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

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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.

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 CCLVI's toll free line, 1-800-733-2258.

Editor: Joyce Kleiber

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From the Editor

Greetings from Philadelphia and Houston! Most of this issue of VISION ACCESS was assembled prior to our CCLVI Convention in Houston. I added highlights of our Convention. If you attended our gathering in Houston, I hope your enjoyed meeting with CCLVI leaders and members. If not, plan to join us next year in Pittsburgh. It is an opportunity to meet others like yourself. We need each other.

Meanwhile, meet the people who have shared their experiences and information in the many articles in this issue of VISION ACCESS. I thank everyone who has contributed. I'd love to hear from you as well. JMK

Organization News

CCLVI Election Results

We congratulate and welcome the newly elected officers and board members of CCLVI. But first, we acknowledge the work of those who have served CCLVI in the past two years: Ken Stewart as President, Barbara Kron as Secretary, Bill Burgunder as Treasurer, and Board Members Herb Guggenheim, Marcie Schott and Robyn Wallen. Those newly elected are: Patricia Beattie, Alexandria VA, President, Bernice Kandarian, Mountain View, CA, Ist Vice President, LeRoy Saunders, Oklahoma City, OK, 2nd Vice President, Karen Johnson, Seattle, WA, Secretary, Coletta Davis, Anaheim, CA, Treasurer, Carl Foley, Kettering, OH, Membership, Ken Stewart, New York, NY, Past President. Newly elected Board Members are: Mike Godino, Baldwin, NY, Imogene Johnson, Little Rock, Arkansas Barbara Kron, Windsor, CA, Skip Sharpe, Silver Spring, MD, and Janis Stanger, Salt Lake City, UT.

Convention Program Highlights
By Bernice Kandarian

Many people attended CCLVI's programs at this year's Convention in Houston.

Dr. Franklin Porter and Randall May, from the LowVision Clinic at the Light House in Houston were presenters at our opening session. They asserted that expectations in discovering one's vision turn circumstances into opportunities for appraising abilities for education and vision optimization. One's vision is a matter of one's interpretation. That is, a person beginning vision rehabilitation might say, "I can't see a thing!" That's his interpretation as he begins. However, as this patient works with his doctor and a vision rehabilitation therapist, he learns to use the vision he has and then give up his original premise.

At another session, a number of exhibitors spoke about the assistive devices that convention goers could explore in the exhibit hall.

A panel of speakers explored the use of Braille, long white canes, and sleep shades in vision rehabilitation programs. Members of our audience expressed their opinions on these controversial topics. Most agreed that individual choice and readiness should be factors in the decisions to use these rehabilitation tools.

Later, Judy Scott of the Houston Lighthouse and Janis Stanger, Vision Rehabilitation Specialist and CC:LVI Board Member spoke about how the Lighthouse and the National Eye Institute programs address low vision concerns.

On the lighter side, CCLVI Convention goers enjoyed a Wine and Cheese Mixer, two dances to the music of Gordon Kent, and a fun filled game night including horse racing, The Dating Game, and Name That Tune events.

Plan to join us at next year's convention at the Westin Hotel in Pittsburgh, PA for a meaningful low vision experience.

Judy Scott Reviews AFB Vision Agenda
By Janis Stanger

One of every six people in the United States over the age of 65 has vision problems. In those over 85, the number increases to one of every three. With these statistics, Judy Scott, of the American Foundation for the Blind, began her presentation of the AFB National Agenda on Vision and Aging. She reported that the purpose of the Agenda is threefold: 1) to increase awareness of the prevalence of vision problems; 2) to work to influence policy change; and 3) to bring about a systemic change in service provision for those with vision problems.

Scott indicated that many agencies are represented in the group formulating the AFB Agenda. CCLVI is represented by Patricia Beatie, and as an affiliate of the American Council of the Blind, by Charlie Crawford. Scott discussed some of the goals of the Agenda as: promote self-advocacy; increase public education; increase funding for programs. She added to the list employment, data collection and staffing issues.

In explaining the Agenda, and discussing progress which has been made, Judy Scott pointed out that there are many areas where work continues to be done. She reported that for those who adventitiously visually impaired, there tends to be an attitude of "accept it." This prevents them from seeking help. The is also work which needs to be done with those who provide services to people with vision impairments, such as independent living centers, and state agencies for the blind. Finally, Scott reported that there is a great deal of work which needs to be done with eye care professionals in enlightening them to the availability and need for special services for those with vision impairments.

As part of her presentation, Scott played two Public Service Announcements which Patty Duke had made for AFB. These announcements point out that people who have vision impairments can and do work and live meaningful lives.

The remainder of Judy Scott's presentation was an update on the public education effort which began two years ago with the distribution of education packets in English. Since that time, 16,000 packets, 160,000 booklets, and 44,000 information cards have been distributed. CCLVI is mentioned as a resource in the public information materials.

Because the campaign has been so successful, materials were also made available in Spanish. To date, 13,000 information cards, 20.000 booklets, and 5,000 packets have been distributed in Spanish. It is an immediate goal of AFB to reach out to other minorities such as Native Americans and African Americans.

In conclusion Judy Scott thanked CCLVI for the work we have done on the Agenda. We contributed financial support for the publication of the education packets. Pat Beattie has given many hours of service to the project. Ms. Scott also stated that she would like to see CCLVI select an alternate representative who could assist with the project when Pat is not able to attend the planning conference calls. The calls are usually held once a month for about an hour at about Noon Eastern Time. Other times the calls might occur are at 8:00 AM Central Time. If you would be interested in helping with this project, please contact Pat Beattie, President of CCLVI.

Blind Services in China
By Janis Stanger

One fifth of the world's blind live in China. More blind people live in China than any other country. In fact, there are over 8 million people in China who are blind. The first organized disability group in China was the Blind Welfare Association, which was founded in 1953.

As in other countries, the blind in China are faced with many problems. The two most crucial are employment and education. Employment among the blind in China is 83 per cent compared to three per cent among the non-disabled community. One reason for this is the closure of "Welfare Factories," where many blind people worked. Another reason for such high unemployment among the blind is a government quota system which requires employers to hire a certain number of disabled people. However, where an employer hires a blind person, he only gets half the credit he would receive if he hired some other disabled person. This penalizes the employer who hires blind workers, and so less blind people are hired.

There are two main avenues of employment for the blind in China today. These are massage therapy and piano tuning. There are 5,000 blind massage centers operated by the blind in China. And it is hoped that 35,000 additional massage doctors, all of whom are blind, will be trained in the near future. Blind piano tuners are trained by people in Germany, Japan and the United States. Many people who are piano tuners go out of the country for training and then return to China to work.

The second main problem for the blind in China is education. Of children with disabilities, 80 per cent are enrolled in school. Among the blind, however, the figure is only 54 per cent. This is the lowest percent of enrollment for any population in China. There are only 374 senior high school students in China who are blind. Of those blind students who graduate from high school, 90 per cent go to college.

There are several reasons for this low enrollment among blind children. First is lack of awareness. Many people are not even aware that there are schools for those who are blind. And many people who are parents of blind children do not let the schools know they have children at home who are blind. A second reason for the low enrollment is the lack of teachers qualified to work with the blind. Finally, there is not enough money to build schools or hire teachers who are qualified to teach.

Lack of education is perhaps the most serious problem faced by the blind in China. One of every three people in poverty is disabled. Of those who are in poverty, 70 per cent have received no education. In 1990 there were over 20 million disabled people who were in poverty, now there are only 7 million in poverty. It is hoped that the disabled poor will be eliminated by 2010.

In spite of the problems facing the blind of China, the Blind Welfare Association of China continues to strive for improvement. There are five motivating elements which push them forward in their work: The belief that no one is insignificant; Leadership which relies on team work; Increased information technology literacy; Negotiating and networking with other agencies, individuals and organizations; Dignity.

Although securing better education and employment for the blind in China presents some serious hurdles for the Blind Welfare Association of China, the members and their leaders have hope in the for a better future for the blind of their country.

Chapter Reports

California Council of Citizens with Low Vision
by Bernice Kandarian

Our May, 2002, Convention took place in San Mateo with great attendance at all three program sessions.

A program item suggestion was to learn more about "Project Insight" so I attempted to give an overview of CCLVI structure, including how CCCLV and "Project Insight" relate. Additionally, James McCarthy, owner of FreedomVision Magnification Center, spoke about his new showroom and the array of products he now carries. After a brief Business meeting, where members decided they would like to become more involved with "Project Insight", James Bliss from JBliss Imaging Systems gave an update on his new browser "Pick 'n Click (PnC)".

The joint session with the Committee on Access and Transportation Friday morning covered such topics as a brief demonstration of the emergency evacuation system being marketed by Sound Alert Technology, an update on the status of accessible pedestrian signals in California and a presentation on guidelines for advocating for the rights of Californians with disabilities in health care.

