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, 6 Hillside Rd., Wayne, PA 19087.

VISION ACCESS is a free publication to all members of the Council of Citizens with Low Vision International. Subscription and membership inquiries can be made to CCLVI’s toll free line, 1-800-733-2258.

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Welcome to your autumn issue of VISION ACCESS! It is a pleasure to send you all that is in these pages. My hope is that these articles will help you to become more comfortable with your own low vision, that your low vision becomes more of a companion on your journey rather than primarily an emotional burden.

I am grateful to everyone who contributed to this amazing array of articles. This is your magazine! Let us hear from you.

JMK, 11-28-03
The Washington, DC area is a wonderful place to live for a veteran low vision advocate like me. Low vision advocacy could be a full-time job if I didn’t already have a job as a professional in the field of government relations. Your board members and other leaders all do their best to keep up with what’s happening in legislation, regulations, and other areas of public policy affecting research, services, technology and public education about low vision. As you will see in the pages of this issue of Vision Access, our Editor, Joyce Kleiber, has sifted information to glean what might be of special interest to our readers. As this issue of Vision Access was heading for publication, Congress acted in two areas—Medicare coverage for vision rehabilitation and talking signs. CCLVI has been an advocate for these causes. Here is a description of these actions.

Congress has, for the first time ever, named vision rehabilitation professionals in the Medicare statute. The Medicare bill just passed by Congress appropriates $2 million to study Medicare coverage for vision rehabilitation services. This study, to be completed by January 1, 2005, is to produce recommendations for funding vision rehabilitation services through Medicare. Now orientation and mobility specialists, rehabilitation teachers, and low vision therapists are recognized as valuable to Medicare beneficiaries. And permanent Medicare coverage for these services now seems to be an attainable goal.

This study will also address two obstacles to Medicare coverage for vision rehabilitation—the lack of state licensure for vision rehabilitation professionals and the small number of vision rehabilitation professionals practicing nationwide.

A Senate Omnibus Appropriations bill, which is still pending, complements this landmark Medicare legislation.

The Omnibus bill conference report establishes a 5-year demonstration project to begin July 1, 2004. This project will lead to the provision of national Medicare coverage for vision rehabilitation services.

The Omnibus bill also requires the federal Center for Medicare and Medicaid Services (CMS) to develop policy recommendations by January 2005. These will allow vision rehabilitation professionals to provide services in patients’ homes and environs. In completing its assignment, CMS is to consult with the National Vision Rehabilitation Cooperative and other interested organizations.

While the 5-year demonstration project is in effect, advocates will seek Congressional approval to establish these services on a permanent basis.

Lorraine Lidoff, coordinator of the National Vision Rehabilitation Cooperative, urges the entire field of vision rehabilitation to strategize and take action now to meet the challenges involved in assuring successful outcomes for these groundbreaking initiatives.

In another arena important to people with low vision, a coalition is forming to seek a $30 million appropriation from Congress to fund a huge demonstration project in the metropolitan Washington DC area. This project requires that “talking signs” be installed to assist vision impaired travelers at all bus stops, on all busses, on subway trains, in subway stations, at the Amtrak train station and at both Washington Dulles and Reagan National airports.
I live here and I can not read signs because of my low vision, and I'm left wondering where all these public transit vehicles are going every single day. So installing talking signs sounds like a wonderful idea to me.

The effectiveness and versatility of talking signs as a way finding and orientation system for people with visual and reading disabilities has been researched and demonstrated through numerous studies, tests and installations for fully twenty years. Installations in the United States, Japan, Norway and Canada are providing reliable, accessible location information.

Advocates believe that orientation to public transportation is a civil right and that this demonstration project will serve to establish the first truly accessible city for people with visual and reading disabilities worldwide.

At this point, the legislative push is coming only from the U.S. Department of Transportation and the Louisiana delegation in Congress. You can help!

Please contact your United States Congressional Representative and Senators and urge the inclusion of The Washington Area Model Accessibility Project (WA-MAP) in current appropriations considerations. Ask that it be included in the new Federal Highway capital budget appropriations known as SAFTEA.

If you'd like to have more information about talking signs, contact Jeff Moyer at 440-442-2997 or jeff@talkingsigns.com

From the CCLVI Office
By Bernice Kandarian

Hurray! To date, our treasurer has not received any returns from the mailing of Volume 10, No. 3 issue of Vision Access. The large print edition was mailed after Labor Day and the electronic version was released a few days later. The cassette edition took a little longer due to cost cutting changes which required quite a coordinating feat and was sent the end of October. We are taking steps to improve our timing for the next issue so the release of all formats will be closer together.

Dues renewal notices will be released shortly. Please provide all information requested so we can send your publications in the preferred medium to the correct address. Be sure to include your email address if you mark email as your choice. And please include your telephone number so I can contact you if the need arises. Your phone number does not go beyond the CCLVI office. It would be greatly appreciated if you would respond to voice or email messages from me. I am only trying to resolve discrepancies.

Remember, if you move, change your name or wish to change your format for receiving Vision Access call the CCLVI toll free line, 800 733-2258. I will be glad to help you.

News from CCLVI Chapters

California Council

Our Fall convention took place in Los Angeles at the Airport Crowne Plaza Hotel October 16 thru 19, 2003.

We departed from our usual program format. The California Council of the Blind Publications Committee, Rehab Services Committee and California Council of Citizens with Low Vision co-sponsored a two and a half hour Writers Workshop Thursday afternoon. The workshop was conducted by Carol McCarl, editor of Dialogue Magazine and Winifred Downing, editor of The Blind Californian. These two women gave a
A brief business meeting was held following the workshop. It was the first time in a long time our CCCLV minutes and treasurers report were given in person; Secretary, currently Joan Black and our new Treasurer, Donna Sanchez. Donna not only has our bank records up-to-date but to the penny. And she has prepared a mailing for dues renewal to the 2003 members, plus she compiled a list of previous members from membership lists going back to 1994 in an effort to increase our membership. First Vice President Beryl Brown gave a status report on the development of the manual for Project Insight California (PIC).

The Friday morning joint session with the Committee on Access and Transportation (CAT) had a two hour workshop on Accessible Pedestrian Signals (APS) by Linda Myers, an O&M instructor in Marin County in northern California and Eugene Lozano, Jr., chair of the CAT. This was a fan out training from an eight hour workshop put on by Western Michigan University earlier this year in Seattle through a grant from Project Action. Materials from this event are also available on the CCB website. Then, Anthony Donaldson from Kaiser Permanente gave an update on the efforts of this gigantic HMO to comply with ADA.

Saturday morning Bonnie Rennie, chair of the Senior Blind Committee, chaired a session during which one of our members, Dr. Flora Beck and Jill Bellows, cruise agent spoke about "Cruisin' without Bruisin'" and Jane Lombard and Socorro Arroyo-Merchain, ILS, Counselors from the Dayle McIntosh Independent Living Center (ILC) in Orange County, described their program and services for people who are losing their vision. It was especially refreshing to learn about this type of program being provided by an ILC. Dr. Bill Takeshita, Director of Optometric Services at the Center for the Partially Sighted in West Los Angeles gave a dynamic presentation. Dr. Bill, as he prefers to be called, announced in January of this year that he is now experiencing low vision. This has led Dr. Bill to look at service delivery methods from a more consumer oriented point of view. As a result, he has been doing training to enlighten his colleagues. This session was also recorded and is available on the CCB website.

Our next convention will be at the Newark/Fremont Hilton Hotel in northern California April 15 thru 18, 2004.

Delaware Valley Council of Citizens with Low VISION, DVCCLV.

We welcome members from the Philadelphia area, Southern New Jersey, and Delaware. We share information about low vision and our triumphs and trials related to our low vision at the support sections of our monthly meetings.

This year, Betty Pannell, developed a website for our chapter. Visit this site at http://home.earthlink.net/~DVCCLV.

In September, members of our chapter went to the IMAX Theater at the Franklin Institute Science Museum. After viewing two the movies on the giant screen, we enjoyed pizza and compared how each member’s particular vision limitations affected his or her perception of the movies we had seen. Although descriptive video is available at IMAX Theaters throughout our country, this is not the case at the Franklin Institute. Therefore we drafted and sent a letter to the director of operations at the IMAX here advocating that descriptive video be offered here.

