VISION ACCESS

Volume 14, Number 3
Fall 2007
Copyright 2007
by
the Council of Citizens with Low Vision International.

VISION ACCESS is a magazine by, for, and about people with low vision. VISION ACCESS is published quarterly in three formats (large print cassette, and email) 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 as attachments to email or on 3.5" disk in a format compatible with Microsoft Word. Submissions may also be made in clear typescript. VISION ACCESS cannot assume responsibility for lost manuscripts. Submissions may be mailed to Joyce Kleiber, Editor, 6 Hillside Rd., Wayne, PA 19087, jmkkleiber@hotmail.com

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.

Council of Citizens with Low Vision International
1155 15th Street NW Suite 1004
Washington, DC 20005  1 800 733 2258
Contents

From the Editor ......................................................................................................................... 3
Organization News
  President's Message ............................................................................................................. 4
  Summaries of CCLVI Board and Membership Meetings ................................................... 5
  CCLVI Chapter News ........................................................................................................... 9
  Mid-Atlantic ACB Affiliates to Hold Regional Convention ............................................... 11
Convention Highlights
  Vision Rehabilitation, By Mary Gilbert Lawrence, M.D. ...................................................... 13
  Ethics in Stem Cell Research, By Mary Faith Marshall, Ph.D. ............................................. 16
  Low Vision and Leadership, By John Vaughn ................................................................. 20
  Focus on Employment, By Sarita Kimble Holiday .......................................................... 22
  Effective Advocacy for Local Transportation, By Ken Stewart ......................................... 24
Science and Health
  Participants Needed for Research Study .............................................................................. 26
  Cancer Drug Curbs Radiation-Induced Vision Loss ......................................................... 27
  Injections into My Eye to Treat Retinal Edema By Joyce Kleiber ...................................... 28
Advocacy
  Congress Voices Concern for Availability of Low Vision Devices through Medicare .......... 33
  Accommodating Individuals Who Are Blind and Vision Impaired at Sports Stadiums, By Rick Morin ................................................................. 36
  Advocate’s Alley, We’ll Speak for Ourselves, Thank You, By Ken Stewart .................... 45
Request for Contributions ........................................................................................................ 48
Resources .................................................................................................................................. 48
CCLVI Membership Application and Renewal ....................................................................... 49
CCLVI Officers and Board Members ...................................................................................... 50

From the Editor

Welcome to the Fall 2007 issue of Vision Access. We feature summaries of presentations at our CCLVI convention last summer in Minneapolis. If you were there, it’s a good review. If you missed our convention, these summaries may help you feel more included. Be sure to notice the announcement of CCLVI’s email list in Bernice Kandarian’s “President’s Message.” Joining this list gives you an opportunity to share ideas and concerns about your low vision. In her article Sarita Holiday offers to respond to your job related challenges. She will do this in a new Vision Access column, “Focus on Employment.” Take advantage of these opportunities.

This morning in my yoga class, our instructor suggested we be grateful for all parts of our body, even those that don’t work as well as we’d like in doing yoga or in doing life. I am grateful for the vision I have, every little bit of it. As I look at the panorama of Fall, I enjoy the darker shadows, the deeper greens, the bluer skies, the beams of golden sunlight streaking through Pennsylvania’s towering trees. Be grateful for your vision. Enjoy this magazine.

Thanks to all who contributed ideas and articles. JMK, 9/14/2007.
Another convention has come and gone and I'm still recovering! Thanks to Editor Joyce Kleiber for reporting on the convention program.

I also want to thank John Horst, Sarita Holliday, Rick Morin and Pat Beattie for coordinating the program events. And Richard Rueda emceed another successful Game Night. We even managed to recover from Barbara Kron's fall and broken arm and got the mixer together, which she was supposed to run. We hear that Barbara is recovering too after surgery and a lot of rest.

Two of our three scholarship recipients were able to attend the convention and both apparently found it a positive experience. Lisa Drzewucki is now on the CCLVI membership Committee and Robin Lipsker is working on organizing a chapter in her area.

At our Post-Convention board teleconference meeting on July 27, the board voted to sanction a CCLVI email list, which has been established and is co-moderated by Richard Rueda and Carlos Gourgey. There has already been a lot of discussion on the list about bioptic driving, technology, coping with low vision and the social attitudes about it and other topics. If you haven't yet subscribed to our list, consider doing so. To quote Richard's instructions:

* To join the list, please email Richard Rueda, CCLVI list owner at richardrueda@sbcglobal.net with the following information: Please indicate your name, should it appear different from your subscribing email address along with a sentence or two on why you would like to join. Your email request should be replied to within less than 24 hours.
* Group name: Council of Citizens with Low Vision International
* Group home page: http://groups.google.com/group/CCLVI?hl=en
* Group email address CCLVI@googlegroups.com
* To post - simply compose or reply to: CCLVI@googlegroups.com

**Summaries of CCLVI's Board and Membership Meetings**

**Preconvention Board Meeting, June 30, 2007**

Scholarship Committee: Two of the three scholarship recipients are attending the convention. They are Robin Lipsker and Lisa Drzewucki. 25 out of 27 applicants were evaluated. Winners were chosen on the basis of community involvement, merit and vision qualifications.

Program Committee: John Horst gave last minute updates and asked for volunteers to assist with events hosted by CCLVI.

Website Committee: Carlos Gourgey said that in 2006 our website was cleaned up and repaired. The committee is developing guidelines for submissions by members. It is hoped that our website will grow and be responsive to members' concerns. A web page devoted to members' submissions will have a disclaimer. Items for this page will be selected by a majority vote of the website committee. Past issues of Vision Access will be archived on our website. Also included will be our constitution and bylaws, Membership and Scholarship Applications, and what the world should know about low vision.
Chapter Development: Sarita Holiday reported that Kathy Casey has formed a new chapter of 10 members—the New York State Council of Citizens with Low Vision.

Resolutions Committee: Michael Byington, Pat Beattie and Ken Stewart offered several resolutions.

Legislative Update: Pat Beattie asked people to call their senators to request funding for the National Library Service to convert Talking Books to digital format. Regarding the Center for Medicare and Medicaid Services, AFB and CCLVI are asking that funding be made available for low vision aids that utilize lenses.

Vision Access: Publications committee is being formed.

Complete Streets: CCLVI may make a monetary contribution to this organization.

Fred Scheigert was chosen as delegate to represent CCLVI at the ACB convention with Ken Stewart as alternate. CCLVI has 12 votes. We now have 308 members, up from 290 in March. CCLVI will support Mike Godino for reelection as ACB treasurer.

Credentials of CCLVI chapters were noted. CCLVI’s contribution of a door prize to ACB was decided—$25.

CCLVI will inaugurate an award in honor of Elizabeth Lennon. It will be known as the Elizabeth Lennon CCLVI Award.