The Saturday morning joint session with the Senior Blind Committee featured a social worker from the Peninsula Center for the Blind and Visually Impaired in Palo Alto who spoke about "Choices and Changes", a six-session introduction to living with vision loss. The Health Library (THL), also at the Peninsula Center, was the subject of a skit presented by two of its volunteers highlighting its services and how to use them. A panel discussion about use of sleep shades for low vision rehabilitation stimulated a lot of audience comment.

CCCLV cosponsored an all-day low vision seminar "Understanding Your Vision: Is It In Your Genes?" at Stanford University Medical Center on May 10. This event was streamed live on ACB Radio and is available in the ACBRadio.org "On Demand" archives.

FCCLV Moves Forward
By Rosanna Lippen, President

Our annual business meeting was held on June 1st in Tampa in conjunction with Florida Council of the Blind's state convention. Many new people attended as well as a number of faithful and loyal rehabilitation stimulated a lot of audience comment.

CCCLV cosponsored an all-day low vision seminar "Understanding Your Vision: Is It in Your Genes?" at Stanford University Medical Center on May 10. This event was streamed live

Our annual business meeting was held on June 1st in Tampa in conjunction with Florida Council of the Blind's state convention. Many new people attended as well as a number of faithful and loyal members. We now have a complete board of directors. Debbie Drylie is our new Vice President and Pat Roberts joins us as a board representative. Both lovely ladies reside in Orange Park. Morry LaTour of Largo will be handling the organization's accounts. We will put our team efforts together and a new issue of the Viewpoint will be out soon. Be on the lookout! If you have any special requests and ideas for our 2003 program, I would love to hear them. Thanks to all who help keep this special interest affiliate alive!

Metropolitan Council of Low Vision Individuals
By Ken Stewart

At our most recent meeting, Mike Godino, one of our members, reported on his visit to the rehabilitation program conducted by the National Federation of the Blind. His observations while escorting a group of young people with vision impairments, sparked lively discussion and was reported by him in The Braille Forum.

There was also a follow-up report on the topic of the Chapter's previous meeting. The subject had been the quality and quantity of stop-announcements by New York City bus drivers. The speaker, Joel Ziev, also one of our own, urged the Chapter to keep the pressure on NYC Transit to adopt the latest technology available for this important communication function. The Chapter did follow up. As our Chapter's representative, I testified at a public hearing soon afterward, portraying the inadequacy of bus driver announcements, insisting that there be documentation and disclosure of disciplinary action for driver failures, and pressing for the early installation of automated stop-announcement equipment.

Our Chapter welcomes CCLVI members from anywhere in the northeast not served by the Delaware Valley Chapter. Meetings are held from Six to Eight O'clock on a weekday evening at 110 William Street in Lower Manhattan, less than one block from a major subway station serving BMT, IRT and IND lines. The Chapter can be contacted at MCLVI, 357 West 55th Street, Suite #1F, New York, NY 10019; (845) 986-2955; cclvi@yahoo.com.

Congratulations to Chapter member Mike Godino on his election to the CCLVI Board of Directors!

Other CCLVI Chapters

In the Philadelphia metropolitan area, contact the Delaware Valley Council of Citizens with Low Vision, 215-735-5888.

In Washington D.C., contact the National Capitol Citizens with Low Vision at 202-537-0346.

For information about beginning a CCLVI Chapter in your area, call CCLVI at 800-733-2258.

Fred Scheigert Scholarship Recipients

Every year the Council of Citizens with Low Vision International awards three competitive scholarships to qualified applicants with low vision. This is possible due to a generous contribution by one of our members, Fred Scheigert. The recipients of the awards are announced at our annual convention each July.

This years scholarships go to Angela C. Winfield or Newburg NY, Christina Chang of Orange CA, and Cynthia Bachofer of Nashville TN. Christina is an entering freshman at Stanford, Angela is studying political science and pre-law at Columbia, and Cynthia is a graduate student in vision rehabilitation at Vanderbilt University.

To be considered for a Fred Scheigert Scholarship, students must have at least a 3.0 GPA, on a scale where 4.0 is equal to an "A." They must also have corrected vision of no greater than 20/70 in the better eye or a visual field which subtends an angle of 30 degrees. To obtain a scholarship application, send a self addressed stamped envelope to Janis Stanger, 1239 American Beauty Drive, Salt Lake City Utah 84116. The deadline is April 15 of each year.

Project Insight Update

Two people joined our staff of Project Insight Volunteers since our last update. They are Debra Carroll from Baltimore MD and Jayne Leone from Pittsburgh PA. Both Debra and Jayne have already experienced the personal satisfaction that comes from sharing resources and information about coping with vision loss with people in their communities. They plan to continue reaching out to others and will respond to callers to CCLVI's 800 line from the Baltimore and Pittsburgh areas. Welcome Debra and Jayne.

Debra and Jayne have each contributed an article to this issue of VISION ACCESS. Get to know them better by reading what they have to say.

People who attended our Convention's Project Insight Workshop shared their views about increasing the effectiveness of this Project.

Project Insight brochures are being revised and readied for printing. Volunteers who want to help with this revision, contact CCLVI through our 800 line, 800-733-2258.

Advocacy

Advocate for Medicare Coverage For Vision Rehabilitation

The National Vision Rehabilitation Cooperative and other advocates have worked vigorously for legislation that will ensure uniform coverage through Medicare for vision rehabilitation services targeted to older Americans. An important and related goal is to establish vision rehabilitation professionals (orientation and mobility specialists, rehabilitation teachers and low vision therapists) as part of the Medicare program. Grassroots efforts brought aboard 132 Representatives and a growing number of Senators as co-sponsors of the Medicare Vision Rehabilitation Services Act (S.1967/H.R.2484).

The focus now is on building Senate support as the Senate begins to consider its own Medicare bill this month. Your help on this important effort would be greatly appreciated. Please visit http://www.medicarenow.org to contact your Senators. Or if you do not have Internet access, write to your Senators directly urging them to co-sponsor S.1967/H.R. 2483, the Medicare Vision Rehabilitation Services Act. This legislation will significantly help older Americans who are blind or partially sighted by providing the same Medicare coverage for rehabilitation services for someone who experiences vision loss as it does for someone who breaks a hip or has a stroke.

The National Vision Rehabilitation Cooperative is comprised of nonprofit vision rehabilitation agencies throughout the United States.

Sidewalk Access Suit Is Revived
By Claire Cooper

Reprinted with permission from The Sacramento Bee, 2002

SAN FRANCISCO -- In a groundbreaking disability rights decision, a federal appeals court ruled Wednesday that local governments must provide sidewalks usable by people with mobility and vision impairments.

The 9th U.S. Circuit Court of Appeals reinstated a lawsuit that targeted bumps, benches and other obstacles that, according to advocates for the disabled, trip up wheelchair and white-cane users trying to navigate the city of Sacramento's 2,200 miles of sidewalks.

The decision in the closely watched case is the first of its kind by an appellate court. A similar suit involving sidewalks was settled earlier in Hawaii in the high-stakes dispute over the scope of the federal Americans with Disabilities Act.

A federal trial judge threw out the Sacramento case last year. In doing so, U.S. District Judge Milton Schwartz said that while federal ADA regulations required the city to provide curb ramps in pedestrian walkways, removing sidewalk obstacles was not a legal duty.

In Wednesday's decision, the unanimous three-judge appellate panel disagreed and revived the case.

The city of Sacramento could now turn to the Supreme Court or ask the 9th Circuit to reconsider its decision.

Otherwise, the case will be sent back to Schwartz for a trial to determine the extent of the sidewalk access violations.

The ramp requirement "would be meaningless if the sidewalks between the curb ramps were inaccessible," wrote Circuit Judge A. Wallace Tashima of Pasadena in the unusually terse seven-page ruling.

The decision continued a trend in which the circuit court has expanded the scope of the federal disabilities anti-bias law at the same time the U.S. Supreme Court has been pulling back the law's coverage.

Just this week, the 9th Circuit used the ADA to broaden the employment rights of former drug and alcohol abusers, while the Supreme Court narrowed employment rights under the statute for people whose disabilities make them susceptible to job injuries.

Attorney Laurence Paradis of Disability Rights Advocates, which won the appellate ruling, hailed Wednesday's sidewalk decision as a critical step in bringing people with disabilities into the social mainstream instead of forcing them "to stay at home, marginalized and isolated." The U.S. Department of Justice participated in the case on Paradis' side, backing his interpretation of the law.

Joining the city in its defense was the National League of Cities and 76 individual cities, which estimated the potential public cost of compliance at $2.5 billion in California alone.

Gregory Hurley, who represented the league as a friend of the court, predicted the circuit's decision would set off "a feeding frenzy on cities" by disabled plaintiffs and their lawyers.

"Every city in California that I've spoken with has been threatened with suits on this," said Hurley, who is defending Riverside in a similar case.

Bringing cities into compliance could take years, he said.

But Paradis said his clients never asked, or expected, everythingto be fixed immediately. He said the plaintiffs and the city were able to negotiate a plan for installing curb ramps over the course of three decades.

"We hope they will sit down with us now and negotiate a similar plan for fixing the remaining barriers on the sidewalks themselves," Paradis said.

