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

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

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From the Editor

'Tis the season for gift giving!-Christmas, Hanukkah, Kwanzaa... I hope you will find many gifts in these pages--the gift of hope as you read Lewis White's story, the gift of better health offered in Out of Sight Fitness, the gift of bringing to birth a new hobby, and many more. Thanks to everyone who shared their unique gifts to make this magazine. I invite you, our readers, to share your gifts and ideas with all of us in future issues. Happy New Year! Email to jmkleiber@hotmail.com, put the words "Vision Access" in the subject line.

JMK, 12/10/2005.
Organization News

2006 Convention Preview
By Coletta Davis, Program Chair

CCLVI's national convention is scheduled for July 8 to 15, 2006 in Jacksonville, Florida. Here are some of the people who will be featured in our program.

Dr. James Nolan, Director of Special Projects and Research for Envision. Dr. Nolan will lead a panel of people who have experienced driving with bioptic glasses.

Dr. Chris Guier, an optometrist from Jacksonville, Florida, will speak about his practice and low vision.

Chris Grey, ACB President, will address us.

Mitch Pomerantz, who is American's with Disabilities Act (ADA) Compliance Officer for the City of Los Angeles, will talk about the ADA and low vision.

Day Al-Mohamed, ACB's Director of Advocacy and Governmental Affairs, will talk about disaster preparedness.

Barbara Milleville, CCLVI Board Member and President of National Capitol Citizens with Low Vision, will give us tips on "Getting Rid of Clutter."

Dr. Edwin Druding, Psychologist and CCLVI Board Member, will lead panelists on the topic "Moving toward a Place of Acceptance."

Ken Stewart, CCLVI Past President will discuss transportation issues for people with low vision.

Our program will give people opportunities to get together. We will offer our mixer, two dances, and Game Night.

Make plans to attend and join us for a good time!

News from CCLVI Chapters

California Council of Citizens with Low Vision

held its Fall Convention last October in Long Beach, California. Here are the speakers and topics we featured.

Day Al-Mohamed, ACB's Director of Advocacy and Governmental Affairs, gave an update on Federal regulations regarding environmental and transportation access.

Eve Hill, J.D., Executive Director of the Western Law Center for Disability Rights, spoke about California civil rights protection and remedies for people who are blind or visually impaired.

Accessible taxi service in the city of Los Angeles was addressed by Tom Drischler, Taxi Cab Administrator, Department of Transportation, City of Los Angeles and by William J. Rouse, General Manager, Yellow Cab Company.

Dr. Bill Takeshita, Director of Optometric Services at the Center for the Partially Sighted, spoke about new drugs and techniques for early detection of symptoms. Such early detection may minimize potential damage. Dr. Takeshita noted that many light bulbs on the general market are helpful to people with low vision. Therefore it is not necessary to purchase specially manufactured bulbs.

Our Spring convention will be held in April, 2006 in Sacramento.

Delaware Valley Council of Citizens with Low Vision

It was on October 22, 2005, at the banquet of the State Convention and Conference of the Pennsylvania Council of the Blind (PCB) in Pittsburgh PA, that Jerry Weinger in behalf of the members of DVCCLV proudly accepted a Special Interest Group Charter of Affiliation with PCB. This affiliation was off to a running start during
the PCB State Convention. Sarita Holliday facilitated a Low Vision Breakout Group in which low vision issues were explored. These issues will be considered by a soon to be created PCB Low Vision Committee, Moderated by PCB First Vice President George Holliday.

It was in late 2003 when George Holliday, then President of the Philadelphia Regional Chapter of PCB, proposed that DVCCLV consider becoming a special interest group affiliate of PCB. With the full backing of DVCCLV members, Jerry Weinger worked out the details with George Holliday. The two organizations plan to work together, with DVCCLV representation on the soon to be created PCB Low Vision Committee. The new affiliation is expected to strengthen both DVCCLV and PCB. As Sarita Holliday stressed at the Low Vision Breakout Group, PCB has no designs on doing the job of DVCCLV or CCLVI. Rather PCB wishes to address low vision issues in a win-win with PCB’s new Special Interest Group Affiliate, DVCCLV.

Last but not least, DVCCLV members can join PCB at a reduced price. For more information please contact: DVCCLV by phone: 215 735-5888 or by Email: dvcclv@earthlink.net, or by U.S. Mail: Delaware Valley Council of Citizens with Low Vision, P.O. Box 58326, Philadelphia, PA, 19102

Metro Chapter
We made a pitch at Yankee Stadium--but not on the field. Three of us were among the more than one hundred accessibility advocates that assembled in The Great Moments Room to review plans for the building which will replace "The House that Ruth Built". Members Raphael Rivas, Dr. Joel Ziev, and Chapter President Ken Stewart, made a pitch for features such as readable signage, well-marked steps, and strong visual contrast in restrooms. Expecting skepticism that people with severe vision impairments actually pay big bucks to attend major league ball games, we were pleasantly surprised to find warm receptivity to the input.

For information about this chapter call 845-986-2955.

NCCLV Meeting Recap
In September, the topic was disasters and how you, as a person with low vision, will handle things if one comes your way. Some of the things we discussed were:
-why you need to have an emergency preparedness plan of your own
-how to decide what to take with you if asked to evacuate
-how to evacuate or get home when public transportation isn't available

In October, we had "Show and Tell". Everyone brought in and demonstrated some of the items that help them compensate for vision loss. We enjoyed seeing and hearing why these aids are favorites of the users. Portable video magnifiers, glasses and magnifiers were popular with the group.