A committee including Mike Godino, Carlos Gourgey and Barbara Milleville was formed to establish policies about reimbursements for expenses on behalf of CCLVI.

Announcements: Members were encouraged to participate in two research projects at this convention concerning people with low vision—one concerns signage, the other concerning curb cuts.

Annual Membership Meeting, July 3, 2007

Chapters and their voting status were recognized.

John Horst gave a convention program update.

Pat Beattie reported on legislative concerns.

Carlos Gourgey gave an update about CCLVI’s website.

Vision Access welcomes submissions and requested revision of deadlines for submission of articles for each issue. This together with future conversion to digital format will be referred to Publications Committee being formed.

Michael Byington presented 5 resolutions.

Nominations Committee reported their recommendations.

Elections: Rick Morin and Carol Ewing, previously appointed as secretary and director, were confirmed. Lindsey Hastings, Brian Petraits, Richard Rueda and Coletta Davis were elected by acclamation. Lindsey, Brian and Richard were elected to three year terms and Coletta is filling a two year vacancy.

The membership voted to contribute $100. to Complete Streets hoping that this contribution will give CCLVI a more substantive role in this organization.

Treasurer’s report was approved.

Membership voted to offer three $3000 scholarships in 2008-09 and to stipend winners to our convention. Efforts will be made to again offer a Carl Foley Scholarship to a graduate student in the field of low vision.

Announcements: A breakfast meeting titled “High Partials in a Sighted World” will be held on Thursday morning.
Minutes of the May 11 Board meeting were read and approved.

Membership Report: This committee hopes to "prospect" for new members in new places.

Pat Beattie gave a legislative update regarding Medicare reimbursement for low vision aids, the ADA Restoration Act, and possible revisions to the Social Security Act.

Joyce Kleiber reported on Vision Access and deadline for submission of articles for the Fall 2007 issue. Publications committee is still being formed. Carlos Gourgey announced that all issues of Vision Access are on our website in rich text format.

This summer's convention was reviewed and recommendations were made. Bernice Kandarian thanked members who helped with the dances, Game Night, and our mixer.

Rick Morin reported on his advocacy regarding sports venues. Pat Beattie recommended that Rick work with the American National Standards Institute through ACB's Environmental Access Committee.

The board voted to approve the creation of a discussion list for CCLVI members and supporters. This list will offer a vehicle for people to respond to issues. Richard Reuda and Carlos Gourgey will coordinate this list.

Bernice Kandarian said the CCLVI Constitution will be reviewed to determine better timing regarding the meeting date of the nominations committee.

The next board meeting will be on September 21, 2007, giving time for committees to meet in advance.

CCLVI Chapter Reports

California Council of Citizens with Low Vision International is planning its semi annual convention for October 25 to 28 at the Four Points Sheraton Hotel in Los Angeles, CA.

Dr. Bill Takeshita, Director of Optometric Services at the Center for the Partially Sighted, will speak about assistive technology for people with low vision,—what's new, what works well. Dr. Takeshita has recently experienced vision loss, so he speaks not just from the point of view of the professional but also that of the recipient of services.

A joint session with the Committee on Access and Transportation will focus on calling bus stops and enunciators.

A second joint session with the Seniors and Vision Loss Committee will address accessible signage. Karen Toji, consultant who serves on the ANSI Standards Committee and whose husband owns a sign business lead this session.

For information about this chapter call 650-969-3155.

Metropolitan Council of Low Vision Individuals continues to have a strong presence at meetings between sports stadium architects and the disabled community. On July 18th, four Chapter members participated in a session at New York's Shea Stadium, and they were heartened to hear back from the lead architect drawing up the plans for "City Field", which will be the new home of the Mets Major League Baseball team, financed by CityCorp. The architect confirmed that he has been hearing and understanding what is being said about what makes paths of travel, signage, rest room fixtures, and seat numbers, highly visible.

Chapter Board of Directors member, Rick Morin, was featured in an article in the nationally distributed Sports Business Journal on a subject with which he has developed a high level of expertise-seating
accommodations at sports and entertainment venues for people with vision impairments.

The Metro Chapter continues to welcome any CCLVI member who resides anywhere near Metropolitan New York, or has any association with our area. For Chapter information, call 845-986-2955 or 212-664-1038, cclvi@yahoo.com.

Mid-Atlantic ACB Affiliates to Hold Regional Convention

An informative regional convention for people who are blind and visually impaired who live in the Washington, DC metropolitan area is scheduled for November 2-4, 2007, at the Holiday Inn, Rosslyn at Key Bridge, located at 1900 N. Ft. Myer Drive in Arlington, Virginia.

Expert presenters and panelists will interact with convention participants in sessions on public and paratransit transportation issues, finding books and accessible book players in the digital age, accessible pedestrian traffic signals, employment issues and training opportunities, and many other vision-related matters. Support group resources for people experiencing vision loss and for their families and friends will also be highlighted at two of the twelve concurrent workshops on Saturday afternoon.

Many vendors of low and high-tech products will be available to demonstrate their products and services.

On Friday evening the

Maryland Area Guide Dog Users, Inc., is sponsoring a reception so that we can welcome all our participants in style.

The convention’s banquet speaker will be Mitch Pomerantz of Pasadena, CA, who is the newly-elected president of the American Council of the Blind.

National Capital Citizens with Low Vision is one of the sponsors of this event. Other sponsors include: The American Council of the Blind of Maryland, District of Columbia Council of the Blind, Old Dominion Council of the Blind and Visually Impaired, and Maryland Area Guide Dog Users, Inc.

Room rates are $99. (plus tax) per night, single or double occupancy. To book a room, phone the Holiday Inn Rosslyn at 703-807-2000 or 1-800-368-3408. Registration fees and forms are available at: www.acb.org/olddominion. For more information, contact Barbara Milleville at 703-645-8716; BarbMill1@verizon.net or Doug Powell at 703-573-5107; oldjock1@cox.net.

Convention Highlights

Vision Rehabilitation

By Mary Gilbert Lawrence, M.D.

Editor’s Note: Dr. Gilbert is Associate Professor and Director of Vision Rehabilitation Center at the University of Minnesota.

Vision rehabilitation needs to be tailored to the individual. There are some programs that are too much and some that are too little. We all need to be advocates for getting
what’s right for patients at the right time. An example of a program that might be too much is the 6 week inpatient program offered by the Veterans’ Administration. This program may not suit an older person with macular degeneration who is responsible for caring for his or her spouse at home and can’t leave home for 6 weeks. The VA is now offering a continuum of care, such as an intensive outpatient program, to meet the needs of their patients.

At the Vision Rehabilitation Program at the University of Minnesota we focus on the patient’s visual goals. We offer tools and strategies to meet these goals. We focus on function, not disease.