As for other cities, he said, "We hope they will voluntarily get on board and do the right thing. It's in everyone's interests, not just disabled people, to make the sidewalks safe and accessible" for parents wheeling strollers, elderly people and anyone else who is impeded by sidewalk obstacles.

The Sacramento Public Works Department referred inquiries to the City Attorney's Office, which did not return phone calls.

In oral arguments before the 9th Circuit in March, Deputy City Attorney Gerald Hicks argued that sidewalk barrier removal wasn't covered by the ADA.

Hicks' brief said the suit would require the city to tear up and replace thousands of miles of concrete and move utility and telephone poles, grates and drainage systems.

Time For Low Vision Pedestrians To Speak Up

By Ken Stewart

Specific Federal regulations detailing what sidewalks, intersections and crosswalks look like, are coming. And pedestrians with low vision should have their say before these regulations are finalized.

Until October 28th public comment is invited by the U. S. Architectural & Transportation Barriers Compliance Board (The "Access Board") about the proposed regulations which were publicly announced on June 17th. The Access Board drew up the proposals, about l6 pages of them, after receiving a thick volume of recommendations from an advisory body it created for that purpose. That body, the Public Rights of Way Access Advisory Committee)"PROWAAC"), held five multi-day meetings over thirteen months. I represented CCLVI on the committee and on a successor committee which meet five more times over another year and a half. The sessions presented a unique opportunity to educate leaders in the transportation industry on what visual features of the pedestrian environment are crucial to travelers with limited vision.

The Committee spent a major portion of its time on the needs of travelers with mobility impairments, focusing primarily on features like curb ramps and sidewalk grades. But some elements which are relevant to the needs of pedestrians with visual impairments were also considered.

The final product now before the public for review and comment has some dictates which represent significant advances. It is by no means an ideal set of guidelines though and all low vision advocates should study the proposed document and submit comments to the Access Board. Indeed, even those provisions that are welcomed by pedestrians who have low vision should be mentioned in response letters to the Board. For example, an advocate might object that there is no provision against hard to see street furniture such as a concrete bench on a concrete sidewalk. At the same time our advocate could commend the Committee for including a provision calling for street edge warning strips which are both tactually and visibly detectable. Feedback should certainly be given on the commendable requirement for pedestrian WALK signals to communicate in non-visual ways too.

Those interested in studying the document can request a copy of the "Draft”

Science and Health

Eye Drops Delay Onset of Glaucoma in People at Higher Risk

Researchers have discovered that eye drops used to treat elevated pressure inside the eye can be effective in delaying the onset of glaucoma. These results mean that treating people at higher risk for developing glaucoma may delay - and possibly prevent - the disease. These findings are reported in the June 2002 issue of Archives of Ophthalmology.

Scientists found that pressure-lowering eye drops reduced by more than 50 percent the development of primary open-angle glaucoma, the most common form of glaucoma and one of the nation's leading causes of vision loss. Researchers noted that 4.4 percent of the study participants who received the eye drops developed glaucoma within five years. By comparison, 9.5 percent of the study participants who did not receive the eye drops developed glaucoma. Additionally, several significant risk factors were found to be associated with the development of glaucoma in study participants. These included personal risk factors, such as older age and African descent, as well as ocular risk factors, such as higher eye pressure, certain characteristics in the anatomy of the optic nerve, and thinness of the cornea.

Elevated eye pressure results when the fluid that flows in and out of the eye drains too slowly, gradually increasing pressure inside the eye. It is estimated that between three and six million people in the U.S. - including between four and seven percent of the population above age 40 - have elevated eye pressure and are at increased risk for developing open-angle glaucoma. Until now, doctors did not know if treating elevated eye pressure - before glaucoma developed - could delay the onset of the disease. Some doctors treat people with elevated eye pressure, others do not. This study provides some important information to consider in reaching a decision about treatment.

"This study showed that treating elevated eye pressure delays or prevents the onset of glaucoma in some people," said Paul A. Sieving, M.D., Ph.D., director of the National Eye Institute (NEI), a component of the Federal government's National Institutes of Health (NIH) and one of the study's sponsors. "The study clearly makes a connection between elevated eye pressure and the onset of glaucoma. However, not all people with elevated eye pressure should be treated with the eye drops. If you are at risk for glaucoma, see your eye care professional to receive a comprehensive eye exam and find out if eye drops might help."

The study - called the Ocular Hypertension Treatment Study - examined 1636 people 40-80 years of age who had elevated eye pressure but no signs of glaucoma. Half were assigned daily eye drops, and the other half were assigned to observation (no medication). In the medication group, treatment reduced eye pressure by approximately 20 percent.

"It is significant that this modest 20 percent reduction in eye pressure had such an important protective effect in the development of glaucoma," said Michael Kass, M.D., of the Washington University Department of Ophthalmology and Visual Sciences and chair of the study.

Dr. Kass sounded a cautionary note. "Eye care professionals should not prescribe eye drops for all people who have elevated eye pressure with no sign of glaucoma," he said. "Doctors should take into account several factors, including the simple fact that 90 percent of participants in the observation group did not develop glaucoma within the five-year study period. An individual's risk of developing glaucoma, along with their health status and life expectancy, should be considered. The burden of daily treatment, including cost, inconvenience, and possible side effects, are other factors that the doctor and patient should discuss." Dr. Kass said that study researchers prescribed commercially available eye drops, either singly or in combination, to reduce eye pressure. "The availability of many different types of pressure-lowering eye drops allows eye care professionals to choose the safest regimen for each patient," he said. In the study, the group receiving the eye drops did not show increased evidence of health problems in comparison to the observation group.

Open-angle glaucoma affects about 2.2 million Americans age 40 and over; another two million may have the disease and don't know it. Glaucoma occurs when the optic nerve is damaged. In most cases, increased pressure in the eye plays an important role in this damage. The damage to the optic nerve causes loss of peripheral (side) vision. As the disease worsens, the field of vision gradually narrows and blindness can result. However, if detected early through a comprehensive eye exam, glaucoma can usually be controlled and serious vision loss prevented. Comprehensive eye examinations are recommended for all people over age 60, and African Americans over age 40.

Glaucoma is the leading cause of blindness in African Americans, according to John Ruffin Ph.D., director of the National Center on Minority Health and Health Disparities (NCMHD), part of NIH and another study sponsor. "Glaucoma is three to four times more likely to develop in African Americans

than Whites," Dr. Ruffin said. "This study took that into account: 25 percent of study participants were African American."

Dr. Sieving said this clinical trial is among the studies supported in the National Eye Institute's glaucoma research program. "We will continue to conduct and support research aimed at finding better ways to detect, treat, and possibly prevent glaucoma," he said.

In addition to support from the NEI and NCMHD, the Ocular Hypertension Treatment Study was supported by Research to Prevent Blindness and Merck Research Laboratories. The study was conducted at 22 clinical centers across the country.

What is Glaucoma

Glaucoma is a group of diseases that can lead to damage to the eye's optic nerve and result in blindness. Open-angle glaucoma, the most common form of glaucoma, is one of the leading causes of blindness in the United States and the number one cause of blindness among African Americans. Glaucoma usually has no early symptoms, and by the time people experience problems with their vision, they usually have lost a significant amount of their sight.

How Open-Angle Glaucoma Develops

Increased pressure inside the eye is an important cause of open-angle glaucoma. In the front of the eye is a space called the anterior chamber. A clear fluid flows continuously in and out of this space and nourishes nearby tissues. The fluid leaves the anterior chamber at the angle where the cornea and iris meet. When the fluid reaches the angle, it flows through a spongy meshwork, like a drain, and leaves the eye.

Open-angle glaucoma gets its name because the angle that allows fluid to drain out of the anterior chamber is open. However, for unknown reasons, the fluid passes too slowly through the meshwork drain. As the fluid builds up, the pressure inside the eye rises. Elevated eye pressure can damage the optic nerve; a healthy optic nerve is necessary for good vision. When the optic nerve is damaged from increased pressure, glaucoma - and vision loss - are the result.

At first, open-angle glaucoma has no symptoms. People are not aware that glaucoma is affecting their vision, and there is no pain. When glaucoma remains untreated, people may notice that although they see things clearly in front of them, they miss objects to the side and out of the corner of their eye. Without treatment, people with glaucoma may find that they have no side vision. Over time, the remaining vision may decrease until there is no vision left.

Antioxidant Vitamins and Zinc Reduce Risk of Vision Loss from Age-Related Macular Degeneration

Editor's Note: Also see "Eating for Eye Health" In VISION ACCESS, Vol 9, No 1, 2002. This study was reported in the Archives of Ophthalmology, 2001.

High levels of antioxidants and zinc significantly reduce the risk of advanced age-related macular degeneration (AMD) by about 25 percent. These same nutrients also reduce the risk of vision loss caused by advanced AMD by about 19 percent. They have no significant effect on the development or progression of cataract. These results are from the Age-Related Eye Disease Study (AREDS), a major clinical trial sponsored by the National Eye Institute, one of the Federal government's National Institutes of Health. The nutrients are not a cure for AMD, nor will they restore vision already lost from the disease. However, they may play a key role in helping people at high risk for developing advanced AMD keep their vision.

