

VISION ACCESS

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by

the Council of Citizens with Low Vision International.

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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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Editor: Joyce Kleiber

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From the Editor

Like many of you, I did not attend the CCLVI convention in Birmingham Alabama this year. Instead I attended the funeral of my dear aunt in Milwaukee, Wisconsin. I missed the chance to meet people with low vision at the convention. But I had the privilege of meeting many of the presenters from our convention by phone. By phone I gathered summaries of CCLVI's convention program for this issue of VISION ACCESS. What special people these presenters are!

As you read this issue, you too will meet these people. You too can feel connected with the low vision community. You will find encouragement; you may feel less alone, you will learn about new devices that can make your life easier. You can experience a support group by reading "Member to Member". Then you might consider joining this on line low vision support group--wgps.

Let us hear from you. Share your experiences with us. JMK, 8-5-04.

President's Message

LOOKING BACK TO BIRMINGHAM AND FORWARD TO LAS VEGAS

By Patricia M. Beattie, CCLVI President

Members who joined us in Birmingham, Alabama for our national convention are still raving about how much they learned and all of the fun they had as they talk with new and long-time friends on the phone and via e-mail. On each of seven days we had one or more events. These included informative programs, board and membership business meetings, support groups, and our four traditional social events--the welcoming and farewell dances, a mixer, and our game night. The exhibit hall was brimming with high and low-tech products ranging from talking or easy-to-read wristwatches and audio described movies to the latest in cell phones, computers and notetakers.

If you have not yet attended a national convention, you'll discover that there also are many other events going on during convention week. The principal national organization at the convention is the American Council of the Blind (ACB), of which CCLVI is a national special interest affiliate. Other special interest affiliates include the attorneys, students, teachers, and veterans as well as groups interested in assistive technology, talking books, women's or aging issues. CCLVI collaborated with the National Association of Parents of Visually Impaired (NAPVI) and with the newly-revitalized Council of Families with Vision Loss. Together we presented an afternoon of programming in which we took a peek at genetics and we shared personal experiences as grandparents and parents. Some panelists had many years of low vision experience and others were new to this community. As you will see in one of the reports from the convention in this edition of Vision Access, the presentation on depression and vision loss was far from depressing!

We are pleased to welcome four new members to the CCLVI Board of Directors. Carolyn Hathaway of Canton, Ohio, is our new secretary. New directors are Lisa Boettcher of Columbia, Missouri; Kathy Casey of Albany, New York; and Barbara Millville of Vienna, Virginia.

As we move into our 2004-2005 year with CCLVI, we are delighted that some of our most hard working leaders will continue in their current roles or take on new roles. Our first vice president, Bernice Kandarian of Mountain View, California will continue to answer our toll-free line (1-800-733-2258); she also will serve as membership records chair, working closely with our new treasurer, Mike Godino of Malverne, New York. The immediate past treasurer and a past president, Coletta Davis of Anaheim, California, is now the second vice president. Another long-time leader, Joyce M. Kleiber of Philadelphia, Pennsylvania, continues as the editor of this publication. Imogene Johnson of Little Rock, Arkansas, will chair the committee to select 2005 recipients of the Fred Scheigert and Carl Foley scholarships.

WE'D LOVE TO HEAR FROM YOU! Are you interested in organizing a Support Group or Local Chapter? We have heard of interest in Seattle, Washington; Austin, Texas; Baltimore, Maryland; St. Louis, Missouri; Pittsburgh, Pennsylvania; and Memphis, Tennessee.

Interested in a scholarship? We give them to college students with low vision and also to graduate students with or without low vision who are planning to specialize in services for people with low vision.

Do you have an opinion about and/or an experience in a rehabilitation program? Were you required to use sleep shades or a blindfold? Did you have to use a specific style of cane? Were you required to learn Braille? I attended a seminar in June where these training program requirements were explained. At this seminar a sighted

orientation and mobility instructor advocated that sighted professionals teach while blindfolded. If they are blindfolded, they would experience the same challenges as their students. The partially sighted students should also wear blindfolds. He said that in training programs the field should be leveled with the use of blindfolds; then people with low vision can gain confidence and begin to use the alternative techniques that are being taught to them. Without blindfolds, clients with some residual vision become sighted guides and help-mates for the totally blind students; and therefore they may not learn new techniques for themselves. It was a thought-provoking day for me.

What do you think should be the characteristics of "large print"? Some of the issues are size, font style, contrast, and placement within white space or on non-glare yellow paper. What about our website at cclvi.org? ACB's website at acb.org and The Braille Forum?

Do you have an idea for an article in Vision Access? How about expressing your opinion in a Letter to the Editor? Write to the editor, Joyce Kleiber at 6 Hillside Road, Wayne, PA 19087, or email to jmkleiber@hotmail.com. Want to help us design a new CCLVI brochure? Want to help on a CCLVI committee or be a mentor to folks who call for help to our national office? There will be formal training at our next national convention in July 2005 in Las Vegas, Nevada, for people who would like to join the corps of folks who are willing to be in touch with these callers - this program is called our Project Insight for people experiencing low vision issues.

While you're thinking about CCLVI, you might want to make a note to pay your 2004-2005 dues. The cost is only \$15. Of course, we'd be delighted if you included a donation to the Scholarship Fund, to support the Vision Access magazine, or to the 800 telephone number. Life memberships are \$150.

So, readers, we'd love to hear from you soon and hope to see you at our next convention in Las Vegas.

Our address is CCLVI, c/o ACB, 1155 15th Street, N.W., Suite 1004, Washington, DC 2005. Our toll-free phone number is (800) 733-2258.

Meet Our Scholarship Winners

The Council of Citizens with Low Vision International gave two Fred Scheigert scholarships for \$2000 each. to Lisa Wayland Boettcher and to Raisa Furman. CCLVI is grateful to Fred Scheigert, CCLVI Board Member, for funding these scholarships. The CCLVI scholarship committee was chaired by CCLVI board member, Imogene Johnson, with members, LeRoy Saunders and Janis Stanger,

The Carl E. Foley Graduate Education Scholarship Committee, Carl Foley, Jane Kardas, and Barbara Kron selected three recipients. The recipients are: Philip Isika Ngali, \$2000 award, Kendon A. Kraska, awarded \$1500, and Lori Michelle Miller, \$1500. All winners are seeking careers of service to people who are visually impaired.

To receive a scholarship application, send a self-addressed-stamped envelop to Imogene Johnson, 5311 B Street, Little Rock, AR 72205-3509 or find an application on the CCLVI web site. The applications must be submitted by April 15, 2005. It is important that applicants follow all directions and requirements listed in the application.

Four of our recipients prepared essays for VISION ACCESS in which they share their experiences and describe their goals.

Lisa Wayland Boettcher

My life changed dramatically when in October 1996 I was diagnosed with Punctate Inner Choroidopathy; this is a very rare retinal disease. In 2000, I became legally blind bilaterally, due to the resulting neovascularization over both of my maculae. Prior to

becoming visually impaired, I had been employed as an intensive care registered nurse. I was unable to continue working as a nurse in early 2000. I found that employers were not comfortable with my use of magnifiers; they felt I was a safety risk to patients. This was a devastating experience. I returned to college in the fall of 1998. My goal was to become a biomedical engineer. I began by completing my Bachelor of Science degree in nursing and biology.

Biomedical engineering was initially my career interest in high school and I had been accepted at some strong engineering schools such as Purdue. When I returned to college in 1998, I realized my recent intensive care unit clinical open-heart experience might fit well with my interest in biomedical engineering. I met with members of the biomedical engineering department, and they confirmed that my career choice would compliment my experience. As my vision decreased, I realized that, with my limitations, working in a fast-paced company would not be the best choice for me. So I considered a doctorate degree to prepare for a career in either teaching or research. I was encouraged by my department and advisor to continue in graduate school.

In the last 72 hours of my undergraduate career as a visually impaired student, I maintained a GPA of 3.45. In our college of engineering, a GPA of 3.0 is required for the Dean's Honor Roll. Engineering is a very intensive and difficult path, and I am very proud that I have succeeded thus far. With determination and persistence I have continued striving for my goal-a Ph.D. In 2003, I was awarded a pre-doctoral fellowship with the National Institute of Health (NIH) to aid my research training. I was told this is an impressive achievement, as I am the only NIH fellow at the University of Missouri-Columbia.

I am also very proud to have won scholarships from the American Council of the Blind in 2003, from the American Foundation for the Blind in 2002, and from the Missouri Council for the Blind. I have been appointed to the State of Missouri Blind Literacy Task Force (2003) and I have been invited to assist Vice President Al Gore prepare for the 3rd 2000 Presidential Debate in St. Louis.