In November members of our chapter attended an audio described performance of the play, "Top Dog Under Dog" at the Plays and Players Theater. What a pleasure to sit in an audience and not feel that we were missing something others who do not have impaired vision can see! Our chapter has been advocating for audio described theater performances.

Contact us at 215-735-5888 or email at DVCCLV@earthlink.net...
Metropolitan Council of Low Vision Individuals, MCLVI.

We welcome members from Northern New Jersey, New York and New England. Our officers are President Ken Stewart, Vice President Isolde Keilhofer, and Treasurer Mildred Spinner. We meet in a Lower Manhattan office building, located directly on top of where a number of major subway lines converge. We have been pleased to offer support and low vision information to several new Chapter members. Much of our time and energy continues to focus on transportation issues. This year we have participated in a series of discussions with local bus officials pursuing ways of gaining better compliance with federal requirements that drivers announce stops. We have given attention to signage in subway stations and Grand Central Terminal and to more effective announcements by commuter rail conductors.

For more information about this chapter call Ken Stewart at 845-986-2955.

National Capitol Citizens with Low Vision, NCCLV

Members were treated to a hike especially designed for those with visual impairments at Rock Creek Park in Washington, DC. An eager to please park ranger discussed the park's topography (AKA layout) and history. She pointed out things that we might not have noticed such as mushrooms (and poison ivy which was especially helpful). She showed us how to identify bird calls and trees. An added bonus...because of Hurricane Isabel, we were able to see and hear things that would not have ordinarily been possible such as a bird's nest and the peaceful sound of waterfalls.

For information about this chapter based in Washington DC contact Barbara Milleville, Chapter President at 301-496-5248 or email at NCCLV@yahoo.com.

Note: To learn more about beginning a CCLVI Chapter in your area, call CCLVI at 800-733-2258.

Advocacy

Women and Vision Loss

Editor’s Note: The following article is presented here with permission from Newswise—an online news service, www.Newswise.com.

A call for public health action, increased funding for research, and creative educational programs in both the developing and developed worlds may be an outcome of the first international conference on women and blindness. Vision experts from around the country and the world gathered to explore why women are nearly twice as likely to lose their vision as men and how to stem the tide of blinding diseases in women. Called "Improving Women's Eye Health: Strategies to Address the Greater Burden of Blindness Among Women" and sponsored by the Women's Eye Health Task Force based at Schepens Eye Research Institute, the conference was held at the Harvard Club on November 7, 2003.

The conference was attended by public health policy makers, health care providers, scientists, organizations for the blind, the women's health collaborative, and vision experts. It is the first public forum held by the Women's Eye Health Task Force, founded in 2002 by a group of concerned scientists at Harvard's Schepens Eye Research Institute in response to a statistic just coming to light—that two-thirds of the world's blind are women.

These Schepens scientists invited and joined forces with vision experts throughout the US to form a national task force to begin a battle against eye disease in women.
The extent of the problem of blindness in women had become clear with the publishing of a meta analysis of more than 70 epidemiological studies on blindness conducted over the past 20 years. These studies showed that women accounted for most of the world's blind. In addition, World Health Organization (WHO) statistics indicate that 150 million people are living with low vision and more than 44 million people are blind. Two-thirds of the people suffering from visual impairment are women. Of the one million blind people in the United States, over 700,000 of them are women. In the United States, 2.3 million women are visually impaired out of a total of 3.4 million Americans with visual impairments.

Although there are more older women in developed countries and more younger women in developing countries dealing with vision loss, the overall statistics remain the same. Scientists theorize that longevity, smoking, nutrition, and environmental factors may be causing increased eye disease in women in developed nations, while poverty and lack of access to health services are contributing to the appalling statistic in developing countries.

"The fact is we don't have all the answers, but what we do know is that living in a developed, industrialized country does not protect a woman from the risk of vision loss," says Iline K. Gipson, PhD, a senior scientist at Harvard's Schepens Eye Research Institute and the chair of the Women's Eye Health Task Force, who gave welcoming remarks at the conference, along with Wayne Streilein, MD, president of Harvard's Schepens Eye Research Institute and vice chair of ophthalmology at Harvard Medical School, and Joan W. Miller, MD, chief of ophthalmology at Massachusetts Eye and Ear Infirmary and chair of ophthalmology at Harvard Medical School.

Gipson continued: "We hope this conference will be the first step in grappling with the reality of this problem and laying out some strategies to address it. There has been greater recognition of the issue and more resources focused on blindness and women in developing countries (although still not enough) than in the West."

Here are some conference highlights.

In the keynote speech, "Translating Research into Public Health Action," Hugh R. Taylor, MD, the managing director for the Centre for Eye Research at the University of Melbourne in Australia described the impact of low vision on the individual and society, the barriers to preventive care and various successful public health initiatives he created in Australia. "We are looking to Dr. Taylor's efforts as model strategies to help us in our fight against blindness in women," says Gipson.

In "Gender and Blindness" Paul Courtright, DrPH -- a lead investigator of the meta-analysis, an epidemiologist at the University of British Columbia and the leader of a gender-oriented outreach program at the Kilimanjaro Centre for Community Ophthalmology in Moshi, Tanzania -- focused on women and blindness in the third world. He described the results of his studies that suggest that attitudes and beliefs held by men in these societies are contributing to blindness in women. Men in some cultures, he has found, believe that medical care for their wives is not as important as it is for themselves as heads of households. He described creative educational programs that target men to convince them that visually healthy wives can be more productive family members.

"Major Concerns in Women's Health," was the topic of a presentation by Julie E. Buring, DSC, a professor of ambulatory care and prevention at Harvard Medical School and the principal investigator of the Women's Health Study at Brigham and Women's Hospital. She talked about vision health issues in the context of all the major health concerns facing women. For instance, she pointed out that lung cancer has overtaken breast cancer as the leading cause of cancer death in women, and that heart disease is the leading cause of death in women as well as men. She also described the risk
factors for diseases such as diabetes and heart disease, which are the same risk factors for eye disease—poor dietary habits, smoking and other lifestyle issues.

In "Sex Steroid Hormones and Eye Disease," Debra A. Schaumberg, ScD, OD, MPH, an assistant professor of Medicine in the Division of Preventive Medicine at Brigham and Women's Hospital and Harvard Medical School, described her landmark studies that indicate a strong relationship between the use of hormone replacement therapy and dry eye syndrome, a painful debilitating eye disease affecting millions worldwide, mostly women.

"Nutritional Factors and Eye Disease" by Richard D. Semba, MD, an associate professor of Ophthalmology, Molecular Microbiology and Immunology, and International Health at Johns Hopkins University School of Medicine and The Wilmer Ophthalmological Institute in Baltimore explored what nutritional factors are known to have an impact on vision and the nutrition prevention measures women can take to increase their eye health. For example, arottenoids and antioxidant vitamins appear to protect people from getting cataracts and age-related macular degeneration. And maintaining a healthy weight can prevent type 2 diabetes, with its disastrous consequences for the eye.

"Autoimmunity in Eye Diseases" was the focus of a presentation by Janine A. Smith, MD, deputy clinical director of the National Eye Institute. Smith discussed the higher incidence of autoimmune diseases in women and the ocular, potentially blinding features of these conditions. She also described her research on an autoimmune disease called premature ovarian failure, which affects women under the age of 40. The ovarian failure leads to decreased estrogen, dry eye and even osteoporosis.

Following each presentation, a panel of experts discussed the issues raised with the presenter and the audience.

The Women's Eye Health Task Force is based at Schepens Eye Research Institute, which is an affiliate of Harvard Medical School and the largest independent eye research institute in the nation.

**Chronic Eye Diseases, Annual Exams: A Study**

Many people with glaucoma, diabetes and age related macular degeneration fail to get annual eye exams. Such exams are important because treatment, particularly at early stages of these diseases, might prevent or delay further vision loss.

A study funded by a grant from the National Eye Institute was reported in the October 2003 issue of Ophthalmology, the clinical journal of the American Academy of Ophthalmology.