Who Should Take the Nutrients? People who are at high risk for developing advanced AMD should consider taking the formulation used in the study after consulting with their eye care professional.

What is the Dosage of the Nutrients Used in the Study? The specific daily amounts of antioxidants and minerals used by the study researchers were 500 milligrams of vitamin C; 400 international units of vitamin E; 15 milligrams of beta-carotene; 80 milligrams of zinc as zinc oxide; and two milligrams of copper as cupric oxide. Copper was added to the AREDS formulations containing zinc to prevent copper deficiency, which may be associated with high levels of zinc supplementation.

Are There Any Side Effects from the Nutrients? The AREDS participants reported few side effects from the treatments. About 7.5 percent of participants assigned to the zinc treatments--compared with five percent who did not have zinc in their assigned treatment--had urinary tract problems that required hospitalization. Participants in the two groups that took zinc also reported anemia at a slightly higher rate; however, testing of all patients for this disorder showed no difference among treatment groups. Yellowing of the skin, a well-known side effect of large doses of beta-carotene, was reported slightly more often by participants taking antioxidants. In two large clinical trials sponsored by the National Cancer Institute, beta-carotene was shown to significantly increase the risk of lung cancer among smokers

Consumers should discuss the use of these high levels of nutrients with their doctors and be certain to include copper whenever taking high levels of zinc.

"This is an exciting discovery because, for people at high risk for developing advanced AMD, these nutrients are the first effective treatment to slow the progression of the disease," said Paul A. Sieving, M.D., Ph.D., director of the NEI. "The nutrients are not a cure for AMD, nor will they restore vision already lost from the disease," Dr. Sieving said. "But they will play a key role in helping people at high risk for developing advanced AMD keep their vision."

A common feature of AMD is the presence of drusen, which are yellow deposits under the retina. Often found in people over age 60, drusen can be seen by an eye care professional during an eye exam in which the pupils are dilated. Drusen by themselves do not usually cause vision loss, but an increase in their size and/or number increases a person's risk of developing advanced AMD, which can cause serious vision loss.

The three stages of AMD analyzed in this study are: Early AMD--People with early AMD have, in one or both eyes, either several small drusen or a few medium-sized drusen; these people do not have vision loss from AMD. Intermediate AMD--People with intermediate AMD have, in one or both eyes, either many medium-sized drusen or one or more large drusen; in these people, there is usually little or no vision loss. Advanced AMD--In addition to drusen, people with advanced AMD have, in one or both eyes, either: A breakdown of light-sensitive cells and supporting tissue in the central retinal area (advanced dry form); or Abnormal and fragile blood vessels under the retina that can leak fluid or bleed (wet form). These two forms of advanced AMD can cause serious vision loss. scientists are unsure about how or why an increase in the size and/or number of drusen can sometimes lead to advanced AMD, which affects the sharp, central vision required for the 'straight ahead' activities in our daily routine, such as reading, driving, and recognizing faces of friends. One observation is that the larger and more numerous the drusen, the higher the risk of developing either form of advanced AMD. People who have advanced AMD in one eye are at especially high risk of developing advanced AMD in the other eye.

The formulation used in the study contained several antioxidant vitamins, which are nutrients that can help maintain healthy cells and tissues. They also contained zinc, which is an important mineral incorporated into many body tissues.

In this trial, the NEI collaborated with Bausch & Lomb, an eye care company that provided the formulation evaluated by the AREDS researchers and financially supported the laboratory testing and distribution of study medications.

"Previous studies have suggested that people who have diets rich in green, leafy vegetables have a lower risk of developing AMD," said Frederick Ferris, MD, director of clinical research at the NEI and chairman of the AREDS. "However, the high levels of nutrients that were evaluated in the AREDS are very difficult to achieve from diet alone.

"Almost two-thirds of AREDS participants chose to take a daily multivitamin in addition to their assigned study treatment," Dr. Ferris said. "The AREDS also showed that, even with a daily multivitamin, people at high risk for developing advanced AMD can lower the risk of vision loss by adding a formulation with the same high levels of antioxidants and zinc used in the study." The Age-Related Eye Disease Study involved 4,757 participants, 55-80 years of age, in 11 clinical centers nationwide. Participants in the study were given one of four treatments: 1) zinc alone; 2) antioxidants alone; 3) a combination of antioxidants and zinc; or 4) a placebo, a harmless substance that has no medical effect. The benefits of the nutrients were seen only in people who began the study at high risk for developing advanced AMD -- those with intermediate AMD, and those with advanced AMD in one eye only. In this group, those taking "antioxidants plus zinc" had the lowest risk of developing advanced stages of AMD and its accompanying visual loss. Those in the "zinc alone" or "antioxidant alone" groups also reduced their risk of developing advanced AMD, but at more moderate rates compared to the "antioxidants plus zinc" group. Those in the placebo group had the highest risk of developing advanced AMD.

Dr. Ferris said some people with intermediate AMD may not wish to take large doses of antioxidant vitamins or zinc because of medical reasons. "For example, beta-carotene has been shown to increase the risk of lung cancer among smokers," he said. "These people may want to discuss with their primary care doctor the best combination of nutrients for them. With the use of the high levels of zinc, it is important to add appropriate amounts of copper to the diet to prevent copper deficiency."

Traveling Exhibit on Low Vision

The National Eye Institute has announced the final 2002 tour schedule for the THE EYE SITE: A Traveling Exhibit on Low Vision for Shopping Centers. During 2002, two identical exhibits are on tour to 20 malls in 9 states. In 2001, the exhibits toured 12 malls in 6 states. Beginning this month, the tour schedule includes the following stops.

NEW YORK CITY
Grand Central Terminal
May 1-2
South Street Seaport
May 6-19
Staten Island Mall
May 21-June 9
Kings Plaza
Brooklyn
June 11-30

ARKANSAS
Fayetteville
Northwest Arkansas Mall
May 11-30

MASSACHUSETTS
Cambridge
CambridgeSide Galleria
June 3-22
Dartmouth
Dartmouth Mall
June 24-July 20

MISSISSIPPI
Hattiesburg
Turtle Creek Mall
July 6-August 1

NEW HAMPSHIRE
Nashua
Pheasant Lane Mall
July 22-August 10

MISSISSIPPI
Meriden
Bonita Lakes Mall
August 3-29

CONNECTICUT
Milford
Westfield Shoppingtown Connecticut Post
August 12-September 12

MISSISSIPPI
Vicksburg
Pemberton Square
August 31-September 30

CONNECTICUT
Meriden
Westfield Shoppingtown Meriden
September 13-28
INDIANA
Indianapolis
Glendale Mall
October 3-31
Elkhart
Concord Mall
November 2-18

WASHINGTON, DC
2003 tour schedule TBD

COLORADO
Planning underway for 2003 tour

NORTHERN CALIFORNIA
Planning underway for 2003 tour
If you have any questions, please give me a call at 301-496-5248 or email me at jh@nei.nih.gov
Jean Horrigan

Note: If you have a diagnosis and you need some confidential health information in accessible media, contact the Peninsula Center for the Blind and Visually Impaired, (PCBVI) through CCLVI's 800 line, 800-733-2258 or email: THL@pa.pcbvi.org

Excerpts from Research reports:
1. NEW YORK (Reuters Health) Apr 29, 2002 Translocation of the retina appears to be a promising therapeutic option for stabilizing or improving vision in patients with exudative ('wet)
age related macular degeneration, according to European investigators. In a prospective case series, Dr. Karl Ulrich BartzSchmidt, of the University Eye Clinic Tuebingen, and associates evaluated outcomes in 87 patients who underwent 360degree retinotomy and macular translocation. (Note-they turned the macula.) The purpose of the translocation was to position the fovea over adjacent healthier retinal pigment epithelium. Significant improvement was observed in 24 patients, while worse outcomes were observed in 29, the authors report in the Archives of Ophthalmology for April. Dr. BartzSchmidt and his associates noted a high rate of post surgical complications; however, they believe that as the surgical technique becomes more refined, visual outcomes should improve. Arch Ophthalmol 2002;120:451459.

2. From Australia
Researchers in Australia say they have developed the world's first flexible artificial cornea. The device is made from a combination of soft plastics and can be implanted to replace diseased or damaged corneas. Celia Hicks, a member of the research team from the Lions Eye Institute of Western Australia, said trials on 41 patients had an 80% success rate. The results were presented at a Sydney ophthalmology conference. Dr. Hicks said the treatment would be a great help to patients whose eyes had rejected corneal implants from donors. "There is quite a high rejection rate for ordinary donor grafts," she said. She said they are an improvement on rigid synthetic corneas currently available. She could not say when the new cornea would be available commercially. Corneal blindness affects about 10 million people worldwide. About 100,000 receive implants each year. Tuesday 23rd April 2002
Contact www.argusbiomedical.com
Source: National Nine News
http://news.ninemsn.com.au/nnhwatch/story_30272.asp

Features

Member to Member
By Charles Gourgey, Ph.D.