My hobbies include staying active and informed politically, doing activities with my husband and three young children, taking walks, attending plays, listening to National Public Radio, cooking and cheering on the Missouri Tiger teams. I like to swim and garden in the summer. I really make an effort to do the activities I used to do before I became visually impaired and I take advantage of available accommodations.

I very much love graduate studies in engineering, and look forward to the day I can become a faculty member of a biomedical engineering department at a major university or at a government agency such as the National Institute of Health or the National Science Foundation. I am very interested in helping visually impaired students who want to pursue engineering or science degrees. I found that vocational rehabilitation agencies are not very supportive of students who want to challenge themselves with difficult career paths. I will use the funds from this scholarship to pay for costs associated with my education, such as educational fees, equipment, and for my medical and living expenses.

Raisa Furman

Until the age of 21 I lived in Russia. There I graduated from St. Petersburg Pharmacy College in 1994. Since coming to New York in 1995 I was determined to get a college education. This was impossible at the beginning because of the language barrier, my financial situation and other circumstances. When I arrived in New York I didn't speak any English. After acquiring some English I started to work for minimum wage and I understood that without higher education there is no access to a

professional career. So, I worked and learned English. At one point I was taking classes in English as a Second Language in two different schools at the same time. I was determined to become proficient in English on the college level.

When, at last, I started my college education I encountered yet another obstacle. My vision began to deteriorate very rapidly, until I became legally blind. My disability puts some limitations on my abilities, but it will not stop me from moving toward my goal, even if I have to crawl in order to get there. I decided that this new challenge wouldn't stop me from doing my best.

I was undecided about my major for two years, until I took an introductory class in psychology. I was able to explore different aspects of this science, and I was hooked when I learned about cognition. The issues of perception, language, memory, intelligence and problem solving became extremely interesting and relevant to me. Ever since I took this class I became interested in human behavior; combined with my own experience of being bilingual, I was intrigued by the cognitive aspects of human nature. Research and education fascinate and motivate me to think unconventionally and to stay on top of the latest achievements in social science. I will do all this as a future cognitive research psychologist.

My disability does not prevent me from seeking my goals. It just makes it harder to achieve them. But I am up to a challenge! I have also satisfied the requirements for a minor in Russian. I am not only studying with a disability, but also educating people about the challenges of having a disability while pursuing higher education. I participate in campus events that address issues of disability. I am one of the initiators and organizers of a support group for students with visual impairments. By providing awareness about students with special needs, our group tries to better the life of all students and faculty. I am unemployed right now; I volunteer as much as I can for organizations that promote humanity.

I became a citizen of the USA at a very difficult time for the nation. On September 11 2001 I was scared and sad for my family and for myself while I mourned the thousands of innocent lives lost in the rubble. On September 14 2001 when the courts finally opened, I walked in and became a new citizen of the United States; these states were actually more united then they were ever before. The judge assured us that at this horrible time of grief we would strengthen our nation by becoming lawful citizens and doing everything in our power to stop the terror.

I use adaptive technology to read, write and perform any other task of everyday life. I intend to further educate my peers, myself and the community, in general, to improve the lives of people. My goal is to contribute in any way I can to the causes that are beneficial to humanity.

This scholarship will help me to become a psychologist. Graduate school is very expensive, especially in a private college like Long Island University, and so financial aid is extremely important to me.

Philip Isika Ngali

I was born in 1972, the first of six children in Nairobi, Kenya. I received a Bachelor of Science degree from Jomo Kenyatta University of Agriculture and Technology in Nairobi with a major in mathematics and a minor in computer science. After my graduation, I attended Kenya Institute of Management for management courses and Infotech Technology College for computer science classes. I have also attended several seminars on counseling as part of my on-the-job training while working at Kenya Society for the Blind. I am currently pursuing a dual master's degree in Rehabilitation Counseling/Rehabilitation Teaching at Western Michigan University. I intend to pursue a Ph.D. in counseling psychology.

I was first employed as a Statistical Data Analyst for one and a half years by Construction Project Consultants Inc. After my education in management, I advanced to Assistant Site Administrator for this same company. Then, Kenya Society for the Blind (KSB) employed me first as a volunteer and later as a manager of the Center for Adaptive Technology. In this position, my major responsibility was to train people with visual impairments in computer adaptive skills. Besides training, I did career counseling with my students. I really enjoyed working with people with visual impairments because it gave me intrinsic as well as extrinsic rewards. I remember during the job interview at KSB I was asked why I thought I could do the job because I had never worked with people with visual impairments. I answered that I love humanity. This job gave me the chance to assist others and it was challenging, as I then had no skills in rehabilitation for the blind. I did independent study and skills development, and with help from colleagues, I was very successful in this job.

My career goal is to create an environment in which people with disabilities will become self-reliant. I want to develop services for people with disabilities where such services do not exist and to improve services where they already are in place. I want to be an advocate for people with disabilities.

In my leisure time I enjoy body building and martial arts. Sports help me to generate energy, to be disciplined, focused, healthy, and to increase my determination. I am also the Secretary/Treasurer of the Student Rehabilitation Association and the Events Coordinator of the African Students Association, both at Western Michigan University. I am a student member of the National Rehabilitation Association and the Association for Education and Rehabilitation of the Blind and Visually Impaired.

Ken Kraska

I have experience in education, communications, psychology and human services. I was born and raised in northeast Ohio, and I've lived in Columbus, Ohio for the past seven years. In high school I read books to a family friend who was visually impaired and lived in a nursing home.

I am a Psychology instructor at Columbus State Community College. I am also an announcer at a classical music station at Ohio State University. In addition, I work as a substitute teacher in the Columbus Public Schools; some of my students have visual impairments. I also serve as an occasional driver and sighted guide for a computer teacher who has a visual impairment. I also read for individuals with various disabilities. In this capacity I have read and recorded exams for a visually impaired stockbroker and I have entered data for a gentleman with a physical disability.

A few summers ago, I volunteered as a camp counselor with Project Support. Here I worked alongside individuals with various disabilities including vision loss. In my spare time, I facilitate the creation of a community radio station for two nonprofit educational and social services organizations.

My past experiences also include developing residential radio stations for retired seniors and for schoolchildren who are visually impaired; I worked with these children for four years as a part-time teacher at the Ohio State School for the Blind. In this role I taught a wide variety of subjects, with children of different age groups and levels of impairment both visual and cognitive.

My prior education includes a Master's degree in Psychology and a Bachelor's in Liberal Studies. As a volunteer I worked with grieving family members as a hospice bereavement counselor. I taught English as a Second Language to immigrants and refugees. Additionally, I served as a reader at the Radio Reading Service for the Blind.

I am now working toward a graduate degree in Orientation & Mobility at Western Michigan University in Kalamazoo. This summer I will study and train in Methods of

O&M, Low Vision Practice, and Adaptive Sports. I plan to use the scholarship money to cover the extra expenses incurred by living and studying out of state.

I wish to express my great appreciation for your generous award. I feel honored to have been selected as a winner of the Foley Graduate Scholarship. Some of the classes I will attend next semester include hands-on mobility training under blindfold and a low vision laboratory. I wish to thank you and the Selection Committee for your support in furthering my career serving people with visual impairments.

After graduation, I plan to work as an Orientation and Mobility Specialist in schools. Areas of interest include assistive technology and bioptic driving instruction. My long-term goals include possibly teaching O & M at the university level.

CCLVI Chapter Reports

California Council of Citizens with Low Vision: We are planning our semi-annual convention. This convention will be held from October 28 through 31 at the Los Angeles Airport Marriott Hotel. Our convention will be held in conjunction with the California Council of the Blind which is celebrating its 70th anniversary. For information call 510-537-7877, the office of the California Council of the Blind or call California Council of Citizens with Low Vision at 800-733-2258.

Delaware Valley Council of Citizens with Low Vision: Our June meeting featured a presentation by Michael D. Kelly, Customer Relations Development, Extreme Shopping USA. Michael's company develops a customer profile for each person who becomes a client. The purpose of this profile is to determine preferred products and quantities required over time. Then products are mailed to customers at appropriate times automatically. You have what you need and want at your door when you need it." As customers shop with this service, they earn points which can be applied to future purchases. The one time fee for this service is \$21.

Some of our members are science fiction fans. They enjoyed the movies I Robot and King Arthur.

Another group of members gathered in July for an afternoon of crafts, sharing projects and ideas.

At our August meeting, Jerry Weinger, CCLVI board member, reported on new developments in assistive technology as he experienced these at the exhibit hall at the ACB Convention.

For information about our chapter serving the greater Philadelphia area call 215-735-5888.

Metropolitan Council of Low Vision Individuals: Our Chapter meets on weekday evenings at various Manhattan locations, always close to public transportation. For information about our chapter call 845-986-2955.