A random sample of Medicare beneficiaries aged 65 years or older was studied between 1991 and 1999. The authors found that 70 to 90 percent of those with glaucoma had annual eye examinations, 65 to 80 percent of those with macular degeneration had eye examinations, but only 50 to 60 percent of those with diabetes had such examinations. Also, more than half of those with at least one of the three eye diseases had at least one 15-month gap in eye examinations. Those with diabetes were more likely to have gaps in eye examinations than those in the other two eye disease categories.

This study indicates that changes in medical practice are necessary if greater compliance with recommended eye exams is to be realized. Primary care physicians and ophthalmologists could become more proactive in directing their patients, especially those recently diagnosed with chronic eye diseases. In addition, the media could publicize the importance of annual eye exams.
People seem to think they know what "blind" is, and they seem to think they know what "sighted" is. But those of us who are neither seem to fall between the cracks. People don't know what to call us - often they don't even seem to know that we exist - and we're not always sure what to call ourselves.

Which term is best? Low vision? Visually Impaired? Nearsighted? Legally blind? Partially sighted? Visually challenged? The National Association for the Visually Handicapped has its own term: "hard of seeing." The multiplicity of terms suggests how difficult it is to categorize people with visual impairments, but any of these certainly beats being called "glasses" or "four-eyes" or "Mr. Magoo" (though I do admit to a certain fondness for that character).

We discussed this topic on WGPS, our Working Group for the Partially Sighted email discussion group. The term "legally blind" got a lot of attention. Some do not like it at all. They find the term vague and confusing:

I have hated the term "legally blind" since I had a colleague who was "legally blind" but drove her car. Are people who can't see at all "illegally blind"?

I have never liked the term "legally blind" either. I prefer the term "vision impaired."

For me when I used to use the term "legally blind" people thought I had a lot less vision than I have. Now that I use the term "vision impaired" they seem to have a better understanding of my vision.

Actually for me legal blindness depends on which eye chart is used to measure my vision. If the standard eye chart is used, my vision tests at 20/200 which is legally blind, but when a more accurate low vision eye chart is used my vision tests at 20/160 which is not legally blind. That is another reason why I use the term "vision impaired" instead of "legally blind" to describe my vision.

However, others actually find the term liberating. From one member:

My experience has been different. The term "legally blind" gives me some official recognition. "Vision impaired" is like "nearsighted" - it can apply to anyone. But "legally blind" is a term that actually means something (even if the precise technical meaning is not always understood).

When I was a student going for my music therapy degree, being able to call myself "legally blind" gave me recognition, respect, and even dignity. My professors understood they had to make reasonable accommodations and they did so willingly. How things have changed since my earlier student days, when I was merely nearsighted," which to most people was a synonym for "inept." Back then the burden was always on me to make explanations and excuses for the difficulties I had doing certain things. It was painful and humiliating.
How refreshing it is now to be able to say there is a recognized disabled group to which I belong. The burden then shifts to the institution to make sure that the disability is accommodated.

I do not want to go back to the old days. I say let's keep the term "legally blind." The illegally blind will have to fend for themselves.

And from another:

Thanks for saying it so well. When my vision was 20/60 in my best eye, I could see but it was never that good. I couldn't use any such term as “legally blind” though so everyone thought I could see normally and then questioned me when I couldn't see something they could.

I am also finding the term “legally blind” one that is helping me accept the place I am now in. I even say “blind” sometimes to people who are really clueless. It helps them accept who I am and helps me deal with the same thing.

Just another opinion. All of us have them!

There are also practical benefits, if one can qualify as "legally blind":

Here in GA legally blind is 20/200 and opens the door to all kind of benefits, like services at the association for the blind, a tax deduction and special consideration by the Social Security Disability folks. Much of this is probably true elsewhere too.

It seems ironic that a term that can so profoundly affect our self-image is dependent on the judgment of a doctor that may be very subjective. As another member states:

When I first had a badge unceremoniously put on my shirt that said "I have Low Vision," I was offended by a probably well-intentioned oculist. I began to try to find the legal definition of “legally blind” in Texas law. To make a bad pun, it's a gray area in the law in this state. A "professional" has to declare that you have low vision "in their opinion." 20/400 doesn't guarantee any diagnosis. I checked again this week with my ophthalmologist during an appointment. What I gathered was that you have to get a professional with enough qualifications to pronounce you “legally blind” (in the eyes! of the law.) When I found out that here, at least, when you are carrying a "blind" cane and are walking on public and business property, you have the right of way; I decided to try never to be without a cane. It was amazing how quickly I got used to it. I prefer "legally blind," because of the legal mantle. I DO expect small but special considerations.

So that is another point in favor of "legally blind": it places one under the protection of the Americans with Disabilities Act, requiring one's employer to make reasonable accommodations in the workplace according to one's disability. Another advantage of the term may be its usefulness in explaining one's condition to others. Even if people don't understand what "legally blind" actually means (and very few people do), the term sounds official and may be all they really need to know.

I can honestly say terminology seems to be a big issue. I prefer "legally blind" or “low vision”. Personally I think we can go too far. I remember when "visually challenged" was the politically correct way to say it. I guess I think of myself more "legally blind" than
“low vision” because when I try to explain my vision to sighted people this one makes the most sense to them.

   True. I can’t really imagine telling people I’m visually challenged” when they ask me why I can’t see so well.

   The bottom line is, these labels do affect how others see us and how we see ourselves, but we can’t let any of them become a definition of who we are. There is no substitute for the knowledge of one’s identity that comes from inside oneself, and that endures no matter how we are categorized or stereotyped by others. Being a member of a group of people with similar experiences can help support that knowledge of one’s identity.

   (If you would like to become a member of WGPS, please send me your request at laflauta@hotmail.com.)

**Showing Children Life with Disability**
By Betty Pannell

Children form their opinions and comfort level about disability from adults with whom they interact. Like many values in life this one is “caught, not taught” as one of my college education professors once said in class.

While riding on the train recently, I overheard a mother explain to her daughter how a seeing eye dog knows the way and takes the person where he or she wants to go. I could not let this go, so I filled in kindly with some correct information. I work as an early childhood teacher and nanny and I have low vision. Here are some things I find helpful when explaining my low vision to children.

1. Whenever possible take time to interact with the interested child. You may be the first person with low vision the child has met. Make the experience a positive one.
2. Be honest about your low vision. Offer answers to honest questions. Encourage questions. If teasing is the reason for the question, don’t honor the request for information. I often will say, “If you really want to know, I’m happy to tell you. But if you’re going to tease me, I won’t answer the question.”
3. Take the mystery out of your low vision devices by letting the child try using them when possible. My nephews and niece all know what my cane is for and its proper use. I will not let them misuse it. As a result, the children leave it by the door. When we go outside, one of the children is bound to hand it to me saying, “Here, Aunt Betty. You need this.”

Do you have tips on this topic? Send your ideas to VISION ACCESS so that we can continue this discussion.

**A Blessing for Berry Pickers (And for Everyone Who Gives Thanks)**
By Mike Vogl

May you enjoy the labor as much as the fruits of your labor—the pickin’ as much as the eatin’.

May you neither miss a chance nor feel guilty to route a berry to your mouth instead of the bucket.
May you never lose a sense of wonder at life’s little surprises—the sparkle of the dewdrop, the glow of the sunbeam.
May you remember that the search is as important as the discovery.
May you live with disappointments, without resentment, when pickin’s are slim, but live gratefully and joyfully knowing that God loves you.
May you never lose hope as you search, and may your faith be deepened.
May you relish the gift of aloneness and never feel the sting of loneliness.
May your pursuit of the humble berry increase your appreciation of the bounty and beauty of nature.
May you savor the simplicity of your endeavor and practice it in all of your life.
May good companions join you in your quest, and may they realize there is a time to speak and a time to be silent.
May you know the ultimate joy that is the gift of sharing your harvest and your self.
May you learn the lesson of the thorn: the flavor of the berries sweetens in proportion to the amount of your scratches and your aches.
May you hear the voice of the Creator in the song of the thrush and in the thunder of the partridge.
May you one day arrive in berry pickers’ heaven where deerflies don’t buzz and chiggers don’t bite, where breezes are cool and the fruit grows at shoulder height.
May your pail overflow with luscious fruit and may your heart overflow with gratitude and love.
And may the Great Spirit fill you heart with sunshine today, and forevermore!