In November, a ZoomText mini workshop was held. Our guest was Glenn Smith of Adaptive 2C. Attendees had the opportunity to network with other ZoomText users and find out answers to things they've always wanted to know about this screen magnification program. Glenn also demonstrated the features of the new ZoomText version 9.0
Regional Event for People with Low Vision

The Delaware Valley Council of Citizens with Low Vision and National Capital Citizens with Low Vision chapters are planning a get together for people with low vision. We will have interesting speakers, a support group and numerous opportunities to network with other people on the East Coast who have low vision.

At press time, here are the tentative details:
Location: Philadelphia, PA
Date: All day Saturday with Sunday morning activities optional.
Exact date is to be determined.

We need to hear from you. Would you attend this event? If there is enough interest, this event will happen. Contact any of the following by February 10th if you’re interested in attending, or want further information:

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People

Meet Lewis White
Based on an Interview by the Editor

Five or six years ago, I noticed that I was losing vision. This loss of vision accelerated in the last year. I have diabetic retinopathy and retinal edema (swelling of the retina). Since this began, I have had 11 laser surgeries to try to close the blood vessels that were opening at the back of my eyes.

In the meantime, I learned that there were two other things wrong. First, Sjogrens Syndrome which makes my eyes and mouth extremely dry. Sometimes I felt like ripping my eyes out because they felt itchy, hot and irritated. Second, I developed Storage Pool Disorder—a blood disease similar to hemophilia. This disorder makes it impossible for me to use drops to treat the dryness of my eyes.

Sometimes I see things clear as a bell. But at any time, even while walking down a street, my vision can totally dissolve. My vision varies from 20/50 to 20/350. My doctors can’t explain this. They have not found a way to control the swelling in my eyes.

I was Finance Director for a small company. I had this job for 3 years. I took a job there as a bookkeeper in order to earn money to support my painting, sculpting and jewelry making. From bookkeeping I advanced to Finance Director because of the valuable suggestions I made concerning the company’s financial practices.

Suddenly I could no longer see my computer screen. But my boss wouldn’t do anything to help, like getting JAWS or Zoomtext. I myself did not know about these programs because everything was hitting me all at once. My boss suggested that I
"take a walk" to relieve eye strain, and he expected me to come to work on the day I had cataract surgery. This boss was not sympathetic to people with health problems. Then my employer said to me "This is your last day at work! I can't have sick people here." I had taken time off (about one day per week for medical appointments) but I was still well ahead in my work. Because my employer had less than 20 employees, he was not bound by any legal constraints in his action to end my work there.

I felt very depressed. I lost my eye sight and I lost my job. Since I was not offered Cobra insurance, I now had to pay my own medical bills.

It took me a good six months to recover from this depression. I contacted the University of Pennsylvania where I participated in a study on treating depression. There I received counseling once a week and antidepressant medication.

Four weeks after losing my job, I walked into the Associated Services for the Blind. I had passed this agency every day on my way to work. They told me I was one of the very few people who walked in without a referral asking for help. There I received mobility training and attended other classes designed to help me cope with vision loss.

One of my instructors, Bette Homer, learned that I am an artist. She recommended that I contact the Philadelphia Museum of Art. This museum offers a program to assist people who have low vision or who are blind to paint and sculpt. After my interview there, I was hired as a volunteer teacher in the museum's Form in Art Program.

I have a Bachelor of Fine Arts Degree from Temple University. I had two one-man shows and I am often invited to participate in art exhibits. I paint, I sculpt, and I design jewelry.

I enjoyed art from the time I was 3 years old. I found and embellished family photographs; for example, I painted a background in a photo of my relatives and I gave my grandfather, pictured at age six months, an argyle sock. My third grade teacher wrote to my parents: "Lewis will not stop drawing during my lectures."

While growing up I had many problems with my eyes. My family insisted there was nothing wrong with my eyes; they said I just didn't want to do things! They still don't understand. They sent me to a psychologist rather than to an ophthalmologist.

My family wondered why I painted things with strange colors. It turned out that I am color blind. In my art I focus on form and shape more than on color. I have heard what other artists say about the colors they use to paint the sky or a tree. I know that sometimes the sky can be purple or pink.

Recently I painted a picture in the colors in which I see. People told me that although I used grey tones in my painting, it was bright and vibrant.

I work on large canvases-five feet by six feet. I use a large magnifier held by a cord around my neck. This magnifier sits on my chest. As I work look through it at a small area of my painting. I paint very large. Aids for low vision, like my magnifier, require intense use of vision and therefore result in eye strain.

Interesting things happen when I teach others who have impaired vision at the Philadelphia Museum of Art. Other volunteers often don't remember that I am legally blind. They say that I don't clean the tables well enough. They notice that I work well with my students. Since I have limited vision and face the same problems as my students do, I can easily relate to their challenges in doing art.

When my students work in paper mache, I tell them not to work gingerly, but to be totally involved, using their hands, not just their fingertips. My students may be covered with paper and paste. Other volunteers think we are just being messy.