National Capitol Council of Citizens with Low Vision: In June, the topic of our meeting was VisuAid's Trekker, a GPS-based orientation and mobility product. It is a personal digital assistant (PDA) application adapted for those who are blind or visually impaired. Brian Sullivan, Sales Manager at Bartimaeus Group in McLean, VA gave us a tour of the unit and showed us how to access the talking menus and maps. Then we hit the streets and put it to use. Without much training at all, we were able to easily navigate to our favorite restaurants. It identified the names of streets at intersections and called out the names of stores and other buildings ahead. We all loved its portability and felt we could wear it all day without getting tired. Attendees agreed that while it will not replace

a white cane or guide dog, it has the potential to provide the user with much needed info about the environment.

Don't hesitate to call me, Barbara Millville, if you need further info about our Chapter. My number is 703-645-8716.

Convention Report

Depression as Related to Vision Loss

**By Dr. Ikan C. Kleerly
(aka Edwin Druding, Ph.D.)**

(This was the topic presented during the 2004 ACB Convention. Due to its popularity your editor requested a summary for this issue.)

Depression. What is it? To the geologist it is a hole in the surface. To the economist it is a slump in the market. To the optimist it is an inverted hill. Everyone has experienced it, some more emphatically and longer in duration than others. Elizabeth Kubler Ross is well known for her Stages of Death and Dying. First is shock or disbelief. "Why me?" The second step is denial. "It can't be happening!" The third step is anger. The fourth step is arbitration. "God, if you make this go away, I'll do....." The fifth step is acceptance. "OK, where do I go from here?" An individual with vision loss experiences the same steps as does the person in grief. Vision is personified and vital. To suffer from diminishing vision is like watching a loved one dying. Sometimes we are that person.

People in the health care profession will tell you that depression accompanies virtually every physical and emotional malady. It is frequently associated with one of the most joyous occasions, child birth. Post partum depression accompanies about one in five women to some degree, even those who anxiously anticipated the arrival of the baby. Some issues contributing to this are a change in focus from Mama to the baby, or that the baby is not the "perfect answer" to her prayers; it cries at inappropriate times, has constant changing needs and the list goes on. Patients have told me "I must be depressed because my doctor is giving me pills for depression." Pills all too frequently inhibit the individual's ability to allow the body to make the adjustments that it was designed to make. Certainly, a malfunctioning pancreas needs to be supplemented with insulin so that the body functions properly. Many anti-depressants medications have more 'side effects' than true benefits. I tell my patients that it takes more energy and uses more muscles to frown than to smile. I also have discovered a simple task that I assign my patients.

* Recognize that depression is a factor that is present in you life to some degree.

* If you focus on the depression it becomes more overwhelming.

* Every day, preferably first thing in the morning (before you have your coffee), take five (5) minutes to be depressed. Don't allow any happy or pleasant thoughts to enter your mind.

* At the end of the five minutes, stop thinking depressing things. If there are other things that need to be considered, tell yourself, "Tomorrow we will have our five minutes to consider that issue."

Try this exercise. You will be surprised to find that you cannot think of something during that time and may snicker to yourself, which is the brain's way of saying, "It was not that important!"

Certainly, vision loss is not a laughing matter. However, think of a person you know or have heard about who has lost their vision partially or totally. If that person seems well adjusted chances are that depression was merely a station along the way, not the final destination.

Low vision support groups can help far more than the pills. It is not what you can GET from the group but what you can GIVE to the group.

Learn to smile! Even laugh at yourself when you do something stupid. Everybody does something stupid at times. Look at history. It is not how many times you trip and fall, but how many times you get up! Apply these thoughts to your everyday life and you will never need my professional help for depression.

Note: Next issue Dr. Ikan C. Cleerly will address Macular Degeneration. Other eye conditions will be discussed in future issues.

Travel and Low Vision

Reporting a panel of Presenters:

Connie Standing Clear says she is addicted to cruises. She works hard and she plays hard. Connie has been on two cruises so far-the first, last autumn up the east coast to Nova Scotia, the second, last May up the inner passage to Alaska. Connie plans a cruise to the Mexican Riviera this September and a cruise to the Panama Canal next April.

Connie is totally blind, lives alone on a farm in Ohio--far from many of her friends, and she works as a vendor in two rest stops on Route 76.

While on a cruise with her standard poodle guide dog, Connie said she has fun and experiences a sense of control. She can choose whether or not to attend a high tea, a comedy night, musical entertainment, etc.

Connie's cruise experiences have been with Damar Travel. She reports that Dave Kronk and his assistants have been employed by Damar Travel to assist passengers with special needs. They met Connie at her hotel and provide transportation from the hotel to the ship. Crew members or guests also assisted Connie at buffets and offered descriptions of sights along the way-like that of the three eagles flying over Ketchikan Bay in Alaska. Even the smallest details are taken care of. Connie likes being pampered with a chocolate on her pillow and her covers turned down.

Connie enjoys meeting people both at her job as a vendor and while on board a ship. She noted that every nationality seems represented among crew members and passengers. The countries that crew members represent may be at war, but no harsh words are spoken during the cruise. Passengers are relaxed and interactions are stress-free.

For all these reasons and more, it is understandable that Connie is addicted to cruises.

Skip Sharpe said he has traveled with the military and that because he is retired from the Air Force, he can still travel with the military at no cost. He has also traveled to England and to Germany as a National Aeronautics and Space Agency employee.

In addition to these ventures, Skip has enjoyed two cruises. The first was a "Music of Your Life" cruise. On this cruise, Big Bands played the music of the 40's, 50's and 60's as the ship sailed through the Caribbean. This cruise was arranged by a radio station for the dancing and listening pleasure of their radio audience. Skip's second experience was on the Island Princess sailing through the Panama Canal. On this cruise Skip said there was plenty of good food and drinks. Entertainment included

Broadway musicals, plays, line dances, singing contests, and a library.

Skip encourages people with low vision to travel. "Don't let your limited vision stop you!"

Billie Jean Keith spoke about her travel experiences with two organizations- Campanian Society and Elder Hostel.

The Campanian Society offers educational travel programs for people who are visually impaired. These programs are designed to meet the special needs of travelers and to provide a rich experience usually unavailable on trips ordinarily scheduled for people who are sighted. Each of these trips offers opportunities for tactile experiences along with on-site lectures, readings, music and audio-description. The programs are limited to approximately 12-15 participants. Sighted guides are a part of all programs.

Billie Jean noted that assistance is appropriate and respectful, not at all patronizing or intrusive. For additional information, you may check www.campanian.org.

Elder Hostel travel programs are less costly than those offered by Campania where part of the fee covers the expenses of the sighted guides. Offered to adults 55 and over, nearly 200,000 people take part in Elder Hostel programs each year. Elder Hostel offers over 10,000 programs a year in more than 90 countries. Participants come from every walk of life to learn together, to exchange ideas, and to explore the world.

Billie Jean went to Key West Florida with Elder Hostel. At the start of the program, Billie Jean's husband, who is blind, asked that other participants lend a guiding arm sometimes. Thereafter, whenever they went anywhere, many people were willing to help. What made this experience special was the chance to meet people who were eager to learn and share. At dinner Billie Jean and her husband sat with different people every time. They attended lectures by expert instructors in the morning, and in the afternoon they visited the sites that were the subject of the morning lecture.

For further information visit www.elderhostel.org.

Parenting with Vision Loss

By Lisa W. Boettcher

In 1996, I was diagnosed with a rare retinal disease that led to legal blindness by early 2000. At the time I became legally blind, I had three children ages 2, 4 and 10 years old. I had worked as an Intensive Care Unit nurse and was forced to leave my career due to my vision loss.

There were many changes that took place in our family after my vision loss. We became a one driver family, had significantly less income to work with, and I had a difficult time doing many family and parenting tasks. I could not see my children if they were in a crowd or too far away, I was unable to read books to them effectively, and I could not see what they were playing with from any significant distance. You can imagine the frustration I felt as a parent!

Some of the methods I used to cope with problems and frustration involved the following:

Explain your limitations

Communication with my spouse and children was a very important issue in coping with vision loss. When I had trouble with a particular task, I admitted it was a problem, and asked for help. For instance, if I cannot see to cut up onions anymore, I don't do it. I ask for help from either my spouse or an older child. I try to find some other task I can do instead. I do not feel guilty about what I can't do; I just concentrate on what I can do.

I make sure I explain to my children what I can and cannot see. They are interested in knowing what it is like to see what I see, and how I see things differently than they do. My children were fascinated with all my new low-vision devices.