Concerns about Power Doors
By Ken Stewart

I have a long standing concern about the design of automatic doors and power-assisted doors relative to people with low vision.

For true “universal design” I believe architects should keep in mind that some of the traditional features of doors aid people whose vision is limited. A person who uses a guide dog told me that those service animals are trained to aim for the handle of a door. Handle free sliding or power doors can therefore complicate the progress of people who use guide dogs. More than once I have approached a large public building, an airport terminal for example, and have faced a long wall of unending floor to ceiling glass panels with no obvious clue about which of the many sections will automatically slide open when I get in the correct position to be detected by the electric eye. A blind user, too, may expect to detect some tactual clue like a door handle, a slight setback, or a prominent door jamb, for guidance—especially if he has been following along the building line and thereby avoided the electric eye’s detection zone.

The solution of course is not to abandon the use of sliding doors, automatic doors, or power assisted doors, but to design them with tactual and visual features which boldly declare their identify as the exact place to enter/exit.

What are your thoughts and experiences and recommendations about such doors? Please respond to the Editor of VISION ACCESS.

Arm Chair Traveler
By Jane Kardas

After a lengthy flight via Chicago, my daughter Kelly and I at last arrived in London, England. The underground railroads were on strike. What would have been a brief ride to our hotel became a long drawn out affair lasting nearly five hours in bumper to
bumper traffic. After checking into our hotel, we set out to see London. Being the first
diners in a fish and chips restaurant that evening, we ate as Americans would, picking
up our fish and chips. It was not

until the restaurant filled with other patrons that we realized the English custom was to
use a knife and fork.

After a good night’s sleep and a ride in a handsome black English taxicab, we
arrived at Paddington Station ready to begin our journey to visit one of CCLVI’s
international members, Sheila Stobart, Sheila lives in the town of Totnes in Devon
County. The train ride was three hours each way. As we traveled through the English
countryside, Kelly described the scenery and towns we passed. Her descriptions made
this trip most enjoyable for me.

The Dart River soon came into view on the left side of the train. Our anticipation
grew as we approached Totnes. I had been corresponding with Sheila on cassette
tapes for two years and enjoying her wonderful English accent. She had shared many
interesting stories about her experiences as the wife of a diplomat, especially the
challenges this presented in traveling with four children.

Sheila met us at the station with a friend who had offered to provide transportation.
She had described herself as short and round and that she would be wearing a bright
red jacket. She was just as she described and her demeanor was as lively and fun as it
had been through our taped letters. We were whisked away to her cottage for a
wonderful afternoon tea. She had a beautiful English garden where we drank wine and
met her companion, a feisty cat named Two Time. Two Time had earned his name by
deserting a neighbor in an adjoining cottage to move in with Sheila.

We walked through Totnes to the Dart River were Sheila told me she often sat on a
bench and recorded her cassettes to me. The streets were narrow; many were
cobblestone winding up and down hills. The town was beautiful with many small
specialty shops. Sheila explained that the area was comprised of people who choose
somewhat alternative life styles; of many were artists. Sheila herself had been an artist
before losing her vision. She was a water colorist and in her cottage we saw some
fantastic examples of her work. She had been able to provide a reasonable living for
herself through the sale of her paintings.

We boarded the train wishing we could have stayed longer and hoping to return one
day. Sheila described London to me as a big city that didn’t depict England. Totnes
she assured us was the real England!

During my correspondence with Sheila so many world events have changed the way
we live in America as well as in England. Following the disaster of the Twin Towers in
New York, I received a somber letter from Sheila expressing her concern for my family
as well as the state of world affairs and terrorism. The following is a portion of Sheila’s
letter to me immediately after the September 11th tragedy.

“My Dear Jane, My thoughts are so much with you and with America and all the
grieving, and with the British families who lost their loved ones in the bombing of the
World Trade Center. I was in the kitchen. I was getting my supper and turned on the
radio. I don’t know about you, but sometimes you don’t really listen, because you’re
getting supper and thinking about slicing onions, or whatever you’re doing to cook
supper, you don’t concentrate too much on the radio, you just turn it on. When
suddenly into my consciousness came this horrific news! I thought to myself, this is a
film or a play, it can’t be real. You know I was absolutely horrified, and I found it very
difficult to imagine, to try to get my head round, as I said it doesn’t equate with any
religion I know of.”

I discovered Sheila through the pen pal section of the Matilda Ziegler Magazine.
I encourage anyone who has a desire, such as mine, to be an armchair traveler to
acquire a pen pal. Doing so can open up a new world, a new culture and establish lasting friendships.
P.S. Correspondence with England can go as Free Matter for the Blind.

Cruise Away on Carnival
By Carolyn Hathaway

A group of blind and visual impaired people took a Carnival Cruise in September. This group included Pat Beattie, Colette Davis and me from CCLVI. We want to let all of you know what a good time we had.

Delmar Travel arranged for our cruise. Five people from this travel agency went on this tour to offer assistance to tourists when needed. We departed from New York and traveled up the New England Coast and into Canada. Since we left from New York, some of us came a few days earlier than our departure date so that we could spend some time in New York City. Our travel agency planned a tour around New York City on Friday. This tour included Battery Park, Ground Zero, and the Empire State Building. We had lunch in China Town and the travel agent read all our fortunes adding the words “in bed” after each fortune. These words added humor to each fortune. Some of us did see some shows on Broadway.

The cruise included stops in Boston, Portland ME, Sydney and Halifax Nova Scotia. In Boston there were many tours of the historical sights. I chose to go to Salem and Marblehead. In Salem I saw the Witch Museum, Lexington and Concord. In Portland I chose the best of Portland, Kennebunk Port, and a light house. There was a tour to an island and a fort on the island with a lobster bake.

In Sydney I went to Fort Louisburg, a French Fort from the French and Indian War. There were only 3 of us on this tour in the morning and the people working there took us behind the ropes and let us touch most of the items. I went on a walking tour of Sydney in the afternoon. There I visited an Alexander Graham Bell Museum. One of the cities in Nova Scotia had a Black History Museum. In Halifax Pat, Colette and I went on the tour of Halifax, Peggy Cove and to a lobster boil.

We did stop at the cemetery where the bodies that were found from the Titanic disaster were buried. There was a tour of the Titanic Museum and a tall ship tour. There were about 5 or 6 tours in each port. I often had trouble choosing from among the options offered.

On board ship we had many different activities from which to choose--a main show after dinner and the late show, a variety of bands in different bars, gambling, art auctions, classical music, tea, and an exercise room.

The nice thing about the large group was that if you didn’t want to do what your roommate did there was someone else to do things with. We made a lot of new friends. If you didn’t know anyone else that was going, Delmar found a roommate for you.

I am going on the next cruise with a person I met on this cruise. Both the Delmar and the Carnival staff were very helpful always asking if we needed help in getting where we were going on board ship.

Two cruises are planned for next year--on May 19th a cruise to Alaska and on September 12th a cruise down the west coast of Mexico. If you are interested in going on any of these cruises, call Delmar Travel at 1-800-999-6101 and ask for Dave Kronk. Hope to see you there.
Publications

Report on Impact of ADA on Employment of People with Severe Visual Impairment

John Jay Frank has published a monograph entitled The Impact of the Americans With Disabilities Act (ADA) on the Employment of Individuals Who Are Blind or Have Severe Visual Impairments. Part 1: Elements of the ADA Accommodation Request Process. This report is the first of three. It examines the impact of the ADA accommodation request process on the employment opportunities of people with severe visual impairments. The monograph includes an extensive literature review of attempts to evaluate the ADA and a qualitative interview study of the accommodation request process from three perspectives: people with severe visual impairments, rehabilitation professionals, and employers. A draft of a survey that will be modified and used for the second phase of the project is also included. The report can be purchased for $20 from the Mississippi State University-Rehabilitation Research and Training Center on Blindness and Low Vision (MSU-RRTC) by contacting Kelly Schaefer (662) 325-7825, email: Schaefer@ra.msstate.edu.

Blindskills Offers Cookbook


The book is available in braille and large print for $20 per copy. Call 800-860-4224 to order. Visa and MasterCard are accepted.

