## **VISION ACCESS**

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

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

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.Organization News

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#### From the Editor

It was a hot, humid Sunday in August. I listened to Dr. Rachael Naomi Remen being interviewed. She is an author and clinical professor of family and community medicine at the University of California at San Francisco School of Medicine. Dr. Remen distinguished between "curing" and "healing". Curing involves a return to health by eliminating the disease. According to Dr. Remen, healing means approaching a level of wholeness which still includes our wounds. Healing often is facilitated by someone who "generously listens" as we tell about what the disease means to us. No two people with the same diagnosis have the same story to tell. This telling and accepting can lead to "healing".

Most of us in CCLVI have a disease of the eye. I hope that each of us has had a chance to tell our special story to someone who has been able to listen generously. In this way we may be more able to accept ourselves as we are with our particular disability.

My hope is that as you read the articles in Vision Access, you will be more able to reflect on and put into words your story, and then find someone who listens well.

Thanks to all who have contributed to this issue of Vision Access. Let us hear from you.

JMK, 8/26/05.

## **Organization News**

Fred Scheigert/CCLVI Scholarships Awarded By Janis Stanger, Scholarship Committee Member

Due, in large part, to the generosity of Fred Scheigert, member of the Board of Directors of CCLVI, and long time member of the organizations, three students with low vision have been named as recipients of the Fred Scheigert/CCLVI Scholarship. Each recipient was awarded \$3,000. This year's recipients are Sarah Elizabeth Long, a graduate student at Lindsey Wilson College in Columbia Kentucky, Brian Petraits, a continuing under-graduate student at Purdue University in West Lafayette Indiana, and

Lindsey Hastings, an entering freshman at Biola University in La Mirada California.

Sarah Elizabeth Long is from Huntington West Virginia. She is working toward a Master's Degree in education and hopes to become a mental health counselor. In addition to carrying a full academic load, she works 30 hours a week in an internship, volunteers as a Girl Scout leader in her community, and is actively involved in various service capacities in her church including teaching Sunday School and advising the college aged youth group.

Brian Petraits is from Brownsburg Indiana. He hopes to earn a degree in industrial technology, management, engineering and distribution. Brian has been active in sports his entire life; he currently covers the Purdue athletic department news for Purdue's daily newspaper, The Purdue Exponent. In high school he lettered in Varsity Sports six times, received academic all-state honors and was a Sports Illustrated All-American. He is currently involved in a co-operative education program where he goes to school one semester, and then works one semester. This gives him the "hands on" experience he needs to succeed in his field after he graduates from Purdue.

Lindsey Hastings is from San Diego California. Lindsey hopes to earn her degree in communication disorders and then continue with her schooling to receive a master's degree in speech pathology. In high school Lindsey has excelled academically, and completed advanced math classes as well as Advanced Placement English and Spanish. She was also active in music studies, participated in the school band for four years, and lettered in marching band. She is a member of her schools Agape club, the Golden Triangle Leo Club, and volunteers to serve in the nursery at her church. She also volunteers at her local library.

These three young people are excellent examples of scholarship and community service. As with all previous recipients of the Fred Scheigert/CCLVI Scholarship, each of them has low vision, and each maintains a grade point average of 3.0 or higher.

If you or anyone you know is interested in applying for the Fred Scheigert/CCLVI Scholarship, you may find an application at the CCLVI website www.cclvi.org, or you may send a self addressed stamped envelope to Janis Stanger, 1239 North American Beauty Drive, Salt Lake City, Utah 84116. In 2006 three \$3,000 scholarships will be awarded to individuals who have low vision and who maintain a GPA of 3.0 or higher.

# **Convention Program Summaries By Edwin Druding**

"Kids, Parents and Grandparents Living with Vision Loss": CCLVI, Council of Families of the Visually Impaired (CFVI) and NAPVI co-sponsored this presentation. This panel discussed problems faced by people of all ages because of vision loss.

One panelist described how she, as a mother who was blind, put bells on her toddler's shoes in order to be aware of her child's movements. This worked until her child learned to take her shoes off! As her children's activities increased, transportation to these activities became a problem. She had to ask other parents for help to transport her children to these extracurricular activities. When her children received their drivers' licenses, she wished she could have given them more guidance. Being calm, patient, and understanding, and being able to engage children in problem solving are important qualities of all parents; these qualities are not limited by visual impairments.

Another panelist emphasized the need for education and emotional support for parents who learn that their child has impaired vision and/or multiple disabilities. Such parents feel stress; they try to give attention to their special needs child and to the other children in the family; they must maintain their job to have income for their family; they must manage medical and educational appointments; medical bills often pose a burden on a family's resources; it's hard to tell grandparents and other people about their child's disability; emotional reactions of each parent may be at different intensity levels and stages, and so communication between the parents can become difficult. For all these reasons, organizations that provide information, support and networking are vital.

The panelist representing the Foundation for Blind Children said that her organization tries to meet the needs of parents of children with multiple disabilities. These children don't seem to fit into organizations that address only one of their child's challenges.

A grandparent who has a visual impairment told bedtime stories about her own life experiences to her grandchildren in lieu of reading bedtime stories from books. Grandchildren can be fascinated by talking clocks and wrist watches.