The two most common goals of people who come to our center are reading and driving. One of four seniors has vision loss, most as a result of macular degeneration. We help these patients with eye movement skills and help them to use a preferred retinal locus outside the fovea. We help people develop lighting strategies to do their reading tasks. Some people do better with full spectrum lights while others prefer halogen lights. Even humidity can increase glare and interfere with reading ease.

Another important tool for reading is magnification. We help people to get the right magnifier and the right power for the task. We also use electronic magnification—the CCTV, computer font enlargement, talking programs for the computer. Audio books are also helpful.

All people, sighted or vision impaired, have an optimal print size, that is, a size of print at which they can read with greater speed. This is a size of print that is neither too large nor too small, and this varies for each individual. Once you know your optimal print size, try to get your reading material in this size that’s best for you. Also give yourself more time because of the slower rate at which you read. If you’re in a two year MBA program, you may want to give yourself three years to complete the program.

Here are some factors that influence rehabilitation success. If vision loss is slow rather than sudden, the individual can adapt much better. People who are referred to rehab early in progressive vision loss have more hope and have a chance to learn to use tool before greater loss of vision occurs. The extent of vision loss is also a factor. If the person is in a stage of denial or anger about their vision loss, they may not yet be open to vision rehabilitation. Stage in life is also important; this affects attitudes and ability to adapt. We try to give people a successful experience early in their rehabilitation process because they are likely to have a more positive attitude as rehabilitation continues. Good family support influences the outcome of rehabilitation in contrast to people who are socially isolated. We address myths about vision loss; for example, the myth that sitting too close to a CCTV or TV monitor may damage the eyes. Transportation options for getting to a rehabilitation center are also critical factors.

Driving is the second most important function affected by vision loss. Driving is an important part of our culture. If you live in Boston, Manhattan or San Francisco, there is excellent public transportation and the ability to drive will not be as critical. But most people with vision impairments do not live there. Many states offer restricted licenses to people with vision impairments. Here is an interesting statistic. Hearing impaired drivers have more accidents than visually impaired drivers. The receipt of a driver’s license is the most important event in a teenager’s life. To not get a license is a very socially isolating experience for a teen. A key predictor of employability for adults is having a driver’s license. It is also important for dating. For people who are older and lose their ability to drive, this may mean a loss of spontaneity,
independence, and social connection. There are also advantages to not driving. Driving can be stressful and expensive.

Traveling with others offers companionship. The need to walk more may have physical benefits.

Ethics in Stem Cell Research
By Mary Faith Marshall, Ph. D.

Editor’s Note: Dr. Marshall is Research Specialist at the University of Minnesota.

As a biomedical ethicist, I teach student preparing for careers in nursing, medicine, dentistry, and pharmacy. I am a consultant to hospitals regarding clinical ethics issues—forgoing life, sustaining treatment, issues at the end of life, issues that arise between a caregiver and a patient. Research ethics is one of my interests. I’ve done a lot of work in federal policy and human subject research. I am a strong proponent of stem cell research.

What are human embryonic stem cells? Stem cells have the possibility of being immortal. In theory one could grow them in a culture dish ad infinitum. In 1998, scientists found a growth medium in which stem cells could thrive.

The egg is fertilized outside of the womb in the fallopian tubes. It takes several days to move to the uterus where it is implanted. As soon as the egg is fertilized, it starts dividing. Each one of those cells in the first 5 days is totally potent. That is it can become any cell in your body—it could become hair, a neuron, skin, the lining of the uterus. That’s the excitement and the beauty of using stem cells in research. Therapeutically we hope to someday direct these cells toward damaged tissue or to create new tissue. For people who are vision impaired and have some sort of neural loss, for people with spinal cord injury or other neurological disease like Parkinson’s disease, we expect to create or regenerate cells that couldn’t do that on their own. The implications are astounding.

In the first 3 days after the egg has been fertilized, you have an entity that is called a blastocyst. The blastocyst contains about 30 to 50 cells which can become any cell in the body. Five days after conception, that blastocyst creates an outer layer of cells that is capable of attaching to the uterine wall. This is the first time that any of those cells differentiate to create certain tissues in your body.

What are some of the issues? These are based on how we conceive of those cells in the first 5 days following conception. Those cells are alive. When does life begin? You might get one answer from a cell biologist, other answers from different schools of religion. Recently President Bush vetoed a congressional movement to change his policy on stem cell research regarding federally funding for stem cell research. The issue there is that President Bush on August 9th 2001 only allowed stem cell research on existing cell lines. The guess is that there were 400 cell lines at that time around the world growing in culture dishes in various labs. Today it is estimated that there are 20 cell lines that are available for research in the United States.

Many of these cell lines came about through technology for invitro fertilization. Embryos created through invitro fertilization have been frozen and stored. They are left over and are likely to be discarded. The cell lines that exist now were created in this fashion. On average in this country in any year there are about 400,000 invitro fertilization produced embryos. In a given year somewhere around 2.8% of those are due to be discarded, about 11,200 embryos that could be used for research. Instead of discarding these embryos, they might be sued in research. People who created them would donate them for research and many people would like to do that. They can’t do this because of the federal policy.
This is a problem for many reasons. Cell lines, as they age are subject to mutations. So these cells are not as helpful for research. They are certainly not as helpful for therapeutic applications when they are older because of genetic mutations occurring in their culture medium over time. It's nice to have new fresh cultures for research.

Next, if we want to study diseases and disorders, some of which are genetic, we want to study them in people who have those diseases and disorders so we can learn how to treat them, learn how they work and understand them. Stem cells from people who have IVF are not representative of the population as a whole and all of the diseases and disorders that we want to understand. Because of this we are limited.

In the United States private money is available for stem cell research. But the problem with that is that it's hugely expensive. First you have to find someone who is willing to fund to do this. Universities can't mix private dollars with federal dollars. Therefore universities have built separate buildings so that public funds are not involved even in turning on the electricity in those buildings where private funds are used for research. Another issue is who is going to own the therapeutic applications? Not government. Therefore the applications will be nongeneric and very expensive. We are all going to pay for this. The biggest cost is going to be that other countries are doing stem cell research and their governments are paying for it—Great Britain, Indonesia, Malaysia, Singapore. The United States is at risk of lagging behind.

Are therapeutic applications going to happen in your lifetime? Yes. There have been Phase 1 trials in humans where they have been able to rejuvenate cells. How does it work? Once we understand the basic biology, and that involves stem cell research, then we can start moving into therapeutic applications. Stem cell research helps us to understand what happens when processes in the body don't work right. What does it work? Once we understand the basic biology, and that involves stem cell research, then we can start moving into therapeutic applications. Stem cell research helps us to understand what happens when processes in the body don't work right.

Low Vision and Leadership
By John Vaughn

When I was diagnosed with retinitis pigmentosa at age 25, I had just left teaching and gone into baking. My doctor told me I would have usable vision till about age 65 and by that time I hoped there would be a cure.