Many of us have struggled simply to get an education. What others take for granted can seem like great hurdles to us: getting access to the assignments, being able to read them on time, finding exams that test only our knowledge and not our visual skills.

When I got my first master's degree conditions were primitive. I couldn't see the blackboard, and it didn't help that other students' cigarette smoke would blow into my eyes. And I'd suffer so much eyestrain from struggling with article after article in small print that I'd wake up every morning unable to open my eyes from the tears and the pain.

When I went back to school years later things were much different. By that time the school had an Office for Students with Disabilities, something formerly unheard of. I could get articles copied in large print, or even have them read at the school's expense. Special arrangements for exams were available, giving me an accessible format and all the extra time I needed. And nobody smoked anymore.

One of the members of our Working Group for the Partially Sighted, WGPS listserv recently shared her own concerns about going back to school:

Frustration alert! Trying to start vocational rehab grad school. The publisher of the textbook does not 'do' cassette versions. Can't afford 2 sets of books for Recording for the Blind ($175). Need to have read first 6 chapters by Wednesday for first day of class. Can't get scanner and Kurzweil to play nice and work together. In fact, I have never used Kurweil before. And it doesn't skim, does it?

Okay, how did you guys do this school thing while being visually impaired? I am so frustrated and beginning to have panic attacks and think I CAN'T do this. I refuse to accept defeat. But I am in such a state of panic I can't think clearly or get a handle on things.

Suggestions?

Signed,

Raving Lunatic

Here are some of the responses:

Dear Raving,

Take a deep breath. We have all been there before. One of the biggest hassles of being visually impaired and in school is gettingthose textbooks. Usually in order to get them you have to order months early and nowadays schools seem to change texts more often than we change socks. So it is a real problem.

Do you have a CCTV at least? Is rehab paying for a reader for you? Geez, I wish I had answers for you, but I DO feel your pain.

****

I do remember those panic attacks, when the books didn't come, the reel-to-reel tapes broke, etc. Is there a Disabled Student Services Office on your campus? Somebody there should be able to help with the Kurzweil (except for the skimming part, of course...). I definitely relied a lot on reader help; sometimes they read to me and I took notes, sometimes they read and I taped on the spot. I wonder if there are any private blindness agencies near you that might be able to tape for you and could send you the tapes as they did them. Or, will the Disabled Students" Office do taping for you?

Hang in there, and try to do things a little at a time, so you don't get too crazed.

****

Many people do this the old fashioned way. They hire a reader. This reader can make a tape. One of the tricks to this Vision Impairment stuff is to start early in finding out what the book is. Good luck.

****

Laney, if you haven't already done so, find out immediately if your school has an Office for Students with Disabilities - most schools dohave them now - and go over there and really make your case. Their assistance was invaluable to me when I was in grad school.

And how about the academic department lending a copy of the textbook to Recording for the Blind and Dyslexic, RFB&D? All these universities want to be politically correct now. Just play on their heartstrings a little. And use the word "diversity" - that gets them every time.

Comments and questions from readers are welcome; send them to Joyce Kleiber, Editor, VISION ACCESS, 6 Hillside Road, Wayne, PA 19087.

Anyone with Internet access who wishes to join WGPS Listserv may do so by visiting http://groups.yahoo.com/groups/wgps. Please introduce yourself when you join so that we may welcome you properly!

Welcoming the Welcomer

By Carlos Gourgey, Ph.D.

Those of you who go to church, have you thought much about what an usher does? When I was a kid and went to the movies, I didn't like ushers much. To me they were just nuisances who made me sit in the children's section, far back where I couldn't see.

But a church is different. There's a lot more to an usher's job than telling people where to sit. The usher is often the first person a new visitor meets. The way the usher greets the person can really make a difference. It helps answer some questions: Will I be welcome here? Is there true warmth in this place, or just cold formality? If I am disabled, will I get the assistance I need? Or will I be ignored, feeling as wanted as a coat rack on a hot summer's day, while church folk go about their real business?

It may be no exaggeration to say that an usher presents the face of the church. There's a lot more to it than handing out programs and showing people to their seats. But what about the ushers themselves? Whose job is it to welcome them?

David De Porte has been an usher at his Episcopal church going on three years now. He started when a parish member asked for his help. David's guide dog Siri joins him in greeting people as they enter, but it's David who hands them the programs. His disability prevents him from assisting them to their seats, but he does help take the collection and he carries the silver bowl of communion wafers during the procession to the altar. And while Siri does not take communion herself, she does receive a special blessing.

David's acceptance in this job was by no means assured. When he was first appointed to the Ushers Committee some objected. They never said whether it was because they thought David couldn't do the task or because he would present a bad image. David suspects it was both. And for a while some of the ushers refused to work with him. But they finally came around once they realized how silly they looked complaining they didn't have enough people while David was only too willing to help.

David's critics are right about one thing: an usher really does present an image of the church. What kind of image could a disabled usher promote? One that casts shame on the church, or one that shows it to be a warm, caring, inclusive community?

Perhaps the most important job an usher has is to make people feel welcome. And people feel welcome to the extent that they are able to participate. David, like many of us, loves to participate by singing the hymns. The hymnal thus becomes a crucial instrument of church diplomacy.

Unfortunately many churches do not realize this. Standard hymnals are difficult to read even for many normally sighted people. Some churches have hymnals in Braille, but this is a rarity. And according to David, many "enlarged print" hymnals are really enlarged paper, with not much difference in the size of the print. The print is barely more than 12 point - hardly "large" by any standard. Sometimes people with low vision use words-only versions, but these too are often far from adequate.

David says it is important for us to let the publishers and distributors of these "large print" hymnals know they are not serving the purpose. Good intentions are wonderful but they don't guarantee readability. David recalls his childhood, when his great-aunt and great-uncle would send expensive Christmas gifts to him and his sister. Invariably these precious items were broken in transit. David

wanted to tell about this so the items could be exchanged, but his parents insisted he keep the broken things for fear of being rude. So the gifts Aunt Ida and Uncle Leo had carefully chosen soon found their way to the trash heap, a waste of both money and kind intentions. There's a reason hymnals are called "service music." If they're not being of service, what good are they?

Finally, I'm sure David would agree that the spotlight does not belong to him alone. He admits he couldn't do the job without Siri, "an excellent worker and great, great friend." But Siri too has her tribulations. Sometimes a congregant will bring her pet toy poodle to the church (and do not be deceived - this one is no toy!). Well that dog just runs around on people's laps, raising all kinds of what I shouldn't say in an article about the church. This can upset Siri; still, she's always on the job, helping David spread good will while presenting an image of the church true to the spirit of Christ, who embraced all and excluded none.

Reading to My Children
By Debra Carroll

Last November I gave birth to our twin daughters, Katelin Michelle and Kayla Morgan. They were born 11 weeks before their due date. We welcomed them and the nurses in the premature infant nursery oversaw their progress. What a happy time in our lives! Our babies are doing well. They do not have retinopathy of prematurity or the retinitis pigmentosa, which I have.

As I looked forward to being a Mom, I wanted the chance to hold my children in my arms as I read to them, just as my own parents had read to me. How could I do this? I have very limited vision and I use a CCTV to read. I don't read with any degree of fluency.

Here is how I solved this problem. Using my CCTV I look at the text in the books I want to read to my children. I memorize the words so that I can say them smoothly, without hesitation. I proceed line by line and record the story on a cassette tape. Then when I want to spend time reading to Katelin and Kayla, I turn on the tape I made and hold my children and the book. My daughters hear my voice as I cuddle them closely while reading to them. What special moments in my life as a new Mom!

Searching for the Perfect Set of Wheels
By Kelsey Reams

Reprinted with permission from Dialogue, Spring 2002.

We Americans love our wheels. They make a statement about who we are, or who we would like to be. More importantly, they give us the freedom to go wherever we want, whenever we want. I feel the same way about my wheels, even though I don't see well enough to drive a car.

When my first daughter was born, I searched for magazines like Stroller Trend and American Muscle Stroller to help me decide which stroller to buy. I was tempted by those sleek little umbrella strollers, what with their sexy good looks and promise of sizzling road performance, but in the end, I went for the durability and load capacity of a full-sized model.

I bought one with a fold-down seat, because I could easily fit six bags of groceries and a kid inside. In a pinch, I could put eight bags of groceries inside, and balance a kid on the pull-out sun bonnet. On shopping days, I'm sure I was a curiosity to passing motorists, but I didn't mind as long as the girls were with me. When they outgrew the stroller, though, I worried that I would look like a "suburban bag lady", rather than a charming eccentric, so I traded my stroller in on a pair of roller blades.

Roller blades appealed to me, because I imagined they would make me look hip like my cousin, who gets around Manhattan on his. This was foolish, however, since it's hard to look hip and terrified

at the same time. The knowledge that an imperfection in the concrete, or a downhill slope could send me hurtling out of control kept me rigid with fear.

