality and tone is another major advance in Extreme Reader. GTI notes that the system has leaped to the forefront in reading systems by incorporating TextAloud software with AT&T Natural Voices technology. AT&T is widely lauded for the quality of voice reading technology and GTI believes that listening enjoyment and duration of time spent reading books on CD will be increased as a result.

System Operation and Specifications

Built on an Intel Celeron PC platform and tightly interwoven with Microsoft Windows, the Extreme Reader is equivalent to a Personal Computer for sighted users and was designed to facilitate reading comfort and ease of use by visually impaired and blind users. Functions are easy to navigate and knowledge of Windows or PCs is not necessary to operate the system.

Two different models of Extreme Reader are offered, the XR1 and XR10. The XR10 offers a word spell feature that allows the user to navigate back to words and spell each letter or character. The XR10 also has a mode key to read column or tabular pages. Documents can be set to read spreadsheets (tabular mode), or normal text (column mode). These additional features in the XR10 are expected to make it an ideal training tool for educational facilities for the blind or visually impaired. The XR1 is designed for those who have recently lost their sight or have become sight impaired later in life and are seeking more limited functions and ease-of-use. Both models use an intuitive, proprietary tactile keypad to control all functions. In addition to the keypad, each XR includes a PC platform with built in Daisy format CD-ROM, 3.5" disc drive, flat bed scanner and speakers with adjustable volume.

Warranty Information: One year limited warranty plus free software upgrades for one year

Pricing: Extreme Reader is priced \$600 - \$1000 less than older competitive products according to GTI

XR10 \$ 2995.00

XR1 \$ 2495.00

For more information please contact WisdomOCR@yahoo.com or call 714-200-6543 or 714-568-1682

Implanted Telescope **By Bette Homer**

Many individuals with partial vision have been searching for a restoration of vision. Those of us who have used low vision devices successfully are always interested in finding devices. We want more magnification, greater field of view and longer working distance. Unfortunately the nature of lens and optics makes it impossible to increase the level of magnification without reducing the working distance and the field of view. The use of a hand held telescope or magnifier requires us to use at least one hand to hold the device. Even though head mounted systems give us the freedom of using our hands to perform other tasks, we are restricted in our head movements in order to maintain the appropriate working distance.

Today I read about a new telescopic implant that has been developed and marketed in Europe. This device is a tiny telescope that magnifies 2 or 3 times. It is surgically implanted in the eye. Forty-six individuals were studied in Europe. There was an improvement in distance and near visual acuity in 97% of the subjects in the study. They appreciated having their hands free and found that they didn't need to move their heads as much. The implanted telescope does create a difference in visual acuity between the eye with the implant and the eye without the implant. About 6 sessions of instruction are required to adjust to the difference in visual acuity. Initially the difference in visual acuity can be disorienting.

The implanted telescope is not being marketed in the United States at this time. Here 30 institutions are conducting trials. Eighty individuals have been selected to participate in the 2-year study.

The implanted telescope is the same size and shape as the lens of the eye. The lens of the eye must be removed due to a medical necessity prior to implantation of the telescope.

The criteria for being a candidate for this study are as follows: 1. You must be 55 years of age or older. 2. You must have inactive wet or dry macular degeneration. Or Stargardt's. 3. Both eyes must be involved. 4. Your visual acuity can range from 20/80 to 20/800.

For more information contact Vision Care, Inc. at 1-888-883-9500. You can also look at their web site at www.visioncareinc.net.

Request for Contributions

CCLVI gratefully accepts contributions from readers and members to help pay for the costs of publishing VISION ACCESS, the costs related to our 800 line and Project Insight, and for funding the Carl E. Foley and Fred Scheigert Scholarships. Please send contributions to CCLVI Treasurer, Coletta Davis 2879 East Alden Place, Anaheim, CA 92806. Our Tax ID number is 1317540.

Resources

America Walks
Congress of Pedestrian Advocates
May 6-8, 2004
Silver Spring, MD
info@americawalks.org

American Academy of Optometry
4330 East West Highway, Suite 1117
Bethesda, MD 20814
301-718-6500

American Blind Bowling Association
724-745-5986

American Optometric Association
243 North Lindberg Boulevard
St. Louis, Mo 63141
314-991-4101

Blind Outdoor Leisure Development
In Pittsburgh, www.wpabold.org
For other areas get listings from ACB's 800 line: 800-424-8666

Guerilla Technologies, Inc
WisdomOCR@yahoo.com
714-200-6543 or 714-568-1682

International Blind Sports Association
www.paralympic.org

Item Coalition
www.itemcoalition.org
National Eye Institute's Nation Eye Health Education Program
www.nei.nih.gov/nehep/index.htm

Prevent Blindness America
800-221-3004

Royal National Institute for the Blind RNIB john.godber@rnib.org.uk

Ski for Light
612-827-3232
www.sfl.org

SportsVision
412-441-4940
www.mysportsvision.org

United States Association for Blind Athletes
719-630-0422

Usability for Visually Impaired People uvip-subscribe@yahoogroups.com

Vision Care, Inc.
888-883-9500. www.visioncareinc.net

Women with Disabilities and Allies Forum
Linking Arms for Equality and Justice
October 17-19, 2003
Washington, D.C.
www.Aapd-dc.org
www.nowfound.org

Working Group for the Partially Sighted, WGPS listserv
<http://groups.yahoo.com/group/wgps>

CCLVI 2003 Membership Application or Renewal

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