Nevertheless, I decided to work hard—extra hours so that I would become very efficient at what I did. I decided to hide my vision impairment. I had a 23 year career in managing investments for a number of banks.

In 1980 I took time off to study special education at Ohio State University's
graduate school. By that time I could no longer read print using my bar magnifier and I had stopped driving 4 years earlier. In 1980 I got involved with ACB and CCLVI. Here Carl Foley introduced me to CCTV's and I learned about vocational rehab and other low vision aids.

Failing to get an internship so that I could complete my master's degree, I decided to go back to banking. I found it hard to get a job in banking until I met someone who said, "I don't want your eyes, I want your mind." I worked for this man, Dick Rosenthal, for 10 years until the bank was sold.

Then I took a one year job for the federal government rescuing S and Ls. After that, again, I could not get a job in banking. When I applied to be a tour guide at a historical site in Virginia, I was turned down. But I was hired in this capacity at another historical site.

Because of contacts I had through this job, I received a call from Virginia's new governor asking me to serve first as Commissioner for the Department for the Visually Handicapped and then as Director of all that state's disability programs. I was happy to use my own experiences in banking and as a recipient of vision rehab programs to influence these state agencies in many positive ways.

After retiring from these posts, I began a business in Florida, training people who have vision impairments in computer technology for employment for the State of Florida.

Last year, because I was remembered for my work in the state of Virginia, I was asked to chair the National Council on Disability.

Hard work, help from people along the way, perseverance to get through periods of frustration, and luck all played a part in my work history.

Here are some strategies I recommend:

- Contact your state rehab agency for help with technology and training.
- Remember that the best strength you have as a person with a visual impairment is that you are an expert at change. All businesses need people who can deal with change.
- Know your strengths and weaknesses. Develop strategies, perhaps technology-based, to deal with weaknesses. Answer this question: "What will help me do a better job?" But don't try to master every new technology.
- Develop methods or schemes to keep yourself focused as you give presentations.
- Know that to be successful you will have to work harder than the next guy, which has always been the case.
- Find ways to deal with transportation issues. Think outside the box.
- Develop organizational skill. Conquer clutter. Use file folders and computer files and the "search" function.
- Be honest with your employer about your limitations. Avoid confidence problems.
- At business receptions, have an associate with you for some of the time to help you contact people you want to see. Or, use a receiving line. Be at the door or at the elevator introducing yourself to others.
- Some people want us to fail. The biggest problems we all face are attitudinal. But don't blame the rejection letters you receive on your vision loss. People with full sight get rejection letters too.

Focus on Employment

By Sarita Kimble Holiday

At the 2007 CCLVI Convention I facilitated two workshops specifically designed to address employment issues faced by people who are visually impaired. For over twenty-five years I have worked as a Disability Employment Coordinator with specialization in job placement, retention, upward mobility and advocacy for people
with disabilities. My professional as well as my personal experience as a person with low vision enabled me to focus discussions in these workshops around the varied issues faced by people who are visually impaired and trying to maintain their independence in the world of work.

Workshop topics were framed around those commonly asked questions associated with disclosure of one’s impairment—“When and How,” the Interview—“How should I Prepare,” Job Jeopardy—“Pulling the Plug, Speak Up Before It Becomes Critical,” and The Technologies Upgrade—“Where Do I Fit In.”

There is a continuing need to dialogue about these and other relevant employment related issues. Therefore I invite you to “Write-In” your question and/or your personal employment challenge as a person with low vision. I will address your questions or concerns in a new column being featured in Vision Access—“Employment Perspectives.”

Stay tuned, as each issue of Vision Access will feature a response in the “Employment Perspectives” column to one of the questions submitted for a response. Now, get busy, send your questions and or personal work concern by email to: rita.kimble@verizon.net. Questions featured in the “Employment Perspectives” Column will not disclose the name of the person responsible for its submission.

Effective Advocacy for Local Transportation, By Ken Stewart

On the last afternoon of CCLVI programming at its July Convention, attendees participated in a lively exchange focusing on improving local transportation services and facilities.

Moderated by Patricia Beattie, Chair of ACB’s Environmental Access Committee and CCLVI’s Immediate Past President, a panel offered ideas and information on the subject. The panel included Dr. Billie Louise Bensen, a professional with expertise in mobility and accessible design, Phil Strong, ACB’s Advocacy Specialist, and myself. The contributions from attendees were wide ranging, but the quality of paratransit service and the paucity of accessible pedestrian signals in urban areas, were among the concerns most often articulated.

Phil Strong described a recent successful effort in Washington, D.C. which resulted in significant improvement in the paratransit service provided in the Capitol District. Dr. Bensen stressed the importance of consumer activism. I identified three primary principles I have followed in my advocacy work; establishing rapport with governmental decision makers in advance of pursuit of solution of a specific problem; understanding the structure of that local governmental entity; and, keeping the option of court action as a last resort.

The most effective advocate with a Town Council, for example, is often the person who has been a regular visitor to Council meetings long before pressing for attention to a particular need. That way the governmental decision makers already are familiar with the advocate and are less likely to dismiss him as a trouble-maker or only self-serving.

The Executive Branch of government frequently has the ability to alter policy or apply more resources to a need, without awaiting legislative action by politicians who are sometimes better at giving "lip service" than "trip service".

After all else fails to solve a problem, litigation may be invoked effectively. Only after about ten years of working with the N.Y.C. Transit Authority to improve bus driver compliance with the ADA requirement to announce all major stops and transfer points, did I file suit in federal court. Within months of that litigation initiation, the compliance rate almost doubled. The agency responded to it with much improved
supervision, monitoring, and disciplinary sanctions.

Discussion during the Convention panel session was enhanced by the presence of two representatives of the local Transportation Department in Minneapolis. They expressed appreciation of the value of good pedestrian signals in response to the statements from several attendees underlining the safety issues facing people unable to see visual signals. Thus, everyone in the Convention meeting room witnessed advocacy in real-time.

---

Science and Health

Participants Needed for Research Study

A research study is being directed by Dr. Rami Burstein, Ph.D., Associate Professor and Vice Chairman, Research Department of Anesthesia and Critical Care, Beth Israel Deaconess Medical Center Department of Neurobiology, Harvard Medical School.

For the past 10 years, Dr. Rami Burstein has been studying the pathophysiology of migraine headache and the different ways to treat it. In the course of his work with migraine patients, he became interested in photophobia, eye discomfort in bright light, perhaps the most common symptom associated with these debilitating headaches. Recently, Dr. Burstein and his team discovered the neural network that enables light to make the pain worse—a puzzle no one understands. To examine the validity of their findings in human subjects, these researchers first studied photophobia in blind patients who suffer from migraine. The scope of their studies is now being extended to include: photophobia in blind individuals who are not migraine patients; migraine patients who are blind and are not photophobic. In addition, the study is also including individuals with albinism, who are and are not migraine patients. Researchers hope to determine if these categories of subjects differ and to better understand the network of neurons that mediate photophobia. Ultimately a drug may be developed that will specifically block photophobia.