Restructure family tasks

I could no longer pay bills, read school notes or help with homework very effectively. I could give baths, fold laundry and provide hugs!

My husband and I traded tasks, with the added help of our older daughter, to make things work.

Develop keen listening skills

With my small children, and my vision loss, I find that my hearing becomes a much more important sense than I ever imagined. I learned to tell what every child is doing by the noises (or lack there of) that I hear. This is a skill that evolves. My children are constantly amazed at what I know by my ears.

Take the time to develop your low-vision skills

I use the teaching services provided by my local rehabilitation for the blind agency to learn easier ways to accomplish homemaking tasks that are now more difficult since my vision loss occurred. This training increased my independence. These agencies can also provide things such as a CCTV or magnifiers I may need. Skilled rehab teachers are an extremely valuable resource for a parent who is visually impaired.

Accept the changes and be realistic with your own expectations.

I am not going to be super-mom anymore, so I don't expect to be. And I do not feel bad or guilty about what I cannot do as a parent. I find other ways to be there for my children such as playing word games; I can participate in such games without seeing well. We like to play 21 questions, which is a game in which one of us thinks of an object and the other players try to guess what it is using 21 questions.

Conclusion

Parenting with vision loss takes problems solving skills as well as creativity. Communication is the key element in working with your spouse and children to find solutions to daily problems. As a parent with vision loss, I think it is very important to be open with your children about your condition and help them to understand what you can or cannot see.

I hope these tips can help other parents that experience vision loss.

What's New from Exhibitors?

Mike May of Sendero Group said that within about one year a Global Positioning System, GPS, for use inside buildings may be available. With this technology, users will be able to locate specific rooms, restrooms, etc. Sendero Group 530 757-6800
www.senderogroup.com gps@senderogroup.com

Jeff Moyer and Ward Bond looked into the near future to describe a seamless approach to transit. Travelers would not only be assisted in crossing intersections with the help of audible traffic signals, but they would carry small receivers which would interact with chips placed on signs on buildings. Travelers would thus be able to find the specific places to which they are going. Such devices will be helpful on city streets, at airports, and at intermodal transit stations where several systems of transportation come together.

Talking Signs Inc.
800 339-0117
www.talkingsigns.com

Wendy Mons, founder and president of Mons International, said that her company offers a variety of devices for people with low vision, featuring video and optical magnification and lighting, including strong magnifiers which can be purchased without prescription.

Mons International Inc.
800 541-7903
www.magnifiers.com

Susan Palmer Mazrui spoke of an accessible cell phone being announced by Cingular Wireless. This phone will speak the numbers being entered, provide an audible caller ID, and tell users when the battery needs to be recharged.

National Center for Cingular Customers with Disabilities
866 241-6568
www.cingular.com

Russell Smith, President of Pulse Data International announced a new video magnifier called "My Reader" which will be released in September. It has unique features, is extremely ergonomic and makes good use of computer technology without being a computer.

Pulse Data Humanware
800 722-3393
www.pulsedata.com

Dave Kronk from Damar Travel discussed accessibility aspects of cruising and related the ways in which he approaches these issues in cruises which he is marketing to members of ACB.

Damar Travel
800 999-6101

Science and Health

Retina Shift Restores Sight

By SARAH AVERY

Reprinted with permission from The News & Observer Publishing Company, Raleigh, North Carolina.

DURHAM -- There is no cure for macular degeneration, but that's a bit of hairsplitting if you ask Alice Haynes.

The eye disease, the leading cause of blindness among older Americans, robbed Haynes of central sight in her left eye and was quickly going after her right. On the advice of a friend, she went to Duke Eye Center for radical surgery.

Now, at 69, the Chapel Hill grandmother of nine is back to driving, and golfing, and reading -- things she thought she'd never do again.

"People will say to me, 'My God, this is a miracle,' " Haynes said. "And it really is."

The surgery is called macular translocation, and it offers hope to people who have lost sight in one eye and are beginning to lose it in the other.

The two-phase procedure involves moving the macula -- the center of the retina that contains specialized cells for fine vision -- away from a diseased area underneath, restoring vision.

Dr. Robert Machemer, emeritus chairman of the Duke Eye Center, was a pioneer in the surgery in the early 1990s, but it is only now gaining momentum. His successors at the center have fine-tuned the process with advanced techniques and tools.

Dr. Cynthia Toth, associate professor of ophthalmology, said she was initially skeptical that the procedure was safe and effective.

"I thought it was too extreme," Toth said. But she had experience with macular degeneration, having watched her grandmother lose her sight to it. And she was compelled by the results, with many patients regaining enough central vision to read again.

She began performing the surgery at Duke in 1996 and has done more than 230 operations. She also teaches the technique to other eye surgeons.

"People can get their vision back," she said. "It just blows you away."

But it's not for everyone. Because of potential complications, a patient is considered for the operation only if he has already lost sight in one eye and is in the early stages of losing it in the other. Complications include such problems as double vision or tilted vision.

The alternative, however, is the certainty that central vision will deteriorate, taking with it many of the activities essential to independent living.

Age-related macular degeneration afflicts 1.6 million Americans in their later years, according to the National Eye Institute. While its cause is unknown, how it works is better understood.

When macular degeneration strikes, deposits form behind the macula, creating a cloudy hole in the central vision. The most common form of the disease, striking 85 percent of the time, is the "dry" form, which refers to the bloodless way the deposits develop.

A less common "wet" form occurs when blood vessels behind the retina begin to leak, creating a bulge that lifts the macular part of the retina away from the eye wall. Brief opportunity

In both cases, the macula eventually thins and dies, leading to permanent damage. Duke's surgery capitalizes on that brief period -- perhaps six months -- when the macula is still healthy but vision is deteriorating as a result of the abnormal growth under the retina.

The first surgery is an exacting procedure that relies on an operating microscope. Enlarged images of the interior of the eye are projected onto a video screen. Toth and a surgical resident sit at the patient's head, peering into the microscope or at the video screen as they work with tiny instruments inside the eye.

The patient, under local anesthesia, is awake, and Toth chatters amiably to offer updates and explanations of the work. As she enters the eye, Toth sets about removing the vitreous gel that fills the eyeball. Then she injects a fluid under the retina to loosen it from the abnormal cells.

Using a tool devised by Machemer, she gently cuts the retina, a fine filament that has the consistency of wet tissue paper, to separate it from the eye wall and rotate it away from the damaged area.

In a recent case, she carefully lifted the deposit that had caused the macular degeneration, much like lifting a scab from skin.

Then, donning special goggles, Toth fired a laser at the edges of the retina so that it would implant back along the eye wall. Finally, she filled the eye with a silicone oil to hold the retina in place. The procedure lasted about two hours.

Haynes, who had the surgery in January 2001, said the first procedure was not painful but required a two-week regimen in which she had to keep her head in certain positions for 12 hours a day -- four hours with her head resting on a table, four hours lying on each side. The positioning was to assure that the retina healed in its new location.

"Friends came and talked with me and brought me tapes to listen to," she said. "It wasn't that bad. I felt that the end result was far worth the inconvenience."

Second round

Because the center of vision is shifted, patients have a tilted perspective from that eye, and Haynes said this was disconcerting, as if everything was tipped to the side. The second surgery is designed to correct this tilt.

At Duke, the second operation is performed eight weeks later by another team of eye surgeons led by Dr. Sharon Freedman. The eye itself is rotated, and the muscles are adjusted to hold the new focus. Haynes said she recovered quickly from the second surgery, although her vision remains slightly tipped at about 5 degrees.

That has created problems only for her golf game, she said: "I have trouble reading the greens."

But Haynes is back to participating in her book club, driving around Chapel Hill, even threading sewing needles. She was so proud of the latter feat, in fact, that she carried her threaded needle to Toth as a testimony to the surgery's success; Toth sports it on the lapel of her white coat.

Glaucoma Research Furthered with Implant

Reprinted with permission from Minnesota Eye Consultants.

March 11, 2004. Minnesota Eye Consultants has been selected as one of only 15 U.S. investigational sites to participate in on-going clinical trials (Phase III) for the Eyepass(TM) Glaucoma Implant. The device represents an emerging surgical treatment option for glaucoma, the second-leading cause of blindness.

"The Eyepass(TM) Implant, an investigational device, is designed to lower abnormally high intraocular pressure, which is the major risk factor for vision loss from glaucoma," said Dr. Thomas W. Samuelson, board-certified ophthalmologist and a founding partner of Minnesota Eye Consultants. "We are very encouraged by the preliminary results from the earlier phases of the clinical trials surrounding the Eyepass(TM) Implant, particularly for patients who have failed to respond to conventional medical therapies or laser procedures for glaucoma."