"The magic of this book is that it appeals to novice and experienced cooks alike," explained Nolan Crabb, Blindskills's public communications specialist. "Those teaching people who have recently lost vision will find this book a tremendous asset in teaching independent living skills."

Carol M. McCarl, executive director of Blindskills, said, "The cookbook is a compilation of columns written by the late Connie Weadon, a visually impaired cook and teacher who wrote for Dialogue, our quarterly magazine, for more than a decade. The recipes range from healthful main and side dishes to rich desserts. You can find recipes suited to someone who has been blind or visually impaired for a long time or someone who is just beginning to deal with vision loss. The book features conventional oven and microwave recipes.

"This isn't just another collection of recipes," Carol McCarl explained. "We've also included a variety of cooking tips and techniques, and the resource section includes book reviews."

Crabb said, "We are pleased to have partnered with the members of the Washington Council of the Blind, whose grant made this book possible. Blindskills is a leading not-for-profit organization which provides information to blind and visually impaired people via a toll-free number, (800) 860-4224. Founded in 1983, Blindskills, Inc. assists people throughout the world. Its extensive information resources are shared with blind and visually impaired people of all ages individually and through the pages of Dialogue. Dialogue is published quarterly in braille, large print, computer diskette and half-speed
four-track cassette. For additional information, visit http://www.blindskills.com on the Internet.

Science and Health

Researchers Explore Two New Ways To Reverse Blindness
By Czerne M. Reid


An interdisciplinary team of experts is working to reverse the effects of age-related macular degeneration -- the leading cause of blindness among Americans over age 65. The researchers plan to use eye tissue transplants for patients who still have some vision and prosthetic chips for those who have lost all vision.

Stacey Bent and Harvey Fishman are working with a prototype chip that someday may help restore sight in vision-impaired people.

"This is a very optimistic and ambitious project," said chemical engineer Stacey Bent, who with ophthalmologist Harvey Fishman jointly leads the research efforts.

Fishman presented the first complete design for a chip that functions like the natural retina of the eye. It uses chemicals to transmit nerve impulses to the brain. He spoke at the annual meeting of the American Academy of Ophthalmology in Anaheim, November 2003. Also in the same week, two of Bent’s graduate students, Christina Lee and Neville Mehenti, presented the group's work at the annual meeting of the American Institute of Chemical Engineers in San Francisco.

Optimistically, human trials of the tissue transplant could begin within the next six months, Fishman said. The retinal prosthesis is a longer-term project -- trials could begin in two to three years. The team already has successfully implanted prototype devices into animals and is refining the surgical techniques to prevent complications such as bleeding or retinal detachments.

Tissue transplant

In a healthy eye, vision occurs when light-sensitive cells in the retina convert light into electrical signals that the optic nerve then transmits to the brain. These cells receive nutrients and excrete waste through a thin layer of cells that covers them. In age-related macular degeneration, this life-giving layer degrades over time, leading to the eventual death of the cells beneath.

Patients with the disease typically lose central vision. In about 80 percent of those patients, some underlying cells remain alive although the cover layer has degraded. The team is recreating the protective cell layer using cells and tissues from other parts of the eye. This involves removing the tissue that normally covers the eye lens and using it as a support membrane on which to grow healthy cells taken from the iris. The iris cells are capable of growing into different types of cells that perform different functions. The lens tissue can be replaced with an artificial lens, as is routinely done during cataract surgery. The newly created layer would then be transplanted into the retina. Since only the patient's own tissues and cells are used, this type of transplantation reduces the possibility that the immune system will reject the implant.

The major challenge to this approach is getting the transplanted layer of cells to look and act like the naturally occurring layer. The cells need to be densely packed onto the membrane and perform the necessary feeding and waste-removal functions. Bent and
her team of engineers are devising ways to modify how the iris cells cluster on the surface of the lens capsule tissue using some of the same techniques used to make patterns on a computer chip. They also are monitoring the biological function of the cells. At the same time, the surgeons are developing and testing microsurgical techniques for transplanting the newly developed materials into the eye.

"That's actually why it's such a fun project, because it's not just academic," said Bent. "These problems have to be approached in both directions -- the engineering and the medical side of it." Fishman says that without the contributions of experts such as ophthalmology Professor Mark Blumenkranz in retinal surgery, and others in fields such as physics, chemistry and engineering, the work would not have been possible. "This is the new generation of super highly collaborative scientists," he said.

'The holy grail of prostheses'

For the remaining 20 percent of patients with age-related macular degeneration, all the light-sensitive cells have died. In those cases, a pinpoint-sized electronic device capable of receiving light and translating it into nerve-stimulating signals would be implanted into the eye. Bent called it "the holy grail of prostheses -- it's coming up with something electronic that could take the place of something that's naturally there but is having problems because of disease."

Bent said the investigators are working toward the most "physiologically correct" kind of prosthesis. They want to stimulate the nerve cells with chemicals, in the same way that neurons work naturally. When hit with light, the prosthesis would release a burst of neurotransmitter chemicals through a system of tiny valves. Those chemicals would stimulate the neurons.

Retinal prosthetic devices developed by others over the last five years stimulate the nerve cells with metal electrodes. But Fishman is concerned about the long-term effects of constantly hitting cells with electrical currents. The early retinal prostheses also have been relatively large and positioned far away from the neurons, so the electricity affects everything in the vicinity rather than focusing on the nerve cells. Fishman compares the process to hitting the nerve cell over the head with a large electrode hammer. "Maybe we can tickle the retina instead," he said.

To do this, the researchers will develop a chip from soft polymer material that can conform to the curvature of the back of the eye. This material would be better suited to the task than a traditional silicon chip. Researchers are developing techniques for extending the nerve cell branches so they can be close enough to the chip to be stimulated individually.

The initial work on the project was made possible by a grant from Bio-X and continued through industry support from VISX Inc., a California-based company that specializes in the design, manufacture and marketing of proprietary laser vision correction technologies. The investigators have applied for additional funding from the National Institutes of Health to continue their work.

The new technologies being developed to solve vision problems may find applications in other areas of medical research for conditions that affect many more people. "We are developing tissue engineering ways to regenerate nerve cells and to release drugs in very selective ways," Fishman said. "This has tremendous implications for the field of drug delivery in the eye and other parts of the body including the brain." He believes that neurodegenerative diseases such as Parkinson's and Alzheimer's may benefit from the technologies being developed.

Czerne M. Reid is a News Service intern.
Summaries of Other Current Research

Editor’s Note: Here are some examples of research concerning vision. These summary reports are based on articles that appeared on several listserves.

1. There is ongoing research to insert genes into tissues cells that are deficient in these genes. Macular degeneration and retinitis pigmentosa are conditions being targeted. First clinical trials are to begin next year. Professor Robin Ali, head of the gene therapy team at the Institute of Ophthalmology, University College London, said animal tests had shown the approach could lead to an effective treatment for inherited blindness in children and visual deterioration in the elderly. For example, to address retinitis pigmentosa, scientists may try to put the missing gene back into the photoreceptor cell.

2. Rhodopsin is a protein used by light receptor cells in the retina to detect and process light. This protein malfunctions and thereby causes retinitis pigmentosa. This malfunction results from improper folding of this protein. This often results from the action of a single gene. John Hwa, MD, PhD, assistant professor of pharmacology and toxicology at Dartmouth Medical School and his team of researchers are trying to determine why rhodopsin is prone to misfold.

   The hope is to find a drug to stabilize the abnormal protein. Rhodopsin consists of more than 300 amino acids one of which is responsible for its abnormal structure. Scientists expect to replace that amino acid with one that allows rhodopsin to function normally. Dr. Hwa and his team claim to understand the structure of the protein. They know which amino acid is at fault.

3. A biotechnology company, Neurotech, will conduct a phase 1 human clinical trial to test the safety of a delivery device containing a drug to treat patients with end-stage retinitis pigmentosa, RP. The treatment of retinal diseases has been challenging. This is because the protective retinal blood barrier makes it impossible to deliver therapeutic drugs to the retina using standard techniques— injection or pills.

   Neurotech, based in France and Rhode Island, developed Encapsulated Cell Technology, ECT—a device which enables controlled, continuous, long-term delivery of a drug called Ciliary Tropic Neuro Factor, CTNF. This type of research has shown promise in animal studies.