Dr. Burstein would like to interview individuals, between the ages of 18 and 65, who:

- Have albinism who, ARE and ARE NOT migraine patients;
- Are blind and photophobic, who ARE and ARE NOT migraine patients;
- Are blind migraine patients, and ARE NOT photophobic.

Questions to be asked include: Define light sensitivity. Do you experience abnormal visual intolerance to light, or, is pain induced by exposure to light? Which light frequency (e.g., blue, red, yellow, green) is most disturbing and what light intensity, etc.? The interview should take 30-60 min.

After the interview, Dr. Burstein would like to spend time with individuals in the Boston area, if possible, for further study. They will be treated with the utmost dignity and respect, which is the standard at Harvard Medical School.

If you're interested in participating in the research study, please contact Dr. Burstein at:
Phone: (617) 667-0806, or, Email: rburstei@caregroup.harvard.edu

---

Cancer Drug Curbs Radiation-Induced Vision Loss

Reuters Health reported that eye injections of the widely-used cancer drug Avastin curb vision loss caused by radiation treatment for eye cancer. This news is the
results of a study conducted by Dr. Paul T. Finger, director of Ocular Tumor Services at the New York Eye and Ear Infirmary. He said that Avastin reduces abnormal blood vessel growth, stops leakage of these vessels in the eye, and reduces swelling—the major causes of irreversible loss of vision in patients with radiation retinopathy. The drug improved or stabilized vision in all 28 patients in this study. Before these Avastin findings, there was no effective treatment for macular radiation retinopathy.

Injections into My Eye to Treat Retinal Edema
By Joyce Kleiber

No doctor ever told me, “There is something we can do about your eye condition.” Then he added, “But this is a new procedure that has been offered for about 6 months, and it is not yet approved by the FDA for use in the eye. It’s an injection directly into the eye with a drug used to treat cancer patients. It stops the growth and leakage of blood vessels that are causing the swelling on your retina and your blurred vision.”

This information left me with mixed feelings. Glad to hear that something could be done, scared about a relatively new procedure that would put a needle and a drug directly into my eye. All my life I have been closing my eyes whenever I get a vaccination or blood test. I don’t like needles. All my life I have been closing my eyes to protect them from dust in the air, a squirt from a grapefruit, and anything else. And this was a new procedure!

My doctor sensed my ambivalence. He told me that one of his patients had not slept for two nights before his injection. He was that anxious. Yet the procedure is one I will not feel because my eye will be numb.

My left eye is very important to me. It is my better seeing eye, the eye with which I read. All my life I’ve had low vision due to inherited optic nerve atrophy. I was desperate to get back the clarity of vision I am used to, yet scared to put my precious eye under a needle.

There were three weeks until my scheduled procedure. I used this time to gain second opinions, to talk with friends, to ask for prayers, and to weigh my options. As the day approached, I decided to trust my doctor and get the treatment he recommended. I wanted to be able to read more easily again.

The nurse who dilated my pupil told me that my doctor does 5 or 6 injections like these every day. She too assured me that I would not feel his needle. The doctor will use a small device to keep my eyelid open for this very short procedure. I was told to return to the waiting room until the time for the injection.

I sat next to a young lady who was talking to her father about an injection into her eye for a condition called uveitis. Since I had at least 45 minutes to wait, I talked with her about the treatment we have in common. I learned about her plans to become an electrician. Her enthusiasm and the uniqueness of her plan as well as the procedure we both anticipated kept me calm and pleasantly distracted.

Then we were both called into separate treatment rooms. A family friend came with me. I sat in a chair with a head rest. When my doctor came in, he gave me as much time as I needed to ask questions. Why injection and not laser? Does this medicine, Avastin, target only the blood vessels that are leaking? Into what part of my eye will the injection go?

With great patience, my doctor responded to my concerns. With confidence he added more numbing drops to my eye. I asked,
"Aren't you going to give me something to keep me calm?" He said "Let your friend hold your hand. That works just as well!" And then my doctor turned my chair and tilted it into a more horizontal position. He propped my eye lid open with a small device, and this did not feel bad at all. He directed me to look up past my forehead. In a second, the Avastin was in my eye.

My doctor gave me some Kleenex and told me to rub my eye. He said that when a new substance is introduced into the eye, it raises the pressure in the eye. The rubbing will reduce the pressure. I rubbed for several minutes. My doctor touched my eye, told me to rub a little more, then touched again and said that the pressure in my eye had gone down and I didn't need to rub any more.

I asked if I would have to put drops in my eye to prevent infection, and he said “No, this has not been found to be necessary.” He said that if I felt any pain, change in vision or redness, I was to call him immediately. Otherwise I was to see him in six weeks.

At home as the numbing wore off, my eye felt a little bruised, probably from the rubbing. I felt so relieved that the procedure was over. I enjoyed being at home with my husband appreciating the normalcy of this evening. When I awoke the next morning, my eye felt fine.

Six weeks later I returned to my doctor’s office. He asked if I noticed any difference in my vision. I said I can read with greater ease than before the injection. He looked into my eye and said he noticed less—material from blood vessels floating in my retina. He said he would inject my eye again because he hoped to maintain the clarity of vision I had gained. He said that because this procedure is so new, doctors do not know how many injections are required. He anticipated a series of injections each spaced further apart from the previous injection. He noted that he would not take any OCT scans of my retina because insurance companies object to frequent uses of these expensive measures. He would rely mainly on what I told him about my vision.

I hope that there will be no swelling on my retina and that the blood vessels will stop leaking.

Quality of Life
Finding the Right Microwave Oven
By Carolyn Hathaway Burley

My microwave oven broke and I had to buy a new one. My husband took me to many stores to look at all the different models. We even went to a friend’s house to look at his talking microwave oven. It didn’t talk all features and seemed to be very limited in what I might do with it.

After comparing many options, I found the GE model JES1142SJ04 had features that worked for me. This model has large tactual buttons. By marking the “5”, “start,” and the “defrost” buttons I can use all the features I want to use. If I push the “start” button, the microwave goes on for 30 seconds. To reduce the power I push the “start” button and the power is reduced by 10 per cent for each time I push it. I can defrost by time or weight and the buzzer goes off half way through so that I can turn the food over. There are buttons for pop corn, beverages, potatoes and warming a plate.
I have found this microwave very easy to use and I like it very much. I did have a sighted friend put the tactile marks on it and tell me what the different buttons are for. After that was done, I can use my microwave independently. I bought it at Loews and also saw it at R. J. Greggs.