Approximately 2.2 million Americans suffer from glaucoma, and as many as 2 million more may be undiagnosed, according to the Glaucoma Research Foundation and the National Eye Institute. "Many patients are unaware that they have glaucoma until it progresses to more advanced stages," said Dr. Samuelson. "While there is no cure for glaucoma, early diagnosis and treatment can reduce its progression by as much as 50 percent."

Glaucoma involves damage to the optic nerve, most often from high pressure caused by poor drainage of a fluid (aqueous humor), which supplies nutrients to the cornea and lens, according to Dr. Samuelson. Some forms of glaucoma cause symptoms such as blurred vision, severe eye pain, headache, rainbow-colored halos around lights, nausea and vomiting.

The more common form of glaucoma, known as open-angle glaucoma, typically does not exhibit any outward signs or symptoms, according to Dr. Samuelson. Rather, the disease develops gradually and can go undetected for years. "An annual, fully

dilated eye exam is the best means to monitor eye health and pressure and detect glaucoma in its earliest stages," he said.

Conventional glaucoma treatments include eye drops or oral medications, laser procedures and/or surgery to lower internal eye pressure by opening drainage passageways for the trapped fluid.

The Eyepass(TM) Implant is promising because it may significantly reduce the risk of glaucoma surgery, such as the potential for serious eye infections for the remainder of the patient's life, according to Dr. Samuelson. "The Eyepass(TM) Implant is intended to bypass the diseased portion of the eye's drainage system, but utilizes the normal fluid pathways downstream from the obstruction," he said. "The Eyepass(TM) Implant may extend the options to potentially provide a vital therapy for patients with open-angle glaucoma who have not benefited from conventional treatments," said Dr. Samuelson.

He added, "Earlier studies suggest its safety and ability to lower abnormally high intraocular pressure. We're looking forward to participating in on-going clinical trials leading to FDA approval."

Dr. Samuelson has been recognized internationally for research supporting the medical and surgical treatment of glaucoma, as well as laser vision correction of refractive disorders. He is president of the International Society of Spaeth Fellows - Wills Eye Hospital's glaucoma fellows program, and a recipient of the American Academy of Ophthalmology's Achievement Award, honoring physicians who significantly contribute to the Academy's educational endeavors.

For more information about glaucoma, or to inquire about eligibility for the Eyepass(TM) Implant or other upcoming research studies at Minnesota Eye Consultant, please call 1-800-EYE-TO-EYE or visit the website at www.mneye.com.

Minnesota Eye Consultants, the ophthalmology practice of Drs. Richard L. Lindstrom, Thomas W. Samuelson, David R. Hardten, Elizabeth A. Davis, William J. Lipham and Patrick J. Riedel, is a nationally recognized leader in the treatment of glaucoma, as well as corneal, cataract and refractive surgery.

Eye Drops May Delay or Prevent Glaucoma in African Americans at Higher Risk

Eye drops that reduce elevated pressure inside the eye can delay or possibly prevent the onset of glaucoma in African Americans at higher risk for developing the disease, researchers have found. This makes it more important to identify African Americans at higher risk for developing glaucoma so they can receive prompt evaluation for possible medical treatment. These results are reported in the June 2004 issue of "Archives of Ophthalmology".

Scientists found that daily pressure-lowering eye drops reduced the development of primary open-angle glaucoma in African Americans by almost 50 percent. Primary open-angle glaucoma is the most common form of glaucoma and one of the nation's leading causes of vision loss. Of the African American study participants who received the eye drops, 8.4 percent developed glaucoma. By comparison, 16.1 percent of the African American study participants who did not receive the eye drops developed glaucoma. The study was funded by the National Eye Institute (NEI) and the National Center on Minority Health and Health Disparities (NCMHD), two components of the Federal government's National Institutes of Health.

The results of this study, called the Ocular Hypertension Treatment Study (OHTS), are a followup to initial results released two years ago. In those findings, researchers discovered that treating people with elevated eye pressure could delay or prevent the

onset of glaucoma. At that time, results for the subgroup of African Americans trended in the same direction, but were not conclusive.

Dr. Eve Higginbotham, M.D., chair of the Department of Ophthalmology at the University of Maryland Medical Center and first author of the journal article, suggested that before determining treatment, the doctor and patient should also discuss the patient's health status and life expectancy, and the burden of daily treatment, including cost, inconvenience, and possible side effects.

The OHTS studied more than 1600 people, including 408 African Americans, 40-80 years of age who had elevated eye pressure but no signs of glaucoma. Half were assigned daily pressure-lowering eye drops, and the other half were assigned to observation (no medication). In the medication group, the number of African Americans participants developing glaucoma was significantly lower (8.4 percent) compared to the observation group (16.1 percent).

"The study also confirms that the risk for developing glaucoma is higher among African Americans compared with others," said Michael Kass, M.D., of the Washington University Department of Ophthalmology and Visual Sciences and chair of the study. "A number of risk factors may be contributing to the increased prevalence of visual impairment from glaucoma in African Americans. These include a family history of glaucoma; earlier onset of the disease compared to other races; later detection of the disease; and economic and social barriers to treatment."

Glaucoma is a leading cause of blindness in African Americans, said John Ruffin Ph.D., director of the NCMHD. "Glaucoma is almost three times as common in African Americans than Whites," Dr. Ruffin said. "However, if glaucoma is detected and treated early in its progression, it can usually be slowed and serious vision loss can be delayed."

Dr. Ruffin said Medicare covers an annual dilated eye examination for people at higher risk for glaucoma. This important preventive benefit defines higher risk as people with diabetes; those with a family history of glaucoma; and African Americans aged 50 and older.

What is the Health Library and How Can It Help You?

The Stanford University Medical Center Health Library believes in making current information about health accessible to everyone. The main library is located in a shopping mall so that people can get information easily. One branch is situated at the Peninsula Center for the Blind and Visually Impaired in Palo Alto California. This branch is staffed by two nurses who are visually impaired, Dawn Wilcox and Jeanie Ackerman, and by Roger Petersen, a former psychology professor. This team makes information available confidentially to callers in large print, audio cassette, Braille, or email. As backup, Dawn, Jeanie and Roger can call on the Main Stanford Health Library, as well as several ophthalmologists, including those serving on the Peninsula Center's Board of Directors.

The confidentiality of callers is protected by HIPAA (the Health Insurance Portability and Accountability Act of 1996); only a record of the caller's location and age is kept by the Health Library's staff. This is for the purpose of securing grants to support the work of the Library.

The Health Library staff has prepared packets of information on various eye conditions including macular degeneration, retinitis pigmentosa, retinopathy of prematurity, glaucoma, diabetic retinopathy, retinoblastoma and cataracts. These packets, some of which are also in Spanish, are offered to callers on CCLVI's 800 line.

To reach the Health Library about your medical concerns, call CCLVI at

800 733-2258, or email thl@pcbvi.org.

Quality of Life
MEMBER TO MEMBER
By Carlos Gourgey, Ph.D.

Low Vision and Depression

In our support groups at the ACB Convention in Birmingham this summer, the topic that most frequently arose was how to cope with depression when facing progressive vision loss. Members shared different strategies: finding ways to maintain as much control of one's life as possible (such as learning low-vision skills), sharing experiences with others dealing with similar problems, and looking for sources of joy in life. (Animals, service and otherwise, ranked high in the joy department among many participants.)

The topic of facing depression also came up recently in our electronic support group. We began by talking about the depression that often accompanies gradually fading vision. When one member described a painful personal situation not directly related to vision, the group rallied to his support. Even at large distances, we can be sources of strength for each other.

For this particular member, spirituality provided the answer. This may not be the answer for everyone, and we never try to impose one member's solution on another. The idea of the group is to listen to each other and share our resources, and one never knows when what helps one member of our group may also help another.

The things that I just cannot seem to find a way to accomplish still nag at me. As I have said before, knowing what is on TV at what time is one of them. I rely on a friend to call me each day with the schedule. Our paper is online but not the TV listing.

Because I am retired I need something to occupy my time but a few of the volunteer projects I did in the past I am no longer able to do. Although I love the talking books and get very involved in the stories I do not want to spend all my time listening to them. I still have my knitting and starting back on the computer as I get lessons. Thought I might do a family history for my nephews. We are a very small family. Some cousins but mostly me and my brother and his family. The boys never knew their grandparents on our side. It seems to me that some record should be kept of our parents, grandparents and great grandparents. Any other suggestions that I might look into. My sight is very minimal but I am good with my hands and memory still works pretty well.

I guess I am still in the anger stage, as I would much rather clutter my garage with a vehicle of any type and gladly pay any outrageous price for fuel, insurance and maintenance. As for the time I save doing other tasks as I read, not in my life. I would rather sit at the table and deal with the newsprint and have my morning coffee! Still bitter and not "over it"....guess so!