   ECT consists of a very small capsule containing retinal pigment epithelial cells, RPE, that have been genetically modified to produce CNTF. The capsule has very small pores through which oxygen and nutrients can enter to keep the cells alive. These pores also allow CTNF to pass out of the capsule. CTNF was chosen for its ability to delay the death of retinal photoreceptor cells in animal studies.

   This first phase clinical trial will test the drug and the ECT device in 10 patients with end-stage RP. If all goes well in this phase 1 safety study, this device will be tried in RP patients who still have vision.

4. An estimated 8 million people in the United States have intermediate age-related macular degeneration (AMD) and are at risk of developing "wet" AMD. Unfortunately, most of those suffering from wet AMD are diagnosed too late for effective treatment.

   Recently, however, Carl Zeiss Meditec Inc. obtained distribution rights for a novel new perimetry device -- called the Preview PHP (Preferential Hyperacuity Perimeter) -- for the early detection and management of AMD. The device, developed by Notal Vision Ltd., in Tel Aviv, Israel, has been shown to be twice as likely to detect the grid.
Families Needed for Study of Macular Degeneration

What is the Family Study of Macular Degeneration? The Family Study of Macular Degeneration is a research program currently being conducted at the Massachusetts Eye & Ear Infirmary in Boston. Principal Investigator is Johanna M. Seddon, M.D. The goal of the study is to learn more about the causes of age-related macular degeneration (AMD), the leading cause of visual problems in people over the age of 65. The goal of this study is to learn more about the genetics of macular degeneration, as well as environmental factors which may be related to AMD. This knowledge will hopefully lead to the development of more effective treatments and preventive reassurances. The results may contribute to saving the sight of future generations.

This study is funded by the National Eye Institute Of the National Institutes of Health. Each family member enrolled in the study will receive a free eye exam at the office of a local retina specialist and have some blood drawn at a local lab. Participants will also complete a written questionnaire about their diet and a telephone interview about their health.

My doctor told me that there is nothing that can be done to treat my macular degeneration. How can participating in the study benefit me? Although participation in the family study may not benefit you directly at this time, your involvement in this research is extremely valuable. Genetic research provides important clues to the biological causes of AMD. When doctors learn more about the cause of AMD, they will be better able to develop effective treatments and preventive measures, which will benefit future generations.

My relative has AMD, but I do not. Why are you asking me to participate in the study? Researches need family members with and without AMD to participate in the study. In particular, it is very valuable to compare siblings who have AMD to siblings who do not have AMD. The more complete information we have about a family the more successful this research will be. The more members of a family who participate the better.

For more information call 800-219-9157.

About Clinical Trials
From The National Eye Institute (NEI)

If you or someone you know is thinking about taking part in a clinical trial, this can answer some of your questions.

The National Eye Institute (NEI) conducts or sponsors clinical trials to find new ways to treat or prevent eye disease and vision loss. Clinical trials in vision research have led to new medicines and surgeries that have saved or improved sight for thousands of people.

What is a clinical trial?

Clinical trials involve medical research with people. Most medical research begins with studies in test tubes and in animals. Treatments that show promise in these early studies may then be tried with people. The only sure way to find out whether a new
treatment is safe, effective, and better than other treatments is to try it on patients in a clinical trial.

What kinds of clinical trials are there?
Clinical trials are carried out in three parts, or phases.
Phase I. Researchers first conduct Phase I trials in small numbers of patients and healthy volunteers. If the new treatment is a medicine, researchers also want to find out how much of it can be given safely.
Phase II. Researchers conduct Phase II trials in small numbers of patients to find out the effect of a new treatment on an eye disease or disorder.
Phase III. Finally, researchers conduct Phase III trials to find out whether the new treatments work better, the same, or not as well as the standard treatments already being used. Phase III trials also help to determine if new treatments have any side effects. These trials—which may involve hundreds, perhaps thousands, of people around the country--can also compare new treatments with no treatment.

Where do clinical trials take place?
The NEI supports clinical trials at about 250 medical centers, hospitals, universities, and doctors' offices across the country. NEI researchers conduct other clinical trials at the National Institutes of Health in Bethesda, Maryland.

How is a clinical trial conducted?
At each facility taking part in the clinical trial, the principal investigator is the researcher in charge of the study. Most of the people who conduct clinical trials in eye disease are ophthalmologists or optometrists. The clinic coordinator knows all about how the study works and makes all the arrangements for your visits.

Treatment for Herpes of the Eye.
The Herpetic Eye Disease Study (HEDS) is an example of a Phase III treatment trial. Herpes of the eye, which is controllable but incurable, can produce a painful sore on the eyelid and inflammation of the cornea, the transparent tissue on the surface of the eye. Previous studies showed that once people develop ocular herpes, they have up to a 50 percent chance of having a recurrence. In one part of the HEDS, researchers followed 703 patients who had herpes of the eye during the preceding year, but did not currently have an active case of the disease. Of this number, 357 were treated with the antiviral drug acyclovir by mouth, and 346 received a placebo.
Results: Scientists found that acyclovir reduced by 41 percent the probability that herpes of the eye would return. The findings from this research have helped to change how doctors treat the disease.
All doctors who take part in the study carefully follow a detailed treatment plan called a protocol. This plan fully explains how the doctors will treat you in the study. The protocol ensures that all patients are treated in the same way, no matter where they receive care.
Clinical trials are controlled. This means that researchers compare the effects of the new treatment with those of the standard treatment. In some cases, when no standard treatment exists, the new treatment is compared with no treatment.
Patients who get the new treatment are in the treatment group.
Patients who get the standard treatment or no treatment are in the control group.
In some clinical trials, patients in the treatment group get a new medicine and patients in the control group get a placebo. A placebo is a harmless substance--a "dummy" pill--that looks like the real treatment but has no effect on the eye disease or disorder. In other clinical trials, where a new surgery or device (not a medicine) is being
tested, patients in the control group may receive a sham treatment. This treatment, like a placebo, has no effect on the eye disease or disorder and does not harm patients.

Researchers assign patients randomly to the treatment or control group. This is like flipping a coin to decide which patients are in each group. Patients do not know ahead of time which group that is. The chance of any patient getting the new treatment is about 50 percent. Patients cannot request to receive the new treatment instead of the placebo or sham treatment. In some clinical trials, where the disease or disorder affects both eyes, one eye may be in the treatment group, and the other eye may be in the control group.

Patients often do not know until the study is over whether they are in the treatment group or the control group. This is called a masked study. In some trials, neither doctors nor patients know who is getting what treatment. This is called a double masked study. These types of trials help to ensure that what patients or doctors might think about the treatment will not affect the study results.

What is expected of patients in a clinical trial?

Patients in a clinical trial are expected to have eye exams and other tests. You may also need to take medications and/or undergo surgery. Depending upon the treatment and the examination procedure, you may need a hospital stay.

You may have to go back to the medical facility later for follow-up examinations. These exams help find out how well the treatment is working. Follow-up studies can take months or years. However, the success of the clinical trial often depends on learning what happens to patients over a long period of time. Only patients who continue to return for follow-up examinations can provide this important long-term information.

Natural History Studies.

Unlike clinical trials, in which patient volunteers may receive new treatments, natural history studies provide important information to researchers on how certain eye diseases or conditions develop over time. A natural history study follows patient volunteers to see how factors such as age, sex, race, or family history might make some people more or less at risk for certain eye diseases or disorders. A natural history study may also tell researchers if diet, lifestyle, or occupation affect how a disease or disorder develops and progresses. Results from these studies provide information that helps answer questions such as: How fast will a disease or disorder usually progress? How bad will vision become? Will treatment be needed?

What are the benefits of participating in a clinical trial?

Participating in a clinical trial can bring many benefits:

There is the hope that a new treatment will be more effective than the current treatment for an eye disease or disorder. Only about half of the people in a clinical trial get the new treatment. If the new treatment is effective and safer than the current treatment, those patients who do not receive the new treatment during the clinical trial may be among the first to benefit from the new treatment when the study is over.

If the treatment is effective, it may help to improve vision and control or prevent eye disease or disorder.

Clinical trial patients receive the highest quality medical care. Experts watch them closely during the study and may continue to follow them after the study is over.