An Accessible Art Museum

The Rubin Museum of Art, a cultural and educational institution dedicated to the art of the Himalayas, is now offering Verbal Imaging and Touch tours for partially sighted and blind audiences. Free with museum admission, tours are one hour in length and take visitors on a journey that weaves the culture, history, religion, and arts of the Himalayas. Group and individual tours offered. Please book two weeks in advance by calling Emilie Dufour for reservations at 212-620-5000 ext. 345 or email at reservations@rmanyc.org.

Advocacy

Congress Voices Concern for Availability of Low Vision Devices through Medicare

On July 2, 2007, the co chairs of the Congressional Vision Caucus, Gene Green (D-TX-29), David E. Price (D-NC-4), Ileana Ros-Lehtinen (R-FL-18), and Patrick J. Tiberi (R-OH-12), sent a letter to Leslie V. Norwalk, Acting Administrator of the Centers for Medicare and Medicaid Services (CMS), expressing their concern over CMS's proposed exclusion from coverage for all low vision devices. The letter's text is provided below.

On May 1, 2006, CMS, the federal agency responsible for management of America's public health care system, published a notice of proposed rulemaking on the competitive acquisition of durable medical equipment, prosthetics, orthotics, and supplies (DMEPOS). This proposed rule contains a provision referred to as the "low vision aid exclusion" which purports to "clarify" that the Medicare statute's exclusion of coverage for traditional eyeglasses bars coverage for all devices that may use a lens. While CMS has made the larger competitive acquisition rule final, CMS has indefinitely postponed final disposition of the proposed devices exclusion provision, meaning that the matter is still very much in play. The scope of the proposed eyeglass coverage exclusion encompasses all low vision devices with one or more lenses regardless of the size, form, or technological features of such devices.

In response to this unreasonable proposal, CMS received an extensive array of comments from consumers and professionals from within the vision loss, eye care, and disability communities. The letter of the Congressional Vision Caucus puts the most interested members of Congress on the record in opposition to the low vision devices exclusion and is intended to continue to draw attention to the need for a more sensible approach to coverage.

We want to recognize the contributions to our work in this area of American Foundation for the Blind Policy and Research interns, Rebecca Price, Stacy Haack, and Martin Monson, whose proficiency with the issues and professional persistence were indispensable to achievement of this result. Congratulations!
Text of the Letter:
Congress of the United States
House of Representatives
Washington, DC
July 2, 2007

Leslie V. Norwalk, Esq., Acting Administrator
Center for Medicare and Medicaid Services
Department of Health and Human Services
7500 Security Boulevard Mail Stop: C5-1124
Baltimore, MD 21244

Dear Ms. Norwalk:
Re: 71 FR 25654

As co chairs of the Congressional Vision Caucus, we are writing to express our concern regarding the exclusion of low vision devices in the Competitive Acquisition for Certain Durable Medical Equipment, Prosthetics, Orthotics, and Supplies (DMEPOS). We strongly urge CMS to reconsider the proposed "low vision aid exclusion."

In the proposed regulation, any device with one or more lenses, regardless of its usefulness to the vision-impaired, would fall under the statutory "eyeglass" exclusion. This proposal would have a tremendous negative impact on vision-impaired seniors who rely on devices such as hand-held magnifiers, video monitors, and other technologies that utilize lenses to enhance vision. Without these devices, many vision-impaired seniors are unable to live independently.

We are also concerned with the precedent that would be set by this proposal of limiting the access to assistive technology for people with disabilities. Rather than establishing coverage denials for all lenses, we respectfully recommend that CMS evaluate the medical and functional purpose of each lens device and make coverage decisions based on these evaluations. If a lens device is determined to fall under a Medicare benefit category, then coverage should be established by CMS.

Consistent with all applicable rules and regulations, we respectfully request that CMS reconsider the "low vision aid exclusion." Thank you for your careful consideration of this matter.

Sincerely,
Gene Green, Member of Congress
David E. Price, Member of Congress
Illeana Ros-Lehtinen, Member of Congress
Patrick J. Tiberi, Member of Congress
For more information, contact Mark Richert, Director, Public Policy at mrichert@afb.net.

Accommodating Indviduals Who Are Blind and Vision Impaired at Sports Stadiums By Rick E. Morin

This document discusses baseball stadiums; however the concepts are applicable to all sports and entertainment venues. There are those within the blindness community who do not wish to be accommodated. We respect a person's right not to be required to accept any accommodation, no matter how well intended it is.

The premise of this paper is that those who are blind or vision impaired who require and request accommodations, should be so accommodated reasonably.

The reader must bear in mind that there are unique differences between the needs of those who are totally blind and those with low vision. One's frame of reference must be clearly understood when using the term "blind" and its derivatives.

Yes, people who are blind and vision impaired enjoy a day at the ballpark! Contrary to stereotypes and commonly held beliefs, many members of the blindness
community can equally benefit and participate in the in-stadium game-day experience by means of reasonable accommodations. Not having such accommodations can pose insurmountable access barriers.

Being a member of the community of fans who gather at a sports event heightens the enjoyment of the game. As it does for all, the ballpark provides an escape from the daily grind and entertainment for those who are blind or have low vision.

Many fans who are blind or vision impaired attend games today – and many do not, believing that their needs cannot be accommodated by the venue.

Vision Impairment Defined

Vision impairments range from total blindness to degrees of low vision. Blindness is a sensory disability that often is not readily apparent, i.e. sometimes referred to as a “hidden” disability. Eighty percent of the legally blind population has useful but limited vision, which allows seeing shapes and seeing movement if close enough.

A person who is legally blind is defined as one whose visual acuity is measured at 20/200 or less after correction in the better eye or someone whose field of vision is 20 degrees or less in the better eye. At 20/200, what a person with 20/20 acuity can see at 200 feet, the person with 20/200 acuity needs to be 20 feet away to see. "Approach Magnification” is the scientific rule of vision that each time the distance is cut in half between your eyes and what you want to see, you double what you can see.

Appropriate Accommodations for those who are Blind or Vision Impaired

Users of low-vision distance-viewing devices (which inherently have limited fields of view) require close proximity to the playing field and unobstructed sight lines over standing spectators, spectators seated in front of the low vision device user and walkway traffic so that vision is not suddenly interrupted in the middle of a play. Losing visual contact with the ball or a player while using a monocular, telescope or binocular in mid-action is akin to a person on a beach losing sight of a ship while looking through a telescope. Recapturing the image takes time, and by then the play is over.

Access to video replays is essential to someone with low vision for the times when tracking the live play fully is not possible. Close proximity also provides access to the sounds of the game.

Those who are blind or have low vision also benefit greatly from short and clear access paths to their seats and stadium amenities that can be located without assistance.

Audio Description

Instantaneous audio description is normally provided by local commercial radio play by play broadcasts and made available on the stadium’s Assistive Listening Devices (ALD) via an alternate channel. To be useful to those who are blind or have low vision, the ALD’s must include a volume control.