I really do not like the term or concept of being "adjusted." We have to deal with the garbage we are dealt, there is simply no choice. If being adjusted means it doesn't bother you, then I'm not adjusted either. I doubt I will ever be.

For example, yesterday, I was given a piece of watermelon still on the rind. It's the first time I could not see the separation between the white of the rind and the red of the fruit. It struck me hard that I have lost so much more of the little remaining vision I had. Am I going to get angry? No. Am I going to cry about it? No. Did I notice it? Obviously. Am I happy about it? No way.

So, I guess the bottom line is that it just takes too much energy to be upset in any way about it. It's wasted energy because I cannot change it.

People say they want a second opinion when the doctor tells them what they don't want to hear. Well, I recently asked my eye specialist a serious question and she told me, no, my eyes will never improve, that we are fighting not to lose what I still have left of my vision.

Today, feeling still depressed I spoke with my diabetic specialist with my spouse and son present, asking him: "If I were to die right now, is there anything you would be able to harvest to benefit a living person?" He wouldn't look at me but said he doubted it. He then put me on Zoloft to help me with depression.

I can only laugh that I am worth nothing. I told my husband to call the rendering company, maybe he could still get lard price per pound. Sure hope that med has me laughing like an idiot in 24 hours or I don't know what else to do. I am going back into the other room if I find a stronger set of lenses, and put another flower onto my Easter bonnet. LOL

It ain't easy for some of us to put in some time on earth, or rather, in this prison. To me it is a prison because we're so confined to the physical plane, stuck in a handicapped body, trying hard to find some sense in it or something to smile about. Back in the good old days when we all could see better it wasn't nearly as bad because we could get around without guidance, and we could hold onto our independence, at least enough of it so that we can smile at the budding nature under the warmth of the sun, or see something humorous in kids as they frolic around us, or at something on TV, or at a joke someone tells.

When we can see we are not as wrapped up in ourselves and we can enjoy life more. But when we can't, are we doomed to a life of darkness? Or can we turn this darkness into the Light of God? Of course we can because His Light is always within us, in our temple. When darkness comes, we should go within and seek for the Light in the darkness--it is there, it is always there, and once you see it you will smile again and life will be worth

living once more.

As long as we live, we will be subject to things that'll make us unhappy. How unhappy it makes you depends on how you feel about a situation. This happens to me all the time--there's no end to it--and I always say to myself, "The river of life flows, sometimes the waters are calm and clear, sometimes it rushes and is muddy, and I'm supposed to go with the flow wherever it takes me." I feel that it is all God's doing, and I must go along with it.

No, it never stops. For instance, just a few days ago my wife of 24 years decided she wants a divorce, in spite of how good I've been to her, and in spite of having a nice house with all modern conveniences. But for some time now she hasn't been mentally right, and no matter what I do or how I try to reason with her, or what doctors have done for her, she is still insistent on going her separate way after the house is sold.

There is no certain thing in life, we have to take each day as it comes, whether that means starting a new life, living somewhere else, or whatever. Maybe we shouldn't get too comfortable with things, maybe we should always be ready for a change when it comes, maybe we shouldn't get too attached to anything because someday a change will come--it always does.

Thank you for such wisdom and Christian love. I am hurting for you about your wife. My husband of then died in 75 and God sent me this fine man and three more children in that same year and we certainly have grown together like we were meant to have been together all along. So, who knows what is ahead. If you are still in love with her, ask specifically for the union to be made strong again. I have asked and been granted so much lately, I never used to think you could ask, but it is part of his wanting us to grow closer, I do think. I got 5 Easter hats ready. Now, deciding? Lol

We are all with you and here to support you. There is no way of knowing why things happen but they do. We can only control our own lives and choices. It is hard to lose someone you care about, but one thing I have learned is that we can and do survive and the hard stuff makes us grow in ways we never knew we would. Just take it all one day at a time and remember, sometimes there are reasons for things we do not understand.

Why is it that we must struggle so much with life as a whole? I know the challenges make us stronger and become different opportunities. My thoughts are with you at this hard time. Keep your spirit strong and with your wisdom and insight, hopefully this obstacle will too become an opportunity.

I too am sorry to hear about your divorce. I've been around twice myself, and I admire your strength and courage. Maybe there is someone special down the road for you in God's time; not ours, which is the most difficult thing to learn, and I am still trying to learn this.

Dear concerned ones:

Life becomes a mystery when we don't understand why certain things happen to us that don't seem to happen to anyone else or other couples. Handicaps and failed marriages. It is like we have a part to play in a human drama upon the stage of life: some parts we play are nice ones, but some are not so nice.

I had always sought for the answers to a lot of my questions. I have cried out in anguish, shaking a fist at the heavens, "How can we have a loving and merciful God when He does this to me. Give me an answer, PLEASE!"

Well, God wasn't doing much talking to me so I went looking for the answers myself, and for many years I searched and searched, and I am now satisfied that many of my questions have been answered, but I had to pour over the writings of Eastern Philosophy/Religion like a ravening animal. I have discussed these findings with various authors and those involved in metaphysical study.

Without going into details I will summarize in just a few choice words that came from a fellow who lives in Oregon and who is currently writing a book. He sent me a sampling for me to review and as I was reading my eyes fell upon this: The question was asked, "Why are we here?"

And the answer was, "Because you chose to be."

The above was a channeled message that he is installing in his book. This is inline with age-old teachings of the Far East, which has not received acceptance in the West, but it explains so much. What he says and what I have learned answers many questions about why we come to earth with handicaps, and why we have to experience the trauma of certain relationships gone soured, and why we have to endure so many types of hardships--all of it, every single one of them are experiences that we souls need for our development into higher spheres, experiences that we asked for because they give us our greatest learning--life's hardships are our greatest teachers.

I've never mentioned this before to the group because this type of talk is too far-out to be believed, so I mostly keep it to myself, except in my writings. What I've learned made me realize that whatever happens to me or had happened, and will continue to happen as long as I'm on earth, is all for my own good. This is why I'm able to handle what comes along, including failed marriages.

I thank you all for your prayers, but don't pray to save this marriage because it has run its course, and now it's time for another adventure.

Prayers are good, especially for the soul, you know. And don't any of you feel sorry that it has happened to me--I'm not a bit sorry. In fact I'm feeling some sort of exhilaration because I had done everything in my power to make this relationship work, but it was not to be. Now I'm ready to move on, ready to go through something else that God wants me to experience. He's behind it all, folks, and He knows what's best for us, even while we moan and cry.

And finally, a response to the member who felt she had become worthless, a thought to comfort those who feel their disability has robbed their lives of meaning:

As long as one is capable of giving and receiving love, one can never say that one is worth nothing.

If you would like to join our group, please write to me at laflauta@hotmail.com.

How Does Your Garden Grow?

Reprinted with permission from Lighthouse International. This article appears in the Community & Lifestyle channel of the Internet portal VisionConnection (<http://www.visionconnection.org>)

If you enjoy nature and gardening is your passion, don't let vision loss get in the way. Here, find some helpful tips and resources. --Set up a basic layout with straight and uniform garden beds; use a cane as a guide for planting a straight row; or lay down two fishing lines and plant seeds between them.

--Place a brightly colored strip down the center of any pathway for easier orientation or use texture like gravel or bark.

--Wear an apron with plenty of pockets or a utility belt to hold your gardening equipment.

--Try sensory gardening. Grow plants with distinguishable scents or tactile clues that help you identify them easily. Good choices: geraniums (mint, lemon, rose) and herbs (basil: broad leaf, thyme: small leaf). Or consider plants with interesting textures like the fuzzy leaves of an African violet or the large flowers of an amaryllis plant. Grow lavender inside and enjoy the smell.

--Use large-print markers or tactual borders (container gardening, for example) to help with plant identification and reduce maintenance time. --Place mulch or landscaping felt between plants and seedlings to help reduce the need for weeding.

--Paint garden tools, such as hoes and rakes, to make them easier to see when you're using them. For example, white paint on the tines of a hoe provides excellent contrast with soil.

--Place high-contrast borders around trees or flower beds to make these

areas easy to identify when mowing the lawn.

--Use a guideline, such as the top of a fence, to help you trim hedges and bushes evenly.

Resources

Getting On With Gardening, edited by Tim Spurgeon, contains advice and tips, details on making gardening aids, tools information, garden planning and practical guidance for people with vision impairments. Available in large print, braille, cassette or disk from the Royal National Institute of the Blind. Cost: £3.00. Call RNIB Customer Service: 011 44 8457-023-153, www.rnib.org.uk.