It's interesting how fear alters one's perception of things. Say, for example, you are on a wide sidewalk, circling a lake. As you crest a hill, you see below you a power-walking grandma in a pink jogging suit. Coming up the hill toward you is a young mother, leading a gaggle of toddlers. The toddlers are scattered across the sidewalk, moving in their unsteady, unpredictable toddler way. You might think, "Life is good. It warms my heart to see the young and old enjoying a beautiful day like today."

Given the identical situation, I thought, "Life is cruel. It makes my blood run cold to see the havoc I could wreak on the young, the old, and me. "I threw myself into the weeds at the side of the path. As I lay there, I wondered what sort of trade-in allowance I could get on a low-mileage pair of roller blades.

I got a great deal on a used bicycle. I have a feeling of control on a bicycle, which is, on the whole, false. I should have recognized this the first time I missed a curb cut and rammed into a vertical curb. My bicycle stopped, and as if in slow motion, I somersaulted over the handlebars, and landed in a sitting position on the ground. If I were more superstitious, I might have taken this for a sign, and quit riding. As it is, I am uniquely qualified to ignore most signs, supernatural or otherwise. I continued riding.

Nearly a year passed without incident, until a day this past summer, when I rode to the park with children and friends. Our route took us down a residential street, dotted with pools of deep shade. A cubic yard of dirt had been dumped into one of these pools, and a wooden pallet tossed on top. My eyes reported none of this to my brain. I clipped the corner of the pallet, and flew into the pile of dirt, dislocating my shoulder. Even I couldn't ignore a sign like that. The bike went to Goodwill, and I bought a new pair of walking shoes.

Walking is slow, but it carries a certain cachet. People who see me walking frequently mistake necessity for virtue.

"You're so good," they say, "we see you walking everywhere!"

I smile in acceptance of this unwarranted praise, while in my hypocritical soul I think, "Just once I'd like to pollute the air, contribute to gridlock, or grow flabby behind the wheel of a candy apple red convertible."

The Miracle of the Moment

By Mike Vogl

The dreadful events of September 11, 2001 affected us all. Sometime after that tragedy I received a letter from a friend who suffers from multiple sclerosis and has impaired vision. Her letter included these words:

"After the 9/11/01 violence, I found myself not being frightened about the future, in large part because I am disabled. We have had our futures compromised by our handicaps. We were faced with accepting that which many of the mainstream don't. Our faith, of course, is the main reason, but we also realize our disability gives us a sense of the order of things important. When I looked at the picture you sent of your son Peter holding the big fish he caught, living that moment, I envy the innocence and lack of anxiety it shows. All we have in the earthly life are "moments". Being slowed by disabilities makes the small moments worth more than wealth, ambition or success. These things matter less when one is disabled."

Living in the moment, being aware of the present-the NOW-is a philosophy that at first glance seems hard to live up to. Living the moment fully-easy to say, tough to do. Alan Watts said, "The harder we try to catch hold of the moment to seize a pleasant sensation...the more elusive it becomes... It is like trying to catch water in one's hands-the harder one grips, the faster it slips through one's fingers."

On the other hand, poets and pundits, saints and scholars have a lot to say about living in the present moment. If we listen to their words, perhaps we will be inspired to try being more alive, being more aware of the "now." Following are some samples of word I've read or heard:

CHERISH TODAY! Yesterday is but a dream. Tomorrow is a vision of hope. Look to this day for it is LIFE.

Yesterday is history. Tomorrow is a mystery. And I know that only this moment is mine to fill to the brim!

Don't miss life thinking of tomorrow. Make the most of today. Be aware of what you are doing and feeling. We hurry to get through things to do better things. When you eat a slice of bread, be aware of the soil, sun and toil that made it. Smell the rain, feel the breeze, listen to the wind. Look, listen, live-now!

The future is what we do in the present. -Mahatma Gandhi

You don't get to choose how you are going to die or when. You can only decide how you're going to live-now. -Joan Baez

Enough happens during the ordinary day of every ordinary person for at least a paragraph or even a chapter in a best seller. The trick is to learn to recognize how truly meaningful is every moment of even the dullest day. -Mel Ellis

...no time is really "ordinary." No matter how routine or uneventful, every moment is like a diamond, sparkling with potential truth or kindness or justice or forgiveness. -Bishop Richard Skiba

Every dewdrop and raindrop has a whole heaven within it. -Henry Wadsworth Longfellow

People with low vision have many hardships to deal with. And hardships are just that, but if we carry them one moment at a time, they can become accomplishments. If we don't give up, we can feel pride in what we have achieved and survived. We soon realize that no one can be totally happy all the time. Happiness comes only in moments. Life is lived in moments. Often joyful moments are quickly replaced by sad ones. Laughter turns to tears, gratitude gives way to resentment, peace fades to worry. All the more reason we must relish those joyful moments-they are the sparkle of life - and they are forever.

The ability to be MINDUL in the present moment will help us cope with stressful situations. We can be mindful of our body, our surroundings, our loved ones. Breathe deeply, evenly, consciously. Practice letting muscles loosen. Listen, feel, look. We will have many aware moments, we will make wonderful discoveries about ourselves, about our surroundings, our loved ones. -Don Norum MSW

Life is a gift, given, not in years, but in one moment at a time. Ziggy says "Each new today is a gift. That's why it's called the present! And each tomorrow is another present we haven't unwrapped yet!"

The Path to a Guide Dog
By Larry Marcum

Recently I embarked on a new and exciting experience. Because of my diminishing eyesight due Retinitis Pigmentosa (RP), I decided to apply for a guide dog. RP is also known as tunnel vision. The cells in the retina die as this disease progresses, and the tunnel gets smaller and smaller; RP

can result in total blindness. Night blindness and loss of visual acuity are also symptoms. My field of vision is less than 10 degrees, whereas a person with normal vision has a field of about 180 degrees.

My training with my Guide Dog was an absolutely incredible month. Before leaving my home in Forest Ranch California to begin my training, I wondered-- What would this experience really be like? What would the school be like? And most importantly, what would it be like to actually have a Guide Dog? I am happy to report that all of this was as much and more than I had imagined!

The school I selected is Guide Dogs for the Blind in San Rafael California. The course is 28 days long, with training 6 days a week. People eligible for a guide dog must be legally blind (corrected vision of less than 20/200 or a field of vision of less than 20 degrees), at least 16 years old, physically, mentally and emotionally able to care for and work a guide dog.

The application process includes doctor's verifications, Orientation & Mobility training (white cane), personal references and both telephone and personal interviews by the school. Just before Thanksgiving the school notified me that I was accepted (and am I thankful!)

This was an exciting time for me. Before I even met my dog, my dog was being trained to help me. This dog will guide me for the next 8 or so years, going most everywhere with me, keeping me safe and allowing me to go places that otherwise would be difficult for me. The dog was born at the school, bred from the schools own quality stock. After six weeks the puppy spent about 18 months in the loving and caring home of a Puppy Raiser. This person then had to part with this puppy that he or she took everywhere as a "Guide Dog in Training". I think about the heartache that this person felt when returning the puppy to school a few months ago. But I also know the pride that this person would fell at the graduation ceremony in February, seeing "their" puppy, now matured into a highly trained, dedicated and devoted guide for me.

For the six months before I arrived at the school, my dog was trained daily in all the skills needed to be a guide. For the first three days that I was at the school the dog's instructor worked with me, all the while evaluating me to make a perfect match of guide and handler. The third day was called "Dog Day"-the day on which I was paired with the dog that had been matched to my particular needs and personality. Talk about the ultimate blind date!

I now have a terrific new friend named Galleon. He is a 70-pound Golden Retriever / Yellow Labrador mix who turned two years old January 29th. We are getting along great, with the bonding process progressing each day like any friendship, a matter of trust and respect growing on both of our parts.

The day that I received Galleon, the third day of class, was filled with much anticipation and anxiety. The instructors had carefully matched a dog that they had been training during the previous months. I am still amazed at how well the instructors do in matching dogs with students. There was not a dog in our class that I would rather have received.

When I was introduced to Galleon it was a moment of indescribable wonder. As each day past Galleon and I learned to dance together so to speak. Learning to walk, turn, stop and react together to so many things that the sighted world never needs to give a second thought to. Curbs, corners, poles, signs, pedestrians and other things that were recently obstacles and a source of great anxiety for me are now things that Galleon gracefully guides me around or warns me about.

We learned to work as a team along rural roads, city streets, in stores and crowds, and on public transportation. I learned to put my trust in Galleon, and he learned of my love and appreciation

Galleon is living up to the meaning of his name. The Spanish Galleons were first built in the early 1500's, had 3 or 4 sails and 3 or 4 decks. These ships navigated the treacherous waters, safely getting to the needed port. These ships were built to withstand severe weather and rough seas. My Galleon has been equipped with the needed training to do the same for me.

The feeling that I experienced the first time I felt his body movements in the harness handle brought tears to my eyes. To be able to feel each of his 4 paws through the handle as they touched the ground is a feeling that will never leave me. But I've noticed as each day goes by our movements are starting to meld into a rhythm, a fluid movement that allows Galleon and me to sense each other's actions. To be able to walk the same speed as sighted people again without the fear of tripping or running into something is independence beyond description.