Besides my volunteer work at the Philadelphia Museum of Art, I teach clay sculpture at the Allen Lane Art Center.

Now I am looking for a way to add earned income to my Social Security benefits. In January, I will begin a "special needs" art program at the museum. I will teach portrait
painting to people with aids, people from domestic violence shelters, people with emotional problems. On Fridays, I will lead a group of 5 or 6 people at a time. We will tour the portrait galleries at the museum, have lunch together, and then spend two hours painting portraits.

I am grateful to Bette Homer, my instructor at Associated Services for the Blind. She noticed my artistic interests and directed me to the Philadelphia Museum of Art. I have always been more of an artist than a financial officer.

I try hard to maintain my health. I try to know as much as possible about the medical implications and treatments for my conditions. I am a militant diabetic. I eat carefully and I walk for two hours each day except when pavements are covered by snow and ice. My Alaskan Huskie walks with me. He came into my life before I lost my vision, so he did not benefit from training as a guide dog. I plan to keep on doing art in spite of vision loss. Some doors have closed, but others have opened.

Quality of Life

Out of Sight Fitness
By Bob Koppenjan

My name is Bob Koppenjan and I developed the Out of Sight health and fitness program. I have been a personal trainer for more than twenty years. Being blind myself, I recognized the need for a program like this, tailored to people who have impaired sight. I understand the difficulties that people who are blind and visually impaired have in getting out to exercise. I also understand the fears and concerns that those who are sight impaired might have in going to and joining a health club as well as all of the costs related to that endeavor. That's why I developed this program.

There are many other programs that are very costly and complicated, but not this one. With the Out of Sight program you don't need large space consuming equipment, you don't need to order pre packaged low calorie meals, and there is no weighing your food or counting calories. What you need for this program is determination and a couple of dumbbells, that's it!

The Out of Sight health and fitness program comes in large print (18pt. Verdana, Bold) and braille. A CD, describing exercises in this program, accompanies the large print and braille texts. The cost is $39.99.

Make 2006 the year of a new and improved you. Take control of your health and fitness. You can do it. You deserve to live a happier and healthier life. This program can help you get started.

For information contact Bob Koppenjan at Duko Health International, 175 Irving Place, Rutherford, NJ 07070, Phone: 201-507-1510, Email: dukohealth@comcast.net

Time for a New Hobby
by Dana Nichols

So you are tired of collecting seashells and want a new hobby. Whether you want to learn a new skill or join other people in an activity, the best way to find information is through word of mouth. The office of a local blindness organization, for example, can often connect you with a blind bowling league or a tandem bicycling club.

Or, finding a new hobby may be as simple as expressing admiration for a friend's knitting. She might offer to teach you. The National Library Service, National Braille
Press, and Horizons for the Blind, all have books on knitting and crocheting that explain the basics as well as provide patterns. For beginners though, nothing surpasses one-on-one instruction.

The same is true of music. If you want to learn a new instrument, friends can help you find a teacher. Music stores have lists of private instructors and contact information for local music clubs. To find a store that rents and sells instruments, ask someone to look in the yellow pages. You can also search online. Begin with your city's Web site, or with a site like www.about.com. If you are musically talented, friends can probably connect you with other musicians; a small informal group of performers might result.

Another way to explore new interests is to take a course at the local college. Through the community education department, many colleges offer six-week classes in a wealth of subjects like ballroom dancing, genealogy, French cuisine, creative writing, and computer usage just to name a few. Get your name on the mailing list or go to the college's Web site for a list of available courses. In these classes, you are likely to meet people with similar interests who have formed clubs such as creative writers who get together as a group to share their latest work. The university near me, for instance, sponsors a ballroom dancing club for the community.

Check with the local board of education, too. The adult education division sometimes offers night classes in area high schools. Transportation at night can be a problem unless you have access to special transportation services, or a friend who is also interested in taking a class. Again, word of mouth is the most efficient approach.

If you are over fifty, a senior center is a great place to take a class in dancing, computers, or crafts like pottery and weaving. Seniors also tend to establish informal groups that meet regularly to play games like chess and bridge.

If you're interested in ham radio, finding a class or club is a great way to begin, but you will need more. The American Radio Relay League has good information about licenses, learning materials, test sites, and dates of hamfests on their Web site, www.arrl.org. If you can't afford a radio, try contacting the Courage Center Handihams (www.handiham.org). In addition to providing education for hams, they will lend radio equipment to members.

Are your interests more artistic? If you enjoy acting, review your city's Web site and newspaper for listings of upcoming professional and amateur productions. You will find announcements of planned shows and dates of auditions. Likewise, upcoming performances of community choral and orchestral groups are listed. My hometown Web site, for example, www.huntsville.org, has a calendar of events. The drama and music departments of the local college can also be a good source of information, or you can try the direct approach. After a performance by Sweet Adelines, for instance, go up to the person in charge and ask how you can try out.

For outdoor enthusiasts, many cities publish a newsletter that lists garden club meetings, hike and bike outings and other activities. Local publications are usually displayed at the checkout in grocery stores. Have your shopping helper pick one up for you.

An invaluable source of information is always the public library. The library is a convenient meeting place for many clubs, and librarians constantly update contact information for local organizations, archive newsletters and other materials published by local groups, and maintain lists of upcoming events. Are you a book lover? Inquire at the library about local book clubs that meet to discuss favorite titles and bestsellers.