Thrive, a UK based organization, offers courses and a telephone advice line for people with vision loss at (0118) 988 6668. Publishes Come Gardening, a quarterly magazine that contains articles and advice about gardening, information about new products and reader inquiries. Available in braille, cassette, computer disk or e-mail. Cost: £5.00, annual subscription. www.thrive.org.uk.

Oregon State University Extension Service offers a variety of publications on adaptive gardening including Adaptive Gardening Techniques for the Visually Impaired, which is available free in print or online. Call 800-561-6719, www.oregonstateuniversityextensionservice.edu.

Kids Gardening features all the ins and outs of growing plants - both indoors and outdoors for children ages 4 - 12. Includes 25 gardening projects, free seeds and shovel and helpful tips from a blind gardener. Available in a large print/Braille edition in one volume from National Braille Press. Cost: \$13.95. Call 800-548-7323.

Sources: Taking Charge of Your Life with Vision Rehabilitation, Lighthouse International, Vision Australia Foundation and Royal National Institute for the Blind.

A 'Wonderful Service' for Those Who Can't See By Valerie Scher

Reprinted with permission from the San Diego UNION-TRIBUNE

Amid the bustle before a Saturday matinee, it's easy to overlook the box of 23 headsets sitting on a table in the lobby of the La Jolla Playhouse's Mandell Weiss Theatre. But these are no ordinary headsets.

They're Sennheiser HD200s - cordless, high-tech wonders that help blind and low-vision theatergoers better understand what's happening during productions. In a sense, they help the blind see.

By wearing the headsets, patrons hear information that sighted patrons receive by reading the program or observing the action on stage during a performance.

How does it work?

Here's the official description: "During pauses in the dialogue, via a small headset . . . patrons hear a trained volunteer describe the stage action - body language, costumes, scenery, lighting, colors - as if a friend were seated next to them, all without disturbing others nearby."

The Playhouse started offering audio description in 1996; San Diego Opera and Broadway/San Diego followed in 2002.

"It's a really helpful service," says volunteer Shari Lyon, the Playhouse's access coordinator and head of its Audio Description Team. "We go in and find what is critically important to describe."

The Playhouse provides the service once during each multi-performance production. Sight-impaired patrons and their escorts -who each pay \$10 for an audio-described performance - sit among the sighted playgoers and listen to volunteers as they speak into microphones from the control booth.

Also included are pre-performance touch tours, during which patrons are encouraged to handle examples of materials used for costumes and props. They may get to stroke a character's spiffy blue suit, touch the snaps that allow actors to change costumes quickly, or even finger a toupee.

"Touch tours help the blind feel connected to the show," says Lyon, who leads the tours that are free to ticket-holders. "They've become so popular that even sighted patrons come to them."

Volunteer numbers: The Playhouse has an eight-person team of audio describers. Broadway/San Diego has approximately 20 volunteers. And the opera expects to increase the number of volunteers from seven to nine for its 2005 season, which opens in January.

Volunteers often have a personal reason for working with the blind and vision-impaired. Lyon, 57, wishes her arts-loving grandmother, who died 30 years ago, had had access to audio description.

"She became legally blind and stopped going to performances," Lyon recalls. "If she was alive today, she would be using this system - yes, absolutely."

One of Lyon's most memorable experiences occurred in 1997 after providing the play-by-play description for the drama "Having Our Say."

As she was collecting headsets and thanking the patrons who used them, one man recognized her voice as the one he had heard through the headset.

He took both her hands in his and said: "Thank you for giving me my life back."

"It was astounding," recalls Lyon. "I was so surprised and so moved that for a few moments I couldn't speak."

Audio description has added much to Mary Blue's opera experience. The 73-year-old San Carlos resident, who has been blind since age 25 due to the condition uveitis, attended San Diego Opera performances for four years before she began using the service last year.

"If you're a real music-lover, you can get along without it. But it's a big help," says Blue, who usually attends three of the company's five productions each season, accompanied by her husband, Henry. "It really enriches the experience."

Her favorite part? The vivid descriptions of the stage and colorful costumes.

"There's a crying need for this, especially as more people become older and get macular degeneration and other conditions," Blue says. "It's so defeating when your vision starts to go. This is a wonderful service that can keep people attending performances."

Intensive process

At the Playhouse, learning to excel as an audio describer is an intensive process can take as long as two seasons. Playhouse volunteers begin at a training class at Lyon's Escondido home, complete with lunch she prepares. (Her husband, Neil Pisk, is also an audio describer.)

"The brilliance of these people is that they're able to get the information out quickly," says Jeanette Horn, the Playhouse's director of education and outreach. "The cardinal rule is to not step on a line of dialogue."

Budding audio describers attend rehearsals, meet members of the cast and crew, and learn to write program notes. As they gain experience, they shadow expert describers in the control booth, studying their play-by-play techniques.

Once they prove they can do it, audio describers begin supplying commentary for productions. Sometimes they need to provide warnings to patrons, as when a production includes simulated gunshots that could startle a blind theater-goer or a service dog.

"We want to make sure that the volunteers are going to stick with us and that they can do what's needed," says Lyon who, aside from her volunteer work, is an actor, director and award-winning teacher at Twin Peaks Middle School in Poway.

Bob Kanish, who has been blind since birth, has attended audio-described performances at the Playhouse and helps train volunteers for San Diego Opera and Broadway/San Diego.

"Blind people like opera and theater as much as everybody else" says Kanish. "To be able to go to a performance and know what's going on - you can't put a price on that."

San Diego Opera's motto is "We make music worth seeing." So what advice does he give volunteers?

Kanish, who is married to Angela Montague Kanish, San Diego Opera's education manager, tells them not to be afraid of saying too much.

"It's important to describe all the elements," he says. "I tell them to be sure and get in all the things that catch their eye and are important to the story."

"Bob really wants the program to be successful," says his wife, who helps coordinate the San Diego Opera's audio-description program in addition to other responsibilities. "It has made him enjoy opera so much more. So I derive a direct benefit."

So far, audio description reaches a small audience - sometimes only a handful of blind or low-vision patrons per performance at the opera, Playhouse or Broadway/San Diego.

"This is a wonderful program - and one of the Playhouse's best-kept secrets," says the Playhouse's Horn. "We'd love for more people to take advantage of it."

Audio description arrived at the Playhouse thanks to the late Gail Lasdon, a Playhouse volunteer. Lasdon had been active in the Washington, D.C., area, where she worked with the Metropolitan Washington Ear, a pioneering organization for the blind and visually impaired.

In 1981, Metropolitan Washington Ear founding president Margaret Pfanstiehl (who is blind) and her husband Cody (who is not) developed the audio-description system. They trained describers, including Lasdon, who spread the system through the United States and abroad.

Six years after the La Jolla Playhouse began audio description, a radio-frequency system was installed in downtown's Civic Theatre and is used by Broadway/San Diego and San Diego Opera. The Civic provided the equipment, the Playhouse supplied the training (with the help of access coordinator Lyon) and Broadway/San Diego contributed administrative support. Volunteers came from the opera, the Playhouse and the Association of Community Theatres.

An audio-description system is not inexpensive. The Playhouse's infrared headsets, for instance, are \$200. Batteries (one per headset) are \$25.

Installing the system (including setting up the transmitter, receiver, mounting plates and chargers) costs approximately \$6,000 at each of the Playhouse's theaters and nearly \$10,000 at the civic (due to the type of radio technology being used).

Gracefully written

The skill of the Playhouse's volunteers was apparent during a recent performance of "Daughters of the Revolution," part of David Edgar's political and social epic "Continental Divide."

Volunteers Deb Sanborn and Janet Schlesinger were in the control booth, seated behind lighted metal music stands that held their material. Just before the performance, Sanborn read her gracefully written program notes, which provided many of the basics about the work, including the tidbit that 15 actors play 50 characters in the two-play cycle.

Her description of the opening set - a modest living room with four television monitors and a changing backdrop - pointed out details that even sighted patrons might miss, such as a hat lying on the floor.

Once the performance began, it was up to Schlesinger to supply the play-by-play. With so many actors and so much talking, it was a tricky assignment. Yet, she managed to slip in pertinent information about the characters' comings and goings, their gestures and expressions.

During an intimate exchange between two of the major characters, Michael and Abby, Schlesinger said that Abby "caresses his face and gives him a long, supportive kiss." It was a revealing moment that would otherwise be lost to those who couldn't see it.

For this season's play-goers, "Daughters of the Revolution" was just the beginning. There will be five more audio-description dates for upcoming playhouse productions, which continue into November.

Many of those who respond to the Playhouse's service are older patrons.

"This is a way of keeping theater alive for people," says Horn, the Playhouse's director of education and outreach. "Going to performances has been a part of their lives for many years and we don't want them to stop.