People who take part in these trials contribute to new knowledge that may help other people with the same eye problems. In cases where certain eye diseases or disorders run in families, your participation may lead to better care for family members.
The Informed Consent.

Once you agree to take part in a clinical trial, you will be asked to sign an informed consent. This document explains a clinical trial's risks and benefits, what researchers expect of you, and your rights as a patient.

What are the risks?

Clinical trials may involve risks as well as possible benefits. Whether or not a new treatment will work cannot be known ahead of time. There is always a chance that a new treatment may not work better than a standard treatment, may not work at all, or may be harmful.

The treatment you receive may cause side effects that are serious enough to require medical attention.

How is patient safety protected?

Clinical trials can raise fears of the unknown. Understanding the safeguards that protect patients can ease some of these fears.

Before a clinical trial begins, researchers must get approval from their hospital's Institutional Review Board (IRB), an advisory group that makes sure a clinical trial is designed to protect patient safety.

During a clinical trial, doctors will closely watch you to see if the treatment is working and if you are having any side effects. All the results are carefully recorded and reviewed.

A group of experts—the Data and Safety Monitoring Committee—carefully watches each clinical trial supported by the NEI. This group can recommend that a study be stopped at any time.

Patients are asked to take part in a clinical trial only if they volunteer and understand the risks and benefits.

What are a patient's rights in a clinical trial?

Patients who are eligible for a clinical trial will be given information to help them decide whether to take part. As a patient, you have the right to:

- Be told about all known risks and benefits of treatments involved in the study.
- Know how the researchers plan to carry out the study, for how long, and where.
- Know what is expected of you.
- Know any costs involved for you or your insurers.
- Be informed about any medical or personal information that may be shared with other researchers directly involved in the clinical trial.

Talk openly with doctors and ask any questions.

After you join a clinical trial, you have the right to:

- Leave the study at any time. Participation is strictly voluntary. However, you should not enroll if you do not plan to complete the study.
- Continue to ask questions and get answers.
- Maintain your privacy. Your name will not appear in any reports based on the study.
- Be informed of your treatment assignment once the study is completed.

Uncovering an Ineffective Treatment.

Decompression surgery was once thought to be a sightsaver for people with ischemic optic neuropathy, a swelling of the optic nerve. An NEI-sponsored clinical trial examined this surgery in 244 patients.

Results: The operation proved to be neither safe nor effective. In addition, nearly half of those who did not have the surgery had improved eyesight within 6 months. Because
of these results, the NEI stopped the study earlier than expected and mailed a special bulletin to 25,000 doctors.

What about costs?
In some clinical trials, the medical facility conducting the research pays for treatment costs and some other expenses. You or your health insurance may have to pay for some things that are considered part of standard care. These things may include hospital stays, laboratory and other tests, and medical procedures. You also may need to pay for travel between your home and the clinic. For clinical trials conducted at the NEI's medical facility in Bethesda, Maryland, medical care is provided at no cost to patients. You should find out about costs ahead of time. If you have health insurance, find out exactly what it will cover. If you don't have health insurance, or if your insurance company will not cover your costs, talk to the clinic staff about other options for covering the cost of your care.

Saving the Sight of Premature Infants.
Retinopathy of prematurity (ROP) occurs when abnormal blood vessels grow and spread throughout the retinas of premature infants. The disorder mostly affects infants who weigh less than 3 pounds at birth. The NEI sponsored a clinical trial to find out whether a procedure called cryotherapy was a safe and effective treatment to prevent ROP. In this procedure, doctors briefly touch spots on the surface of the eye with an instrument called a cryoprobe. This freezes parts of the retina to stop the growth of abnormal blood vessels.

Results: Fewer of the infants’ eyes that were treated with cryotherapy became blind compared with the eyes of untreated infants. Researchers continue to follow these children to gain information about the long-term effects of the procedure.

What questions should you ask before deciding to join a clinical trial?
Questions you should ask when thinking about joining a clinical trial include the following:

What is the purpose of the clinical trial? What are the standard treatments for my disease or condition? Why do researchers think the new treatment may be better? What is likely to happen to me with or without the new treatment?

What tests and treatments will I need? Will I need surgery? Medicines? Hospitalization? How long will the treatment last? How often will I have to come back for follow-up exams?

What are the treatment's possible benefits to my condition? What are the short- and long-term risks? What are the possible side effects?

Will the treatment be uncomfortable? Will it make me feel sick? If so, for how long?

How will my health be monitored?

Where will I need to go for the clinical trial? How will I get there?
How much will it cost me to be in the study? What costs are covered by the study?

How much will my health insurance cover?

Will I be able to see my own doctor? Who will be in charge of my care?

Will taking part in the study affect my daily life? Will I have the time to be in it?

How do I feel about taking part in a clinical trial? Are there family members or friends who may benefit from my contributions to new medical knowledge?

Laser Treatment for Diabetic Retinopathy.
Two NEI-sponsored clinical trials examined the use of laser treatment in patients with diabetic retinopathy, a disease that damages the blood vessels in the retina. About half of the 16 million Americans with diabetes have this disorder, which is a leading
cause of blindness in working-age adults. Laser treatment was given to 4,453 people with diabetes at 25 medical centers. One eye of each patient received laser treatment. The other eye was not initially treated.

Results: Laser treatment was very effective in preventing vision loss in more than 90 percent of patients with diabetic retinopathy.

What clinical trials are being held? Who can take part in them?
The NEI conducts or sponsors research on many eye diseases and disorders. Because funding for eye research goes to the medical areas that show promising research opportunities, it is not possible for the NEI to sponsor clinical trials in every eye disease and disorder at all times.

Not everyone can take part in a clinical trial for a specific eye disease or disorder. Each study enrolls patients with certain features, or eligibility criteria. These criteria may include the type and stage of disease or disorder, as well as the age and previous treatment history of the patient.

You or your doctor can contact the NEI to find out more about specific clinical trials and their eligibility criteria. If you are interested in joining a clinical trial, your doctor must contact one of the trial's investigators and provide details about your diagnosis and medical history.

The NEI's Website lists the clinical trials the NEI is helping to support. Each trial description includes information on its background and purpose, as well as patient eligibility. There is information on how to participate in a trial and how to refer a patient to a trial.

Preventing Blindness in People with AIDS.
Many people with AIDS have an eye infection known as CMV retinitis. Drugs such as ganciclovir can control the infection and reduce the chance of blindness. In the past, doctors gave the drug through a tube that had to remain in a vein. It took 2 hours to give each dose. Another way to give ganciclovir is through the use of a tiny implant in the eye. The implant slowly releases the medication for several months. The NEI supported a clinical trial to find out whether this implant was safe and effective.

Results: Almost all of the eyes treated with the implant had complete control of their eye infection and maintained nearly perfect vision. The implant also improved the patients' quality of life by making treatment easier.

What is the National Eye Institute?
The National Eye Institute (NEI) is one of the Federal government's National Institutes of Health. It was established by Congress in 1968 to discover safe and effective ways to prevent, diagnose, and treat eye diseases and disorders. The NEI is the major sponsor of vision research in the United States. For more information about the NEI, contact:
National Eye Institute, 2020 Vision Place, Bethesda, MD 20892-3655, Telephone: (301) 496-5248, E-mail: 2020@nei.nih.gov
Frustrating! That’s what glasses were for me. As a kid, I’d get peanut butter and fluff on them and even when spotless, they didn’t help much. So when I was 10, I discarded them altogether. My frustration ended in February, when I visited Rehabilitation Engineer Bob McGillivray at the Carroll Center for the Blind in Newton, Massachusetts. He’d been showing me a new CCTV, warning me not to be frightened when it talked. This was too much! My husband said jokingly, “All they need to make now are glasses with a magnifier inside so you can walk around.” Bob smirked; and, without a word, opened a small case. He pulled something out and placed it in my hands. “Try these on,” he said.

It was like a combination of magnifier, telescope and video camera. The first thing I noticed was that Bob had a mustache. I’ve known him for 12 years and had never realized it. Then I saw my husband and daughter clearly from several feet away. Incredible! I was so impressed that these glasses magnified so well, I contacted the company to request one for a review.