In addition to books, the public library has many resources to help you develop new hobby interests. For example, you might find recordings of birdcalls. Learning to identify birdcalls is the blind equivalent of bird watching, a good outdoor hobby.
No matter what you are interested in doing, the best sources of information are the library, the Internet and best of all, your friends. Friends can even give you information about collecting as a hobby, whether it is seashells, coins or beanie babies! Resources


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To Go Along, Get Along
Finding Wheels
A Book Review by Ken Stewart

I spend much of my time in Manhattan. Not infrequently I get on the phone just before heading out to a meeting in an office building in an unfamiliar area, or to a retail store never visited previously. I first get on the phone seeking additional information to help me find the place. But, getting that help from the person on the other end of the line is not always easy. Even after I explain that I am vision impaired, I am likely to get the dismissive, "You can't miss it". Well of course, I can. And I do. In my telephone queries, I have learned not to ask, "Which corner is it on, the northeast? northwest?". New Yorkers don't know their north from their south, their east from their west. So my question has changed to some version of, "Is it on the Brooklyn side of the street, or the Jersey side? Uptown or Downtown?"

Not long ago I received a perfect straight-line, "straight" as in a joke lead-up, not as in the shortest distance between two points! I was being given phone directions to a midtown office building. When I asked which side of Madison Avenue, she replied, "it is on the right". Then she put me on HOLD while she got more details from someone else, when I wanted to know, "Right when I'm walking north to it or south to it?" She returned to the phone with the great straight line, "The building is on the east when you are walking north". Inevitably, my smiling counter was, "What a coincidence! Then it's on the east if I'm walking south too!"

In Finding Wheels, Ann Corn and Penny Rosenblum ably discuss the practicalities of getting clear directions from people when planning a trip as a non-driver. In fact, everything they do in their book (which has recently become available from the National Library Service on cassette [RC 57825]), IS DONE ABLY. Ann and Penny are well known to CCLVI, and the research leading up to this publication touched some of us directly.

I hadn't listened to much of the text before I concluded it was a very clearly and well organized presentation of the obvious and self-evident. On second thought, that was an unfair conclusion, considering that the authors’ intended audience is young people who are just coming to the point of facing the harsh realities of having many places to go without the eyesight to drive there. The book is even more suited for educators who are in a position to nurture independent travel skills in their students who have impaired vision. Another demographic cluster who certainly can benefit from this reading is seniors who are just arriving at the stage of life when leaving the car keys at home is prudent. Veterans of a lifetime of dependence on public transportation
and negotiated favors from relatives and friends may not learn much from this volume. Indeed, we may be eager for a Part Two, perhaps entitled something like, Fighting for Wheels, with the subtitle, "Effective Transportation Advocacy in the Era of the A.D.A.". The publication here reviewed, includes a Unit Six, "Hired Wheels: Taxis and Drivers". The discussion notes the value of alerting a dispatcher in advance that the customer is vision impaired so the driver will not expect the person to locate the taxi when it arrives. What many guide dog users are experiencing though, is the unlawful avoidance of customers who have guide dogs, that avoidance facilitated by the advance notice to the dispatcher. Successfully coping with this reality calls for a more nuanced strategy when booking a taxi.

Another section of the book feels a bit anachronistic. Appropriate interchange between boarding rider and bus driver is explained. But the context does not reflect the federally imposed requirement that major stops must be announced ALL THE TIME. There is considerable anecdotal evidence that a bus driver who thinks he can spot (by a white cane, for example) those particular customers who need a stop-announcement, erroneously uses that diagnosis to relieve himself from the responsibility to make all required announcements all the time. Admittedly, discussion of the tactics called for under these circumstances, is beyond the scope of "FINDING WHEELS".

Finally, in the interests of full disclosure, for reasons made obvious early in this article, this reviewer did not read this very well organized and articulate publication in its entirety. But the reader who is not seasoned in the life of transportation-dependency may derive many useful tips from the very illustrative case studies. They tell tales of "going along" (for the ride), by "getting along" (nurturing good rapport with drivers). There is quite practical advice here- bartering, pizza treats, paying for the gas, and of course, 'Be On Time!'

So That All May Read

A free library service is available to help people of all ages whose low vision, blindness, or physical disability makes it difficult to read standard print. The National Library Service for the Blind and Physically Handicapped (NLS), Library of Congress, and the network of regional libraries bring books and magazines on audiocassettes and in braille directly into the hands of eligible readers.

The program loans members a wide selection of recorded books and magazines, braille books and magazines, and music scores in braille and large print.

Applications for this service may be requested from the regional or sub regional library closest to the eligible reader. A searchable list of locations is available at www.loc.gov/nls. The application requires the signature of a certifying authority such as a doctor, caseworker, or an NLS regional librarian.

After an application is submitted, the playback equipment for the talking-book program will be sent within three working days. An initial shipment of books and catalogs is usually sent within the following two working days. An NLS reader advisor may follow up to help personalize the selection of materials. Materials are shipped and returned via the U.S. Postal Service at no cost.