Many spectators who are blind use their own personal radios to listen to the game in-stadium. When broadcasters choose to delay the broadcast (e.g. to sync up with TV during playoffs), provisions must be made for the patrons who are blind to receive the audio descriptions without the delay.

Reasonable protection from foul balls and bats is essential, as many fans who are blind and vision impaired attend the games without sighted companions to protect them - (nor should people who are blind or vision impaired be required or expected to have sighted companions). The commonly held belief that people who are blind or vision impaired are usually accompanied by
sighted companions is a false characterization. The fact that some people who are blind or vision impaired attend events with sighted companions is often an indication that the venue is not navigable independently by those who are blind or with low vision.

An appropriate amount of space is absolutely required for guide dogs and other service animals.

Viewing locations for fans who are blind and vision impaired must be dispersed throughout the venue in all price categories, as for wheelchair users and those with other mobility impairments.

Proposal for Universally Accessible Accommodation

Rick Morin, Director of two American Council of the Blind affiliates and Board Member of a third ACB affiliate, points out that "... ADA Accessibility Guideline specifications for the location and configuration of wheelchair accessible locations, when properly dispersed, create stadium seating accommodations that are also appropriate for individuals who are blind or with low vision.

Beside certain wheelchair accessible locations, seats that accommodate the needs of the blind and vision impaired are extremely limited in number and often are held by season ticket holders or under the control of Major League Baseball, event promoter, or the ball club or venue itself and not made available to the general public.

The American Council of the Blind affiliates propose that wheelchair accessible locations be offered to the blindness community in proportion to the total population of individuals with disabilities. People who are blind and vision impaired make up roughly 10 percent of the total number of people with sensory and physical disabilities.

To take this a step further, it is proposed that certain locations be reclassified as universally accessible to all individuals with disabilities. Such locations must also accommodate individuals with multiple disabilities (e.g. a blind or low vision wheelchair user with a service animal).

Today, vision impaired individuals requesting accommodations are often turned away by venues, while unsold wheelchair accessible locations are released to the general public or, worse yet, obtained fraudulently and resold on the secondary market.

When you factor out those individuals who fraudulently obtain wheelchair accessible seating, seldom, if ever, does the demand from wheelchair users exceed the supply of wheelchair accessible locations as stipulated by ADA Accessibility Guidelines.

Some stadiums routinely offer wheelchair accessible locations to fans who are blind and vision impaired as well as other disabilities, while others site that they are precluded from doing so by the Department of Justice.

There is great confusion and inconsistencies venue to venue and sometimes event to event as to whether and how venues are required to accommodate individuals who are blind or vision impaired.

Proposed changes to ADA Accessibility Guidelines

The Federal Access Board has published proposed changes to the ADA Accessibility Guidelines that decrease the number of required wheelchair locations and companions from 1 percent of all fixed seats to .5 percent. Applying a fixed percentage across all facilities creates inequities that are exacerbated when the fixed percentage is reduced across the board in the proposed manner.
Clearly, 1 percent of a 100,000 seat stadium over-alllocates the number of accessible locations, while 1 percent of a 10,000 seat arena allocates an appropriate number of accessible locations.

The Access Board is strongly urged to reconsider the approach to arriving at the minimum number of accessible seats required at a venue. Recommended is a tiered approach that alters the percentages based on venue seating capacity.

Attention, diligence and strong advocacy must be applied during the public review period of the new ADA Accessibility Guidelines standards.

Ticketing and Fraud Mitigation

Wheelchair and companion locations and seating allocated for other disabilities, both sensory and mobility related, are scarce in number and intended solely for the use of those individuals who are disabled and their companions.

It is well documented that the secondary market is very active for sports and entertainment events. The economic gain that can be achieved by selling accessible locations in the secondary market and/or the attractiveness of these accessible locations has attracted unscrupulous able bodied individuals to fraudulently represent themselves as disabled to obtain such tickets. Certain individuals with disabilities also buy accessible tickets with the sole purpose to resell them to the highest bidder. ADA ticket fraud is rampant as illustrated in the July 16 Sports Business Journal article titled “Tickets for Sale.” ADA ticket fraud is causing those who are disabled to be denied access and thus discriminated against.

Accessible locations must be explicitly requested by the individual with a disability or someone representing a person with a disability. Anyone so doing has identified themselves or the person they represent as being disabled. The venues must be given parameters under which they can validate a person’s eligibility for such accommodations.

Validating a disability to prevent fraud and protect those who legitimately require such scarce accommodations is even more essential with “hidden” disabilities such as low vision.

While some individuals with disabilities will resist such validation, most will agree to it when it is explained why such validation is necessary. Those who are disabled undergo eligibility validation for services provided by Title II of the ADA.

Season Ticket holders are subject to accepting the terms and conditions of the season ticket program. This sets a precedent that a class of patron can be subjected to rules and regulations unique to that category.

The effort to protect the civil rights of individuals with disabilities by not requiring any substantiation of the disability at public accommodations is causing greater harm to the disabled community than reasonable eligibility validation whose sole purpose is to screen out those who fraudulently represent themselves as disabled.

When a person with a disability is unable to use tickets for special accommodations, they must be given the option to: 1) sell the tickets to another disabled person or 2) exchange the tickets at the box office for another comparable date or event. These measures should help mitigate those who are disabled and those who fraudulently represent themselves as disabled from buying tickets with the sole purpose being to sell them on the secondary market to anyone at economic gain.

“Welcoming” Environment

Venue operators can mitigate many of the
design constraints in their facilities by making the facility more “welcoming” to those who have a disability. This can be accomplished by providing day of game staff specific training on how to effectively interact with and assist those with disabilities. Examples of the types of assistance that can and should be offered to fans who are blind and vision impaired to be more welcoming include way finding assistance upon entering (e.g. seat locations, rest rooms, locations of concessions and reading the menus, etc.) and providing materials and a guide to the accessible features of the facility in multiple formats accessible to fans who are blind and have low vision.

Call to Action

Rick and the ACB affiliates invite dialogue and collaboration between the Department of Justice, Stadium owners and operators and cross-disability advocacy groups to arrive at workable and consistent solutions that are equitable to all individuals with disabilities and, from the perspective of the venue owners and operators, have no revenue impact, do not pose undue administrative burden, and mitigate litigation exposure and Department of Justice scrutiny.

Anyone interested in participating in this process may reach Rick Morin at rick.morin@comcast.net for additional information.

Advocate’s Alley
We’ll Speak for Ourselves,
Thank You
By Ken Stewart

One recent evening, I heard a National Federation of the Blind leader in the New York area, express a strong advocacy opinion that was totally in sync with my own view. He was adamant that, of all the blindness organizations in New York State, only his organization and the American Council of the Blind are authentic voices on behalf of the blind. The very next day, I was vocal on the same point.