We took some night walks while we were in San Rafael. I am night blind, which means that I practically have no vision at all at night. Can you try to imagine what it was like for me the first time in my 50 years to safely walk at night at normal speed without the deep concern of running into things? To safely cross an intersection with a trained dog whose total focus is to safely guide me is a true blessing.

Before the graduation ceremony I had the privilege of meeting the person who raised Galleon as a puppy. This person taught him the habits that are so crucial in laying the foundation to become what he is today, a well-focused guide, able to follow directions and ignore distractions that would take any other dog, or person, as far as that goes, off course. Like the ships over the centuries, he will safely bring me into many a port in the future. Thank you my Galleon.

For more information on Guide Dogs for the Blind, you can call them at 1-800-295-4050 or visit their website: www.guidedogs.com

Guide Dogs--Facts and Misconceptions
By Larry Marcum

Wow, what an experience it is now having a Guide Dog to guide me. Galleon and I are getting along fine, he is doing a terrific job and I am still learning how to handle him. It is still amazing how quickly he learns, responds and surprises me.

Guide Dogs are trained to be mobility partners for people who are blind or visually impaired. The handler has gone through an extensive training program to learn how to work and care for the Guide Dog. The guide is a specially trained dog, bred from stock that has been carefully selected for its even temperament, intelligence and good health. The dogs are taught good social behavior from the time they are puppies. They respond to obedience commands in addition to guide work, and they are trained to lie quietly when not guiding.

In order for the dog to maintain focus on its guide work and to ensure the safety of the team as it travels, the dog and handler must form a very close bond and learn to communicate with each other. The handler will need to act in ways that will reinforce this bond and maintain the training the dog has received. Therefore, it is important for friends and neighbors to respect the handler's needs and not do anything that would lessen the bonding process between the dog and its handler.

Although it is very tempting to approach and pet a Guide Dog, it is important that you greet the handler first and ask permission to meet his or her dog. Never distract a guide while it is working, because you may endanger the safety of the team or erode the dog's training. The dog should be on leash, under control, and not feel cornered when meeting people for the first time. Individuals should approach one at a time, speak softly to the dog and offer the back of their hand for the dog to sniff.

There are many misconceptions that the public has about Guide Dogs, and I thought I'd write about some of them.

"You have a Guide Dog and you are not totally blind?" Many people with Guide Dogs do have some vision, at least when getting their first dog.

It takes a lot of close work when learning to handle a Guide Dog. The Guide Dog handler needs to know how to get from point A to point B, the dog does not know this until he learns the route through repetition. I've had people come up and ask me "Is he in training?" My response is "No, we're the real thing!"

Because most cannot tell by looking at me that I am visually impaired, they wonder why I have a Guide Dog, or why I'm bringing a dog into a public building. Little do they know that as my vision is diminishing I would be mowing them down without my Guide. Like me, many people who once had fairly good vision may not "look blind" even after their vision is totally gone. The other day we were in Wal-Mart and I overheard a woman say to her husband "Hey Henry, look at the pets they let into these places nowadays". Maybe I should have gone back and explained to her why Galleon is not a "pet".

"Can Guide Dogs read Stop signs?" No, they cannot read Stop signs or traffic signals. The way that Galleon works is that he guides me along a sidewalk or road until we get to the corner or a curb, or a complete obstruction. At that point he stops, which tells me that we are at an intersection or curb, then I probe out with my foot to feel the change while he waits for me to give him a direction command to proceed. It is up to me to listen to traffic patterns or use other cues to decide where and when to go next. If I give Calleon a command that will put us in danger, he will stay put or pull me back, while probably thinking "Yo, human, don't you hear that truck coming?"

The dogs have been trained to follow lines when possible, like curbs or road edges, so Galleon knows to stop when we approach a corner without a curb or intersections with wheelchair ramps.

"Guide Dogs Are Overworked". Although Guide Dogs are called "working dogs", they do not "pull" us like sled dogs do. They guide us, and the harness is what we hold on to enabling us to follow them. Guide Dogs are treated with a lot of love, caring, praise and respect. They are housedogs when at home, are groomed daily, and have plenty of play and rest time. When I put Galleon's harness on him, believe me, he is anxious and excited to start working!

For more information on Guide Dogs for the Blind, you can call them at 1-800-295-4050 or visit their website: www.guidedogs.com

POWER, CONTROL, CONFIDENCE, AND COURAGE

By Jayne Leone

These four words are scary--especially when grouped together! Overwhelming, maybe! But essential if one is to survive and to cope with life. Let's examine each of these words in the context of living with a visual impairment.

I. Power. Power can be positive, or it can be negative. Power that is used to overwhelm, to subjugate, or to compel conformity is negative. Power that is used to enhance or enrich is positive.

Empowerment is positive. Empowerment may be enabled, but in order to be real, it must come from self; that is, it is self-motivated--and self-motivating. Associated with empowerment are concepts such as vigilance, persistence, persuasion.

2. Control. Like power, control can also be either positive or negative. It relates to making choices, establishing priorities, using will power. In the positive sense, control relates to the ability to function either as an individual or to act for the good of a group. Words such as responsibility and far-sightedness may be associated with control in its positive sense. In this sense, a bus driver who manages to maneuver his vehicle through traffic with skill in order to deposit his/her passengers safely at the curb uses a large measure of control. In its negative sense, control involves domination. We can control our access to information, our ability to be mobile. Holding back positive emotional reinforcement and limiting our options are other examples of control used negatively. Negative control is associated with repression.

3. Self-control, Control of self is essential for empowerment. When we feel frustration, anger or rage at the attitudes or reactions of loved ones, friends, colleagues or society toward us as people who have visual impairments, self-control enables us to remain rational and to function effectively within our home environment or the community. Self-control is an empowering dynamic. Self-control helps us to be good examples to others; it enables us to discuss with and teach others how we, as people with disabilities, manage to cope. Self-control enhances our credibility and contributes to self-esteem.

3. Confidence. Confidence is the product or result of one's past experience. It is related to one's value system, to one's system of strategies for solving real-life problems, to knowledge of self, to one's general outlook. Confidence is affected by such conditions as isolation, integration within a

social group, level of functioning or degree of independence. Associated with confidence are concepts such as assurance, assertiveness, conviction.

Self-confidence, confidence in oneself, is a quality that, along with self-control, can enhance empowerment because it can help to generate or increase motivation to achieve goals.

4. Courage. The dictionary tells us that courage is the ability to do what needs to be done, even under adverse conditions or circumstances. It is my opinion that courage also has a spiritual, mental, emotional and physical dimension. Of these four, one dimension may be more or less stronger than another, from individual to individual. These components make for an odd combination, puzzle or design. This may explain, in part, why courage--courageous acts or decisions--manifests itself differently among individuals. I believe there is within each of us the potential for being courageous--to dare to do and to be. The recipe is a balance among the four qualities I have been discussing: empowerment, self-control, self-confidence, courage.

In my experience as a person with low vision, the sense of empowerment, self-control, self-confidence, a deep breath, a moment of prayer, have given me the courage to get through some very trying times in my life. We are never fully aware of what our courage--or the collective of empowerment, self-control and self-confidence--can do for, or show to, others around us. We can affect others and each other on so many levels without being cognizant of it. The times we feel the least effective and the least courageous may be the times we help those around us the most. There is an old saying: "No man is an island."

Also, there are always those members of society who look around and observe how others act, react and interact in various situations and under various circumstances. Proffering support, encouragement and help can be a gate, a pathway, a bridge to many others around us.

Related to the word courage are the words encourage and discourage. (In fact within the word courage is the word rage). Think of the times we have encouraged ourselves or encouraged others. Now think of the times we have discouraged ourselves and discouraged others. There are many buzz words being used today--such as empowerment, challenged, support--used by many professionals, when in reality the operative words are courage, encourage or discourage. As we well know, many social institutions can encourage us or discourage us who have disabilities. They can help us be empowered, help us to maintain self-control, help us be self-confident, help us gain courage. By discouraging us they can do the opposite.

We must assume a proactive, assertive--and at times aggressive--stance relative to our destiny. Just because our vision may be impaired or in a state of flux, because we are not able to do many very commonplace things without assistance, such as reading our own mail, reading a current book, the daily paper, or a menu, does not give others the right to take power or decision-making away from us. Nor should we be too willing to relinquish them --by perhaps talking ourselves out of doing something we are really able to do. True, we may have to do them differently, at a different time, with more conscious attention. But so many things can still be done; some with help. And it is permissible to try things and to fail until we can find a successful strategy for doing what it is we are trying to do. Those around us may say "Isn't it amazing that that person (with a visual impairment) can do things so well!" or "Isn't it amazing how they try." Yes, we can do many things well; we just don't see well. In fact, we may not see at all. But we are just as valuable--we have just as much worth--as any other human being.