For more information or additional assistance, call 1-888-NLS-READ (1-888-657-7323).
Those Hard to Distinguish Dark Colors
By Bernice Kandarian

Do you have trouble distinguishing those dark colors-black, navy, purple, and dark green? Here is one possible solution to this problem-Aluminum Braille Clothing Tags. And you don't have to be able to read braille to use these tags! Two braille letters are embossed on each tag."bl" for black, "br" for brown, "gr" for green, for example. A card on which the braille symbols and comparable letters of the alphabet are listed comes with these tags.

I sew these tags at the bottom of the shirt tail hem on the button hole side of the shirt. On pants, I place the tag on the waist band to the left of the button or snap. If a garment is multicolored, I use two or three tags. The top tag will indicate the dominant color. There are two holes on each side of the tag and I sew one stitch through each hole and the tag is in place.

These tags come in packs with assorted colors and they are free of charge. To obtain tags, write to Mrs. Nick Dudas, 499 Grove Avenue, Edison, NJ 08820.

A Perennial Comfort Food-
Mashed Potatoes
By Joyce Kleiber

Have you ever combined mashed potatoes with either cheese, garlic, chives, parsnips, caramelized onions, or horseradish? These are just some of the possible variations.

Here are some great tips for fine tuning your preparation of mashed potatoes-a part of most traditional holiday dinners. Many of these ideas were shared in an article in this week's Philadelphia Inquirer Food Section. The article was authored by Carole Kotkin of Knight Ritter Newsservice. I liked what Carole Kotkin said. I cut out this article, put it into my recipe collection and sent a copy to my daughter, Katharine.

Start with potatoes that have low water/high starch content. The author suggests potatoes like russets or Idahoes. I like the flavor of Yukon Golds. About 2 pounds of potatoes will serve 4 to 6 people.

Cut the potatoes into 2 inch chunks. Boil the potatoes in lightly salted water until you can pierce them easily with a fork, about 15 to 20 minutes. (They should not lose their shape.) Meanwhile, warm (but do not boil) your choice of milk, buttermilk, or broth that you plan to mix into the potatoes. You will need about 1 cup of liquid for 2 pounds of potatoes.

Drain the potatoes, return them to the pot, and put them over high heat for 30 seconds so that extra moisture evaporates. Shake the pot while the potatoes are back on the burner. With the moisture gone, the starch cells can absorb the milk or broth and butter that you add. Then mash the potatoes while they are hot adding milk, buttermilk or broth, 1/4 cup at a time until the consistency is right for you. Add up to 4 Tablespoons of butter. Season to taste with salt and pepper.

If you like your mashed potatoes lumpy, use a hand potato masher. I use one that belonged to my Grandmother-which adds to my comfort! For a more rustic effect, you can leave the peels on the potatoes! Using a ricer or food mill will give you a smooth texture. Be careful if you choose to use an electric mixer. If you over-whip, the potatoes may become gluey in texture. The same result is inevitable if you use a food processor.
Mashed potatoes can be prepared up to 6 hours before dinner is served. Cover them with plastic wrap and refrigerate. Reheat at dinner time in the microwave.

Here are some interesting add ons. The amounts given are for 2 pounds of potatoes. 4 ounces Swiss, parmesan or goat cheese, 2 T. fresh minced herbs, 1/4 cup pesto, 8 cloves of roasted garlic squeezed from their skins, or simmer 1/2 cup of prepared, drained horseradish in cream or milk.

One of my family's favorites is parsnips with mashed potatoes. Cook an equal amount by weight of parsnips with the potatoes. Cut the parsnips in 1 inch pieces and the potatoes in 2 inch pieces so that they will cook in the same amount of time. Cook them together. Then mash them adding liquids and butter as described above. Enjoy!

Advocacy

CCLVI Board Member
Speaks Out on Capitol Hill

Representatives from the Coalition to Preserve Patient Access to Physical Medicine and Rehabilitation Services hosted a press briefing on November 16, 2005, at the Rayburn Building on Capitol Hill. The purpose of this briefing was to encourage Congress to overturn or rewrite legislation regarding in-office therapy for Medicare patients.

The policy in dispute is one the Centers for Medicare and Medicaid Services (CMS) revised without Congressional approval and began enforcing in June 2005. It prohibits Medicare reimbursement for therapy services provided by anyone other than a physical therapist, occupational therapist or speech and language pathologist. This means that most vision rehabilitation teachers and orientation and mobility professionals will not be reimbursed for the important services they provide to Medicare recipients.

In her presentation, Barbara Milleville, Board Member of CCLVI, expressed concern that the recent ruling will have a significant impact on the delivery of quality vision rehabilitation services to people with low vision. She stated that vision loss brings with it unique challenges and that it is essential that vision rehabilitation and orientation and mobility professionals are trained in these specialized areas of service.

ADVOCATE'S ALLEY

Giving Credit Where Credit Is Due
By Ken Stewart

The bus terminal just a block away from Times Square in Manhattan, is the busiest bus terminal in the world. It is a major destination point for massive numbers of commuter routes and, it is the home of Greyhound and other long-distance carriers.