Enhanced Vision in Huntington Beach, California is the maker of Jordy (Joint Optical Reflective Display). It’s a complete low vision system that can magnify up to 30x at a distance and up to 50x close-up. It can even be used as a full-color CCTV when placed in its docking stand (sold separately).

Jordy can help many people with low vision. In certain cases, someone with 20/400 vision can improve to a near-perfect 20/40. If you’re looking for a hands-free tool that is both powerful and versatile, then this may be ideal, but it’s not necessarily ideal for everyone.

"As with any low vision device, individual responses may vary,” cautions Bob McGillivray. He’s demonstrated Jordy to more than 50 people and sees the best results with those who are comfortable using low vision equipment. People who anticipate wearing Jordy and seeing exactly as they once did may be disappointed. It’s meant to be used while sitting or standing still because there’s no magnified peripheral vision. Also depth perception and perspective are diminished. But, those who can accept its few limitations and learn to use it to its fullest potential will find it to be a very powerful tool.

Jordy arrives in a small protective case fully assembled with its lithium battery charged. Each charge lasts two to three hours and an AC adapter is included, too.

You also get a Sony battery charger, glare shields for outside use, a cleaning cloth, an extra nose piece and a belt clip. It comes with a video-out cable, a video-in cable and a coupler for watching TV. The instruction manual clearly explains how to use Jordy and you can call technical support for additional help. The distributor you buy it from will likely train you, too.

Two miniature TV screens are what you see as a tiny computer chip captures and projects images. (If you wear prescription glasses for distance, use them with Jordy.) A wire connects the glasses to a small control unit which can be held, clipped onto a belt, or slipped into a pocket.

There are several buttons on top of the control unit. These control functions such as power, auto-focus, and brightness. On the side of the control unit is a square button for locating objects. Press and hold this button as you look through the glasses. What you’re viewing will shrink in size so you can have the widest field of view. Once you find the object on which you’d like to focus, lift your finger and Jordy will automatically return to the original size you selected. This is helpful when you’re feeling lost; I sometimes got disoriented when I wore Jordy in a moving vehicle.
Everything whizzed by my window and it was hard to figure out what's what. By using the locator button, I could see the big picture and find the area I'd like to view. A little preplanning enabled me to focus on objects as we approached.

In the middle of the control unit is the largest knob used to set magnification. There are 16 preset levels from which to choose; a simple turn locks in the size you need. I have a 10x telescope I use; Jordy outperforms it. Not only are objects bigger, but the lighting makes everything clearer as well.

Finally there's a round button which selects viewing mode. Full color or black and white are used for distance or close-up viewing. High-contrast positive or negative can be used for reading. Positive provides a white background with black text or negative, a black background with white text. To read, the user slides the reading lens to the left and holds the material about 14 inches away.

The unit can also be used to watch TV. Either look directly at the TV while wearing Jordy, or connect it to your VCR. A direct connection to the VCR will result in a clearer picture than merely looking at the screen. You can't change the size while it's connected to the VCR, but you can control the brightness. You can even view a computer monitor using Jordy, but the refresh rate needs to be changed. I changed mine with no problem.

My Jordy experience was amazing. At a bookstore, I read titles on shelves without having to pick up the books; and, in a restaurant, I scanned a menu with ease. My few concerns are minimal. Colors are sometimes slightly off--like how they appear on TV. Also, I wish Jordy did a better job of magnifying small print. (Of course, my visual limitations are such that others may find Jordy's magnification of small print sufficient.) I'd request an over-the-head strap; after wearing Jordy for awhile, my nose felt uncomfortable because of the weight. The glasses weigh only eight ounces, but my nose wasn't used to it. Overall though, Jordy is the most effective and versatile low vision tool I've ever used. It's way more convenient than carrying everything I need to see easily. I'd either need my CCTV, telescope, stand, and screen magnification software, or Jordy. The convenience and portability can't be beat.

Jordy's suggested retail price is $2,795. To find a distributor near you, visit www.enhancedvision.com or call 888-811-3161. For many people, these glasses will end frustration, as long as you keep your peanut butter and fluff in your sandwich and off your Jordy!

**Citrix and GW Micro Promote Access to Computer Applications and Information**

Citrix Systems, Inc. and GW Micro, Inc. announced an alliance to provide visually impaired users with full, interactive access to their corporate desktops and to any application centrally hosted in Citrix® MetaFrame XP™ Presentation Server environments. GW Micro produces one of the industry's leading software screen readers called Window-Eyes, which gives the visually impaired the ability to hear and feel their Windows operating systems through speech synthesis and Braille displays, while Citrix access infrastructure enables anytime, anywhere, any-device, any-connection access to applications and information. Together, the two technology solutions are a major breakthrough for the visually impaired. Window-Eyes is currently available for beta testing on Citrix MetaFrame XP Presentation Server, Feature Release 3.
BrailleNote GPS Aids Travel

BrailleNote’s Global Positioning System software helps people with impaired sight to know where they are faster and easier. This software uses a cell-phone size GPS receiver to relay information from GPS satellites. It calculates where you are and plots the route to a destination you choose. This state of the art software means you can use your BrailleNote or VoiceNote to:
* Easily calculate the distance and direction to a street address or intersection
* Find out the relative location of hundreds of thousands of Points of Interest
* Automatically create routes for either walking or riding in a vehicle and,
* Provide you with detailed information about your speed, the direction you are traveling and your altitude.

For more information call Pulse Data HumanWare at 80-722-3393 or email usa@pulsedata.com, www.pulsedata.com

A Cell Phone That Speaks

The first cell phone designed specifically for blind and partially sighted people has been developed by a company in Spain.

This phone has no visual display but uses a speech synthesizer to speak everything that would normally appear on the screen. This cell phone gives audio feedback when buttons are pressed and it can send and receive text messages. It will speak the name or number of incoming callers.

The phone is made by a Spanish company, Owasys - pronounced “oasis”. It is on sale in Spain and will be sold in Britain early in 2004.

Owasys hopes the mobile phone will retail at around £250. Company representatives consulted blind and partially sighted people throughout the development phase. The finished product reflects the feedback of potential customers.

This phone is likely to appeal to more than just blind and partially sighted people. Many people just want a device that's easy to use and friendly.

Selecting and Dispensing Magnifiers Made Easier

Now free, from Vision Aid Services, the Optigram Process is a set of new tools that make selecting and dispensing magnifiers easier. Ralph Sherman, an optician who has specialized in dispensing magnifiers since 1989, designed the original Optigram in 1993. Thanks to the Internet the newly revised and updated Optigram Process is now available for free, in an Adobe Portable Document Format (pdf) at www.visionaid.com/cclvi.htm.

Anyone who dispenses magnifiers should give the Optigram Process a try. This simple process is highly reliable and effective. The single most compelling reason to use the Optigram Process is that it takes the guesswork out of the assessment and trains patients in the proper use of their magnifiers, at the same time. This time tested
process streamlines the delivery time and improves patient satisfaction because your patients are learning how to use a magnifier while they are deciding what power is best. With your professional guidance and the Optigram Process your patients will feel confident that they are getting the best service and most appropriate magnifier for their needs.

Request for Contributions

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

Resources

American Foundation for the Blind Aging and Vision Loss Task Force
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CCLVI Chapters
California Council
800-733-2258

Delaware Valley Council:
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Email: DVCCLV@earthlink.net.

Metropolitan Council
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Citrix Systems Inc.
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Dialogue Magazine
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Enhanced Vision
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Jeff Moyer
440-442-2997 jeff@talkingsigns.com

Matilda Ziegler Magazine
212-242-0263
Email: blind@bellatlantic.net

Medicare Rights Center
www.medicarerights.org

Mississippi State University-Rehabilitation Research and Training Center on Blindness and Low Vision (MSU-RRTC) Kelly Schaefer
662-325-7825,
email: Schaefer@ra.msstate.edu.

National Eye Institute, 2020 Vision Place, Bethesda, MD 20892-3655, Telephone: (301) 496-5248, E-mail: 2020@nei.nih.gov

National Vision Rehabilitation Cooperative
www.Medicarenow.org

Newswise
www.Newswise.com

Prevent Blindness Ohio
Sherry Williams
614-464-2020

Vision Aid Services
6032 SE Pardee Street
Portland, OR 97206
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