"We want people to hear the vision."

Conferences

"Discovery 2004, The Low Vision Conference", will be held October 14-16, 2004 at the Congress Plaza Hotel, 520 South Michigan Ave., Chicago, IL.

For more information write to: Discovery 2004 The Low Vision Conference, c/o Chicago Lighthouse, 1850 W. Roosevelt Road, Chicago, IL.60608, or phone 312-666-1331.

California Council of Citizens with Low Vision Convention, will be held from October 28 through 31, 2004 at the Los Angeles Airport Marriott Hotel. For information call 510-537-7877, the office of the California Council of the Blind or call California Council of Citizens with Low Vision at 800-733-2258.

Advocacy

ADVOCATES ALLEY

By Ken Stewart

When Universal Design Isn't Universal

In the early years of the Americans with Disabilities Act, it was fashionable among modifiers of the physical environment to say that the changes being espoused would actually benefit not just the subject group of disabled but would be a benefit for

everyone. But the enthusiasm for universal design exceeded the wisdom in some of their actions.

I recall attending a seminar on the subject sponsored by a prominent vision rehabilitation organization. A speaker, one of the department heads in the agency, gave a slide presentation about all the different classes of people who make good use of a curb ramp. The presentation, which was not accompanied by adequate verbal narration of each slide (ironic for the setting, eh?), depicted a woman pushing a baby stroller and a man maneuvering a heavy handcar of merchandise, as well as a person in a wheelchair. The vision impaired person sitting next to me and I exchanged disbelieving groans. This high-level professional in this vision-service agency had no idea that full-height curbs are extremely important to the safety of at least one class of pedestrians. We in that group feel the curb location of course, and many of us get helpful visual information from the curbs shadow line.

The Interagency Committee on Disability Research in Washington is currently reaching out for public comment on proposals for research. I have submitted a suggestion that instances of adaptive measures for one set of persons with a disability, cause unintended negative impact on other disabled people.

After noting the now-well understood example of curb cuts, I discussed several others I have been collecting. The elevator with a lowered control panel is helpful to the rider with limited vertical reach. It also forces a person with low vision to do a deep squat to select his floor. It is awkward for a braille reader to place the heel of her hand comfortably beneath the markings.

Some bank service counters are now designed for the height of a wheelchair user, requiring the close-looker to bend way over to sign paperwork.

An organization serving blind and vision impaired clients, fitted its brand new public Men's Room with urinals accommodating people of short stature. Every urinal was mounted very low. To make targeting even harder for the predominantly blind visitors to the facility, the chief interior decorator on the project must have decided that full-size urinals would look silly so close to the floor, so fixtures of smaller dimensions were installed! Eventually the mistake was reversed by retrofitting larger and better positioned fixtures.

The public pay telephone mounted low is a strain for a person with back problems. And, I wrote in VISION ACCESS previously on the subject of automatic sliding doors which can visually baffle both a vision impaired entrant and a guide dog trained to aim for a doors hardware.

The research I proposed would certainly not lead to a conclusion that physical modifications of the built environment be halted. All of us with any disability celebrate when anyone else's life with a handicapping condition is made a little easier. The research might though prompt more careful evaluation of side effects of modifications and encourage more attention to solutions that avoid such negative side effects.

Replacing removed curbing with detectable warning strips is becoming generally accepted now, although implementation around the country is very slow. Customer service counters often offer portions at different heights. Some elevators with a control panel on each side of the doors, may feature one high and one low, now and then. An architect once confirmed my notion that it is possible to remove the one-step entrance barrier at many retail stores with an interior rather than an exterior ramp, thus preserving the unobstructed street wall many of us white cane users trail.

I am reminded of the woman who described her experience in a large retail store when she wanted to use a restroom. She asked for its location. She was greatly amused when told by the clerk who noticed her blindness, "You cant use it. It's not an accessible bathroom." The clerk seemed to have no awareness that a public restroom gets labeled Accessible solely by its features to accommodate a mobility impaired user.

Editors Note: Reactions from readers to ADVOCATES ALLEY columns are encouraged. Communicate to the editor jmkleiber@hotmail.com, or send mail to Joyce Kleiber, 6 Hillside Road, Wayne, PA 19087.

Assistive Technology

Prototype System Developed by Wright State Computer Engineer Allows Blind to "See"

Nikolaos Bourbakis, Ph.D., Ohio Board of Regents Distinguished Professor of Information Technology at Wright State's College of Engineering and Computer Science is the principal investigator. The project is a cooperative venture with Arizona State University (ASU).

"Our object is to develop intelligent assistants that can help blind and visually impaired individuals efficiently conduct daily tasks, such as reading a book or newspaper and efficiently accessing the Web and participating in classes," explained Bourbakis, who has been involved in computer engineering eye research for 20 years.

Tyflos, the Greek word for blind, is the name of the portable, wearable device Bourbakis has developed. The partnering project at ASU is called iLearn. A tiny camera is mounted to glasses and connected by a thin wire to a modified lap-top computer the individual carries on his or her back. The Tyflos system operates by identifying the images "seen" by the camera and converting this to audio information the subject hears from small wires connected from the backpack to the ear. A small microphone is attached for receiving commands or requests from the user.

Bourbakis, who started on this project in 1995, plans to work with the WSU Office of Disability Services to test the device's capabilities on visually impaired students. In addition, he is working on an extension of the Tyflos system that enables blind individuals to independently navigate their working and living environments. Two future extensions of the Tyflos system will offer writing and drawing assistance that will enable the visually impaired to visually express their artistic talent beyond the usual levels.

"The Tyflos camera captures images from the surroundings, and the portable computer reconstructs the 3D space for motion detection, body tracing, face recognition and moving objects," explained Bourbakis, who also directs the Information Technology Research Institute and the Assistive Technology Research Laboratory at Wright State.

"This will make it possible for the blind and vision impaired to improve their independent mobility and social interaction, while succeeding in their professional endeavors. It is a great feeling for visually impaired people to make the first call in a conversation, like 'Hi John', rather than waiting for somebody to talk to them. We are using state-of-the-art computer vision and robotics technology that will help the users tremendously in recognizing faces, objects, reading books, surfing the Web and safely navigating in dynamic environments."

Funding for the project includes a \$1.1 million grant.

He said the applications of the project are substantial, with an estimated 45 million blind individuals in the world, according to a World Health Report.

For more details on Tyflos, contact Bourbakis at (937) 775-5138 or boubaki@cs.wright.edu. http://www.wright.edu/cgibin/news_item.cgi?663
<http://www.medicalnewstoday.com/index.php?newsid=6649>

Funding for the project includes a \$1.1 million National Science Foundation grant to ASU and Wright State.

People

Meet Skip Sharpe By Joyce Kleiber

"As soon as you believe your vision loss will ruin your life, it will," said Skip Sharpe. Skip Sharpe did not let his vision loss ruin his life!

Skip lost his excellent vision in an accident while serving as a pilot in the Air Force. This accident meant the end of Skip's military service, the chance to advance from 2nd Lieutenant to higher rank, the end of his ability to drive the sports cars he loved, the end of his driving in general. But he did not let this tragedy ruin his life.

Before his accident, Skip had earned a Bachelor's degree in mechanical engineering-a natural course of study for him because he is talented in math and science. After his accident he took advantage of the GI Bill and returned to school. He earned a Master's degree in education and then taught high school for two years. Then he achieved a Master's degree in mechanical engineering. With these credentials Skip went to work for the National Aeronautics and Space Agency, NASA. He was the first veteran to acquire a closed circuit television, CCTV, which he used at this job. Skip adapted equipment so that he could do the research his job required. He used a thick marker to enlarge the numbers on a pressure gauge so that he could read this gauge more easily. He procured a digital volt meter with a large numerical display. He found ways to do his job. Skip is a problem solver. On his team at NASA, he was the expert in cryogenics-the science that deals with gases that have been cooled down to their liquid state. For example, liquid hydrogen is at -423 degrees Fahrenheit.

Skip has logged an impressive 37 years in government service, including almost 2 years in the Air Force. He now lives in the Washington D.C. suburb of Silver Spring, MD. Skip has served as President of the Blind Veterans of America. He is now President of the Maryland/National Capitol Area Council of the Blind. He is also a member of the American Federation of the Blind's Careers and Technology Information Bank. In this capacity, Skip agrees to mentor people who are visually impaired and are seeking careers in engineering.

Skip is the father of four children, all of whom have graduated from college. He says he became instantly rich when his last child completed college.

Skip has somehow come to terms with his vision loss and found ways to have a meaningful life.

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, Mike Godino, 104 Tilrose Avenue, Malverne, NY, 11565-2040. Our Tax ID is 52-1317-540.

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