The terminal was built, and then greatly expanded, before there was an Americans with Disabilities Act. Yet I rate it the most enlightened design of any transportation depot of all those I have ever visited on four continents. Perhaps some of the features which are notably friendly for travelers with limited vision were accidental; that is, design decisions made for other reasons have resulted fortuitously in high visibility elements.
Whether or not purposeful or accidental, I felt its proprietors deserved credit for the result. For that purpose, and, in hopes of influencing future transportation center designs, I arranged with the Port Authority of New York & New Jersey, to conduct a tour of their facility for its staff. Six Port Authority personnel joined me on November 17th for the walk-around. Judging from the notes being taken and photos being snapped, they were very receptive to my commentary. I was able to identify many physical aspects of the building which assist people with low vision find their way, get information, and avoid hazards. My presentation had the benefit of input from a number of colleagues who gave me their ideas beforehand.

The list of friendly features is too long to detail in this ALLEY, but they include; conspicuously dark "shorelines" along concourses with light surfaces, evenly distributed moderate artificial illumination, very large and high contrast gate numbers, and, rest rooms which avoided the usual white-on-white-on-white motif of public restrooms.

The Port Authority Bus Terminal is not nearly a perfectly designed building, and some of the most obvious shortcomings were dully noted during the tour. That list included one area with a walking surface with a confusing light-dark pattern, and a very shiny floor similarly mischievous.

Only time will tell whether the information exchanged during the tour will reach decision makers now creating at least three other major transportation facilities in New York City, one of which will be a Port Authority hub at the World Trade Center site. All of us who recognize opportunities to educate architects and designers, must seize each of them to articulate what works best for us. We have a significant advantage from the reality that many of the best design features are cost-neutral. Making that column which stands right smack in the middle of our path of travel conspicuous, costs not a penny more than putting it in a disguise so that it smacks us!

Science and Health

Macular Degeneration and Retinitis Pigmentosa
By Dr. Ikan C. Kleerly

Have you ever had what I refer to as a "Brain Overload"? The Foundation Fighting Blindness, FFB, is a very outspoken advocate for research on all issues affecting people who are blind and visually impaired. This was really impressed upon me this past week-end when I attended a symposium in Salt Lake City co-sponsored by FFB and the University of Utah. Six presenters from the Moran Eye Center, many with multiple doctoral degrees, presented the latest research in various eye diseases. They presented us with such an array of new research that our brains were trying to catch up during the next couple of days. That's "brain overload!"

Stephen Rose, Ph.D. is Chief Research Officer for FFB, the largest organization of its kind. He said that since 1971 FFB has spent $250 million in research for various types of diseases related to blindness. FFB focuses on the innovative functions of research and is currently funding 150 research studies at 55 different institutions.

Randall J. Olson, M.D., Chair of Ophthalmology, University of Utah and Director of John A. Moran Eye Center discussed the updates on research.

The National Neurovision Institute (NNRI) is the organization that takes the research into the clinic. They organize volunteers who have been carefully diagnosed and screened to carry out the treatments that have proved promising in the laboratory. Stem cells extracted from mice were implanted in the mice that developed retinal
diseases. These actually allowed the blind mice to discriminate movements. These animal studies of stem cell implants have demonstrated that such implants stop or slow down the degeneration of the retinal cells. This is exciting research. Whereas human stem cell experiments come under discrete observation, the clinical research has opened up doors to creating human's own stem cells and replanting them in retinal areas of that person with some encouraging success. In addition, at this date, over 100 different genes have been cloned.

DNA studies have discovered that RPE 65 gene is the culprit in Retinitis Pigmentosa. In a study at the University of Pennsylvania a dog named "Lancelot" was born with advanced RP. After Lancelot was treated with LCA, an experimental substance, he was able to see well enough to get around.

NeuroTec implants a molecule into the retina of the eye to replace one that is missing. Nano-sized particles are injected into the eye to eliminate proteins that may destroy the weaker cells.

India and China are able to move more rapidly in the areas of biological human research than the U.S. This is due to the control factors of the FDA. It takes at least 10 years for the FDA to arrive at an approval rating for a substance or appliance.

Paul Bernstein, M.D., Ph.D. Moran Eye Center Nutritional Intervention Department spoke about the importance of diet and eyesight. He cited that certain factors are non-modifiable: age, heredity, gender, pigmentation, race and iris color. He also cited those factors which are modifiable and recommended to prevent or slow down the progress of AMD: smoking, alcohol, cardiovascular (high blood pressure), nutrition, genetic factors, blood filtration, and excessive light exposure.

Kang Zhang, M.D., Ph.D., Moran Eye Center, earned a medical degree in China then came to Harvard to earn another medical doctorate in Ophthalmology. He then returned to Harvard to earn a Ph.D. in Neurophysiological Transmitters. He stressed that his Chinese ancestors have used herbal teas for thousands of years with great success without FDA approval. Moreover, it works. The Clinic is continuing to pursue the non-traditional herbal approach with some of its clients in research programs.

Nutrients necessary for healthy eyes are: zinc and copper, selenium, polyunsaturated fats, and vitamins A, C and E. Also helpful are such herbs as bilberry, polyphenyls, beta-carotene, and herbal green teas.

Other specific foods he recommended were: carrots, squash, cantaloupe, leeks, kale, spinach, corn, and fish oil.

Understanding the disease is fundamental in curing or treating the disease. If the researcher understands that a retinal cell is deficient in some microscopic element or substance, he can use his research to find ways to supplement that substance. If the cell has some additional substance that is an antagonist, then he looks for ways to eliminate that substance.