We can look after each other, those of us with similar conditions, such as vision loss or impairment. We can 'listen; we can show empathy toward those who are confronting problems and undergoing adjustments that we have already experienced. They, in turn, may be able to provide support for us when we need to overcome hurdles they have already negotiated successfully. It is a reciprocal process or exchange. We can share information, experiences, fears, hopes, dreams, ideas, and knowledge. We can help each other to set and attain goals. We can encourage each other without being judgmental. After all, this is what advocacy is all about: To create an environment and the opportunity for people to live full lives, even with adversity.

In the midst of working toward overcoming our disabilities, we should take time to focus on our special skills and talents. Maybe we are here on this earth at this time in order to teach or to encourage others around us. Something to think about.

Day-to-day living with a disability and attempting to exercise empowerment, self-control, self-confidence and courage can be tough. Sometimes society can be controlling of our lives by doing too much for us or not doing the correct thing(s) for us. The challenge is to persuade society to allow or enable us to have the courage to try to do the things we are able to do. On the other hand, if we need special help or support, we should not be too proud or afraid to ask for it.

Let me give you an example of the payoff of a little, but important, help. At an event I attended recently, an 80-year-old woman was playing the piano. I walked over to compliment her on her playing. While talking with her I learned that she has macular degeneration and her husband is suffering from Alzheimer's disease. This lady used to be the pianist for the Pittsburgh Opera. As we talked, she was playing Gershwin's "Rhapsody in Blue" from memory. She told me that she had felt so depressed that day until I came over to spend time with her. Before I left, I took down her name, address and phone number. The next day I went to the Pittsburgh Blind Association, PBA, and bought her a 20/20 pen, a tablet of large print paper, and a signature guide. I told her that her bank could order large print checks for her use. I told her about the Carnegie Library for the Blind so that she and her husband could read together at night when he could not sleep. And I gave her the number for the Greater Pittsburgh Guild for the Blind from which she subsequently received instruction at her home. Later she and her husband moved into a more supportive facility where she was able to receive help in caring for her husband as well as for her own needs. For the first few months after our meeting she called me regularly to tell me how grateful she was for the kindness I had shown her and the help I had provided. In reality it was very little help; it was more like giving direction, showing her where she needed to go. This woman demonstrated great courage in a difficult time of her Iife.

I do not tell this story to get "a pat on the back." but rather to make the point that the little things we do for others who feel defeated, depressed, unsure, can open up for them gates and pathways that can lead to wonderful changes for them and alter their lives significantly.

I guess this is really my reason for writing this article--for all of us to think of strategies to help ourselves and to help others. In the days to come try to think of the ideas of empowerment, self-control, self-confidence and courage and how they can apply to your situations and your lives. Try to think of how the media and society views us who are people who are visually impaired or blind. I believe that within the next 10 years the number of senior citizens with visual impairments will increase. People will be living longer; but unless they are very fortunate, they will not escape the ravages of time. The eye seems to be very vulnerable to the aging process. The point is that the media and society will have to take a more insightful look into their feelings and attitudes about people who have impaired sight because there will be so many more of them to deal with. Many advocates in the disabled community (including some Board members of Western Pennsylvania Council of Citizens with Low Vision, WPCCLV) have seen action in this direction already. Implementation of the American's with Disabilities Act, ADA, has given more rights to disabled people in the workplace and made possible more access to information.

I urge all of you to become active participants in what happens to you. Doing so will increase your self-esteem and contribute to your self-actualization. To do this, you will need to feel empowered, to exercise self-control, to feel self-confident and to have courage. We all have doubts, fears, insecurities; but we must rise above them if we are to help ourselves and help others. I believe we can. Do you?

Assistive Technology

Next Generation Technologies, Inc. Announces JawBone Version 60.402

Seattle, Washington-June 9, 2002: Next Generation Technologies, Inc., a Lynnwood WA based alternative access technology consultancy, today announced a significant product revision to JawBone software with the release of JawBone version 60.402.

Providing interoperability between ScanSoft's Dragon NaturallySpeaking Professional version 6.0 and Freedom Scientific's Jaws for Windows version 4.02 this latest product release now supports the Windows XP Home/Pro operating systems.

In addition, the new media tutorials provide support for features that are familiar to the extensive user base, as well as the newest commands and capabilities. Daniel S. Makus, developer of JawBone, has developed an improved method for accessing information from the NaturallySpeaking Correction Dialog. The user requests choices to be read, spelled, etc.-rather than have them read automatically. In beta testing, this new feature proved to be significantly easier from the user's perspective than previous methods.

Other new features include:

. improved support for Word tables
. a new command to access the Application Key (right mouse button)
. improved spelling support for highlighted text
. commands to support Jaws for Windows for Bosse said he
. better support for the Internet and more flexible commands for accessing information, links, etc.
. support for Eudora Pro and Outlook Express

The current version 60.402 has expanded support for Internet access, which includes the ability to turn off the echoing of dictation, and commands in Internet Explorer. This minimizes possible auditory distraction while users are accessing information from the net. In addition, the new Get Text Only command moves the cursor to the first occurrence of 15 not linked characters. giving the user an easier way to find text on Internet pages. With the Virtual Cursor toggle command, the user toggles between the JAWS virtual cursor and the PC cursor.

"With a host of new features, and what we hope will be an easier user interface, we expect to JawBone version 60.402 to continue the advancement of this exciting technology." says Ed. Rosenthal, President and CEO of Next Generation Technologies, Inc. "I think that Daniel, and the design team, overcame a number of programming obstacles to create what is possibly the best JawBone interface since we started. We believe even greater numbers of individuals who are blind, experience low vision, work with learning disabilities, or cope with mobility impairment and repetitive stress injuries will be able to access PC/computing technology."

AVAILABILITY AND SYSTEM REQUIREMENTS

JawBone supports Windows 9.x and Windows 2000/XP. System minimum recommendations are Pentium IIIR 600 MHz processor with 256MB RAM.

JawBone is supported by a dedicated team of distribution professionals that can provide support and training.

Founded in 1994, Next Generation Technologies, Inc is headquartered in Lynnwood, Washington. More information on JawBone and Next Generation Technologies, Inc. can be found on the World Wide Web at:http://www.ngtvoice.com/software/JawBone.htm Edward S. Rosenthal- Pres.&CEO, Next Generation Technologies, Inc., 20006 Cedar Valley Rd. #101, Lynnwood, WA 98036, Phone: 425.744.1100, Fax: 425.778.5547, Email: edward@ngtvoice.com
URL: http://www.ngtvoice.com

Telesensory Announces Portable Video Magnifier

People with low vision can read anytime, anywhere with the MiniViewer from Telesensory. At home, school, work, or on the go, this portable video magnifier enlarges text or images up to 15 times on a full color, high resolution screen, so reading greeting cards, personal mail, recipes, and menus is made easy! The lightweight design with optional

battery pack and carrying case makes the MiniViewer the first truly portable low vision solution.

The MiniViewer comes with risk free, 30-day money back guarantee. For information or to arrange your free, no-obligation demonstration, call 1-800-804-8004, ask for operator 63, or visit www.telesensory.com/miniviewer

Low Vision Conference

Discovery Conference

Discovery--The Low Vision Conference 2002-- will take place from September 26 -28, 2002 at the Congress Plaza Hotel, 520 South Michigan Avenue, Chicago, Illinois, 60605.

Come to this Conference to gain a comprehensive perspective on low vision and vision rehabilitation. This conference will bring together people with vision impairments of all ages, their families, educators, doctors, rehabilitation professionals and vendors. Sixty presentations and many exhibits are planned.

Registration fee is $50 per person before September 1st and $80 per person after that date. Mail registration to Discovery 2002, c/o The Chicago Lighthouse, 1850 West Roosevelt Road, Chicago, IL, 60608.

Room rates at the Congress Plaza Hotel are $122 single, $132 double, plus 14.9% tax. For room reservations, call 1-800-635-1555 by August 25th and mention the Discovery Low Vision Conference.

For more information about this conference call the Deicke Center at 630-690-7115 and ask for Leah Gerlach.

CCLVI Convention 2003 in Pittsburgh, Pa

CCLVI 2003 Convention will be held at the Westin Hotel in Pittsburgh, Pa. Convention dates are June July 5 to July 12, 2003. Plan now to join us. First time convention goers are especially welcome. Call the Westin Hotel for reservations at 800-228-3000. Suggest topics for programs speakers or for convention events to the Program Committee by calling 800-733-2258.

Resources
The Health Library
THL@pa.pcbvi.org

National Eye Institute
2020Vision Place
Bethesda, MD 20892
301-496-5248
2020@nei.nih.gov
Dialogue Magazine

Guide Dogs for the Blind,
1-800-295-4050,
www.guidedogs.com

Next Generation Technologies, Inc.
http://www.ngtvoice.com/software/JawBone.htm
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Telesensory
800-804-8004, ask for operator 63, or visit www.telesensory.com/miniviewer

Working Group for the Partially Sighted
http://groups.yahoo.com/groups/wgps

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, 1155 15th St. NW, Suite 1004, Washington, DC 20005. Our Tax ID number is 1317540.

CCLVI 2003 Membership Application or Renewal
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