It was during a site visit in Grand Central Terminal with MetroNorth Railroad’s Director of Customer Service and its ADA Coordinator. I was presenting a proposal to relocate recently installed track number signs where they will be much more accessible. The Customer Service Director asked the ADA Coordinator what input on the issue had been received from a particular well-known organization that offers services to blind clients. The Coordinator responded with the name of another high profile service organization for the blind which had been consulted prior to the Railroad’s well-intentioned but useless installations. I thought to myself, "No wonder they got it wrong!" The words that came out of my mouth were more temperate, but I then repeated the theme heard less than twenty-four hours earlier from the N.F.B. leader.

The Director of Customer Service resisted my dismissal of the legitimacy of blind service organizations speaking on our behalf, and I grew more insistent. I related to him my experience with the Training Director of the local Department of Buses. While questioning him under oath during federal court litigation on bus stop announcement compliance, I referred to the
ADA's regulation that transit agencies consult the disabilities community regarding their training curriculum. I asked him where his agency got its input. His sworn testimony was that it came from Special Education professionals and, that same high profile service organization mentioned moments earlier in Grand Central Terminal! I can report in this VISION ACCESS column, by the way, the situation with respect to bus driver training has now been corrected, following the completion of the litigation. There is a new Director for bus driver training, and he has agreed to reach out to the American Council of the Blind, and the National Federation of the Blind, and Guide Dog Users Inc., and, of course, the Council of Citizens with Low Vision International's local chapter.

The confrontation with the MetroNorth Railroad personnel ended amicably also. I assured them that any agreement reached on a better signage strategy will have the endorsement from these same member organizations. I also assured railroad management that the final plan would not violate any law or regulation. And, I offered assurances that we the legitimate representatives of the blind and vision impaired ourselves, would be there by their side with "cover" if anyone threatened them with legal action over the installations agreed upon, the revision constituting a major change from the previous arrangement sold to MetroNorth as faithful to the ADA.

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 131754

Resources

Advocacy, Medicare
Mark Richert, Director, Public Policy
mrichert@afb.net.

Advocacy, Sports Venues, Rick Morin
rick.morin@comcast.net

CCLVI Listserv
To subscribe:
CCLVI@googlegroups.com
Home Page:
http://groups.google.com/group/CCLVI?hl=en

Focus on Employment
rita.kimble@verizon.net.

Research Study
Dr. Rami Burstein
617-667-0806
rburstei@caregroup.harvard.edu

Rubin Museum of Art
Emilie Dufour
212-620-5000 ext. 345
reservations@rmanyc.org
Name___________________________________________________
Address_________________________________________________
City_________________ State _____ Zip Code _________________
Country ________Phone _________ E-Mail ____________________

Membership Status: I am:
___ New member.                        ____ Life member of CCLVI.
___ Renewing my membership.        ____ Life member of ACB.

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

I wish to receive the CCLVI publication, Vision Access in:
___ Large print    ___ Cassette    ___ E-mail    ___ Do not send

Please send the American Council of the Blind Braille Forum in:
___ Large Print    ___ Cassette    ___ Computer Disk
___ E-mail    ___ Braille    ___ Do Not Send

Dues Structure (Payable in up to three annual installments):
___ Individual $15.00
___ Organization or Agency $25.00
___ Life Member $150.00

Payment Due:
$_______ Annual Dues
$_______ Life Membership Dues (full or installment)
$_______ Additional Donations
$_______ Total Amount

Make check or money order payable to “CCLVI” and send to
CCLVI Treasurer:  For Office Use Only:
Mike Godino Date Paid: ______ Date of Dep______
104 Tilrose Avenue Check # ______$______ Cash______

Council of Citizens with Low Vision International
1155 15th Street NW, Suite 1004
Washington, DC 20005
(800) 733-2258
http://www.cclvi.org
email: info@cclvi.org

Officers and Directors 2007-2008
To contact officers, directors, and committee chairs listed below, use our 800 number or email address.

President Bernice Kandarian (06-08, 1st term)
2211 Latham Street, #120
Mountain View, CA 94040-1652
650 969-3155 h
bernice@tssoft.net

1st Vice President
Ken Stewart (06-08 1st term)
Warwick, NY 10990

2nd Vice President Barbara Milleville (06-08, 1st term)
Vienna, VA 22180

Secretary Rick E Morin (06-08 Partial term)
Waltham, MA 02452

Treasurer Mike Godino (06-08, 2nd term)
Malverne, NY 11565

Past President
Patricia Beattie (06-??)
Alexandria, VA 22312

Directors
Kathy Casey (*05-08 1st term)
Albany, NY 12209

Coletta Davis (*07-09, partial term)
Anaheim, CA 92806

Carol Ann Ewing (06-08 partial term)
Las Vegas, NV 89128

Lindsey Hastings (*07-10, 1st term)
San Diego, CA 92129

John Horst (05-08, 1st term)
Elizabethtown, PA 17022

Jessie Johnson (06-09 1st term)
Jacksonville, FL 32204

Jane Kardas (06-09, 3rd term)
Ukiah, CA 95482

Brian Petraits (07-10, 1st term)
Brownsburg, IN 46112

Richard Rueda (07-10, 1st term)
Union City, CA 94587

Editor: Joyce Kleiber
610 688-8398 h
jmkleiber@hotmail.com

Chapter Contacts:
California Council of Citizens with Low Vision Bernice Kandarian, President
650-969-3155
bernice@tssoft.net

Delaware Valley Council of Citizens with Low Vision
Joyce Kleiber
215-748-3822
jmkleiber@hotmail.com

Florida Council of Citizens with Low Vision
Sharon Youngs
727-937-8631
Sky11@tampabay.rr.com

Metropolitan Council of Low Vision Individuals
Ken Stewart, President
National Capital Citizens with Low Vision  
Barbara Milleville,  
703-645-8716  
cclvi@yahoo.com  
New York State Council of Citizens with Low Vision  
Kathy Casey, President  
518-462-9487  
ncclv@yahoo.com  
Committee Chairs  
Budget, Finance and Investment  
Mike Godino  
Malverne, NY  
Chapter Development  
Sarita Kimble Holliday  
Philadelphia, PA  
Constitution and Bylaws  
Michael Byington  
Topeka, KS  
Convention Program  
John Horst  
Elizabethtown, PA  
Legislative  
Patricia Beattie  
Alexandria, VA  
Membership  
Carol Ann Ewing  
Las Vegas, NV  
Nominating  
Jim Jirak  
Omaha, NE  
Publications  
George Covington  
Alpine, TX  
Resolutions  
Michael Byington  
Topeka, KS  
Scholarship  
Catherine Schmitt Whitaker  
Diamond Bar, CA  
Website  
Carlos Gourgey  
New York, NY