All of the researchers were prompt to point out that in all eye diseases, smoking and the use of alcohol are the culprits and that people must change their life style to eliminate those items. Diet and choice of foods which enhance vision were also recommended by all of the researchers. Zinc and copper, leuten and carotene including yellow and orange vegetables are vital natural supplements. Some copper needs to be taken to replace that removed from the body by taking zinc. Recommended amounts are to be religiously followed. Wearing sun glasses that filter out harmful rays can help people to save their vision.

Raymond Lund, Ph.D. Retinal Disease Experimental Department, Moran Eye Clinic, described RP as a retinal disease of the peripheral field that progressively restricts the central vision. Night blindness is one of the characteristics. It is an autosomal condition related to the X chromosome, therefore it is genetic in nature.
Scientists are working to be able to "zap" that gene to potentially eliminate the transmission of this condition in the family.

One of the sad parts of this eye condition is that many people with RP obtain a driver's license. They continue to renew it for years and are completely unaware of their limited field of vision until they have more than a slight fender bender. Several of the attendees shared their horror stories about hitting a pedestrian that they never saw, or of taking out the tree in their driveway that had been there for ages that they also did not see. One man was even granted a renewed license when he went into the Department of Motor Vehicles with his white cane!

Some day soon, with all of this research, we might discover that Macular Degeneration and Retinitis Pigmentosa are as easily corrected or eliminated as are cataracts today.

Prevalence of Cataract High
Among U.S. Hispanics

CHICAGO, Oct 17 - The prevalence of cataracts causing significant visual problems appears high among older U.S. Hispanics who also often encounter barriers to access to care according to a study published in the September 2005 issue of the Archives of Ophthalmology.

Although cataract is the leading cause of visual impairment in the Hispanic community, there has been little research on the prevalence of cataract, cataract surgery or factors that may affect whether Hispanic individuals are able to obtain cataract surgery.

Aimee Teo Broman, M.A., of the Johns Hopkins School of Medicine, Baltimore, and colleagues conducted a survey of visual impairment and blindness of Hispanic individuals 40 years or older living in southern Arizona between April 1997 and September 1999. Individuals completed a questionnaire, in either English or Spanish, to determine their history of visual problems and eye care as well as their socio-economic status, medical history and preferred language, country of birth and other questions relating to adapting to U.S. culture. Participants' acuity was also assessed.

Of the 4,774 people who participated in the interview and examination, 2.8 percent (135) had a visually significant cataract and 5.1 percent (244) had undergone bilateral cataract surgery. The researchers found two factors were important in determining whether individuals received cataract surgery: whether they spoke English and whether they had medical insurance.

"Our data suggest that even after adjusting for high rates of diabetes mellitus, U.S. Hispanic individuals are at a greater risk of having a visually impairing cataract than either African American or white individuals," the authors report. "Cataract is the leading cause of visual impairment in this population and is associated with lower levels of self-reported quality of life; however, a significant percentage of those who likely need cataract removal have never obtained surgery in the population.

The research team highlights the need to address both the language and financial barriers that impede access to surgery in this population.
Intelligent Designer-An Essay
By Ron Strickland

Recently, I was at a meeting, intently listening to what was being said. Suddenly, above my head, the light bulb came on, just like in the cartoons. The switch was thrown, light radiated into one unused brain crevice, a few neurons woke up, a couple of synapses fired and, voila`. I was having an original thought. Well anyway, it was original for me.

What caused this mini-flurry of cerebral activity? Why, adaptive technology, of course. Specifically, the scanner and the human eye piqued my interest. How did the two develop and how do they compare? The wheels began to turn.

I started to think about how far back into history the components of the scanner reached? Likewise, how much farther was the reach of the compounds and substances of those components? And, what about the eye and its parts?

How did all of these things come to be, I thought? Was it through some collection of serendipitous events or, were those events orchestrated and purposeful? Both camps have their followers.

In my mind’s eye, I saw a bag containing all of the parts of a completely disassembled scanner. Represented in this bag was every type of simple machine ever invented and developed by man. Also, in the bag, were the laws, principles, and, theories of chemistry, biology and, physics. They, too, had been discovered and developed by man.

Next the contents of the bag were shaken and mixed thoroughly. Assuming that the bag actually exists, who, upon looking into the bag, would expect to see a fully assembled and functioning scanner? Suppose we repeated this action ten times...one hundred times...one thousand times...one million times?

This next statement could be written in stone. I do not think anyone could disagree with it. So, here it is. There is only one scenario that I can think of that would result in a working scanner and that is the intervention of an intelligent being like man.

Now, let's take a cursory peek at the human eye. Here, is an organ that is smaller but, does a bigger job than the scanner; it has simplicity of design but, complexity of purpose; it is simultaneously multi-tasking 24-7, and even when it's malfunctioning, in most cases, it still out-performs that scanner.

Now, if the lowly scanner could not spontaneously bring itself into existence, how then could the eye? In my opinion, the eye whose level far exceeds that of the scanner, by many orders of magnitude, must have had an intelligent designer. I call that designer God.

Technology

What is the Color-Reno?
By Mary Brucker

If you experience vision loss, you may find it hard to identify colors. When I ask people who are newly visually impaired how they pick out their clothing, they often tell me that their spouse or a relative picks their clothing for them. Although this may seem like a small request, it’s yet one more way in which the person with the visual impairment is dependent on others.

Here are some ways to identifying colors whether it be for clothing, furniture, etc. First I will discuss my experiences with a device called the Color Reno. Then I will suggest some simple tips to aid in color identification.
The Color Reno is a small handheld device. It looks like a remote with two buttons. One button identifies colors and the other button helps to detect light. This device is most reliable for primary colors. For example, it will tell you if your shirt is light or dark blue. If the fabric is a multicolored print, the Color-Reno will only tell you the color to which it is pointing. It will not tell you the actual picture or print on the fabric. However, it will distinguish between dark colors--blacks, browns, navy blues, etc.

In my experience, the Color-Reno is not as reliable when detecting mixed colors. If you have a dull green fabric, it may say gray-green. Instead of the device identifying maroon or burgundy, it will say red-brown, or dark red-brown. The Color-Reno takes double AA batteries, and it shuts off automatically. It comes with a small carrying case and is very portable.

Color Reno can be purchased from several low vision catalogs and from stores that specialize in low vision aids. The cost is $200.

Here are some other ways to identify your clothing. First, try to memorize any distinguishable feature of your garment, i.e. any pockets, collar, unique buttons, seams, ruffles, lace, etc. You can also distinguish clothing by the material itself.

Next, you can place safety pins in the tags of clothing if you have two or three similar items.

Additionally, low vision catalogs offer various clothing identifying kits for purchase.

But what I find most helpful is using braille tags. Braille is a very useful tool for labeling clothing and other items. Braille color tags are made by using Teflon tape with a one-lined slate and stylus. The Teflon tape comes in a roll, like dymo tape, but it has no sticky backing. The braille shows clearly through the tape, and holds up for several washings. You then sew the braille tag in your clothing, linens, etc.

All of these ideas can help us all to be more independence.

**New Desktop Video Magnifier**

Freedom Scientific announced a new line of video magnification products. These new products enable low vision users to read printed material and easily customize how the information is displayed. A large illuminated working area makes activities like sewing, painting, and repairing items easier as well.

The Topaz(tm) Desktop Video Magnifier, available in five models, makes for easy reading of a wide variety of printed material including numbers in the phone book, labels on prescription bottles, tiny printed contracts, bills and much more. Simply place the material on the movable slide table and adjust the magnification level for the best reading comfort. With 16 magnification levels, the Topaz with a 19-inch LCD flat panel monitor can magnify material from 2X all the way up to 70x.

The five Topaz models range in price from $1945 to $2995, depending on monitor size and type. Products will begin shipping in January 2006.

**Victor Reader Wave Now Shipping**

Montreal, September 19, 2005. HumanWare is pleased to announce that Victor Reader Wave is now shipping. Greatly anticipated since its debut at the 2005 CSUN Technology conference in March, the Wave is the latest model in HumanWare's popular line of Victor Reader DAISY CD Digital Talking Book Players.
Based on the popular Victor Reader Vibe, the world's first mainstream MP3 player adapted to play DAISY books, the Victor Reader Wave has the same advantages of an adapted mainstream player with its portable design and affordable price but it includes many enhancements over the Vibe:

The Victor Reader Wave features

--The popular clam shell style lid of the Vibe remains but has been modified to use the familiar telephone style keypad of the Victor Reader Classic+ player.
--Enlarged file system to play complex DAISY books.
--Expanded memory to store hundreds of bookmarks.
--Saves playback position of DAISY, MP3 and music CD's.
--Audio prompts have been added for MP3 CD playback.
--Learning disabled users will benefit from a larger screen with text feedback for commands and display of book title and current section heading.

The Wave is currently available in English only. More languages will soon follow. The Wave can be obtained from our distributors, listed on the following Web page: http://www.visuaid.com/HW/en/distributors.asp#victor

The Victor Reader Wave includes earphones, a power adapter, a carrying case and rechargeable batteries. Batteries can be recharged directly in the unit. Victor Reader Wave’s compact size and rechargeable batteries allow you to take and use it anywhere.

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 number is 52 1317 540.

Resources

Aluminum Braille Clothing Tags
Mrs. Nick Dudas,
499 Grove Avenue, Edison, NJ 08820.

CCLVI Chapters
California Council of Citizens with Low Vision
800-733-2258

Delaware Valley Council of Citizens with Low Vision 215-735-5888

Metropolitan Council of Low Vision Individuals
845-986-2955

National Capitol Citizens with Low Vision
703-645-8716
ncclv@yahoo.com
Freedom Scientific
800-444-4443
www.freedomscientific.com

Horizons for the Blind
815-444-8830
www.horizons-blind.org/

HumanWare
175 Mason Circle
Concord, CA 94520
800.722.3393

Victor Reader Wave

National Library Service
(1-888-657-7323
www.loc.gov/nls.

Out of Sight Fitness
Bob Koppenjan at Duko Health International,
175 Irving Place,
Rutherford, NJ 07070,
Phone: 201-507-1510,
Email: dukohealth@comcast.net
Council of Citizens with Low Vision International
An Affiliate of the American Council of the Blind
2005 Membership Application

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___ Renewing my membership.           ____ Life member of ACB.

Visual Status: I am a:
___ person with low/no vision.         ___ fully sighted person.

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_____ Organization or Agency $25.00 _____ Life Member $150.00

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