#### "Get Rid of the Clutter in Your Life!"

It's challenging for most people. Barbara Milleville gave a lively adaptation of this topic for people with low vision. Here are some of her tips for success;

Begin your decluttering mission with clear answers to questions such as -"What are my priorities?" and "What do I really want in life?" Set some basic guidelines about what you'll part company with: For example, get rid of it if you haven't used it in two years, it doesn't fit any longer or if you can get the same info on-line. Make room in your life for things that really matter to you. De-clutter.

It's important to do some soul searching. Realize how all of the clutter got here and why it's essential we get rid of it.

Getting started is one of the toughest parts of decluttering. Pick an easy area first to build momentum. Use a timer to help you stay focused. Commit to spend just 30 minutes per day. Once you get immersed in the project, you'll find yourself spending more time on it Break large tasks up into smaller ones. This will allow you to feel good about what you have done. Stay focused by working in one room only at a time. This will allow you to see the progress you've made.

Engage a friend to be your conscience especially regarding items that have sentimental value to you.

Don't keep memories in a box in the closet. For example, take those tea cups your favorite aunt gave you out of the carton and remember her by displaying then in a china cabinet. Only save the ones that have special meaning to you; give the others away so that others can enjoy then too. Buddy up with a friend who also wants to declutter. Check in with your friend once a week to trouble shoot hang-ups and to celebrate successes.

Organize a neighborhood garage sale and vow that you'll stay away from other peoples' "treasures".

Ask yourself "Why am I saving this item?" If you have no good answer, toss it. Reward yourself for a job well done.

Once decluttering has been accomplished, establish a new system of organization. Find a home for everything. Put things away when you are done with them. Store items where you use them. For example, keep hard to find magnifiers and pens in the places where you read or pay bills. File, don't pile.

An area that is particularly challenging for those with visual impairments is handling paperwork. Make filing fun! Take advantage of colored file folders. Put everything into a file folder. Use a different color for each activity so they're easier to spot; label each folder with your favorite marker so that you'll only have to look at it once to see what's inside. Use staples, not paper clips, to group papers so they don't get lost. Use eye time wisely; for example, tackle mail in the morning, if morning light works best for you. To minimize paperwork, store things on the computer, pay bills on line or have payments automatically deducted from your bank account. If you collect menus from restaurants, date them so that you can easily discard those that are no longer current.

Learn what documents should be kept and for how long. Toss those that are not needed. Set an appointment with yourself to purge clutter every 6 months.

Barbara included tips for dealing with other potentially challenging areas such as the kitchen. Store cans and boxes in rows by type so they are easier to locate. For example, put all of the canned vegetables together. Newly purchased items should be stored behind the older ones. This will decrease the chances of something spoiling. Keep fruit, vegetables, milk, etc. in designated spots in the refrigerator so you can find them easier.

Toss recipes you haven't used. Do you have a cookbook from which you've used only a few recipes? To save space, copy your favorites and toss the book.

In the closet, keep black and navy blue garments at opposite ends of your closet so you won't be tempted to wear the navy skirt with the black blazer.

Store your CD collection in a motorized rack so you find your favorites easier. Remembering the time and effort it took to de-clutter will help you to maintain the new order you have created.

"How and Why I Became an Advocate" This was the topic addressed by a panel composed of Judith Lesner from National Association of Parents of the Visually Impaired (NAPVI), Barbara Milleville, President of National Capitol Citizens with Low Vision, and Barbara Friedman, attorney and Tai Chi instructor and jazz singer from New York. These panelists discussed their experiences and frustrations in dealing with educators and legislators. Barbara Friedman noted that as she became more comfortable with herself through the practice of Tai Chi, she became a more effective advocate.

"Education for People Who Are Visually Impaired-Then and Now": Panelists were Lynne Sadler, Foundation for Blind Children, Phoenix, AZ; Judith Lesner, NAPVI; Lee Robinson, Retired Superintendent of the Utah State School for the Deaf and Blind; and Paul Edwards, Director of Disabled Student Services at the North Campus of Miami Dade Community College in Florida.

Records of residential schools from years ago noted the "reason the child was referred to the school." Typical reasons were: "He can't see", or "He is blind". Causes for impaired vision were not listed. Identifying these causes might have lead to more individualized educational planning for students. In 1975 federal law began to address the importance of tailoring education to the specific needs of individual children. Panelists seemed to agree that we are still falling short of where we need to be in providing adequate educational opportunities to children with disabilities.

## ACB Convention Breakfast Support Group--High Partials in a Sighted World

A group of people with high partial vision gathered for an early breakfast at Kady's Coffee Shop on July 4th, 2005. We discussed issues particular to us as well as issues

we have in common with the rest of the blind community. We listened intently as everyone shared their challenges of sometimes being in that in-between world where in some ways we don't fit into either the sighted or the totally blind worlds. We had a good turnout for the meeting especially since most of us could have been sleeping. We began to tackle subjects such as:

- -How and when to share that you have a visual impairment if you don't use a cane or guide dog
- -Appearing to have no visual disability while playing "catch-up" with sighted people -Developing effective communication in business meetings

This meeting was co-chaired by Barbara Friedman and Barbara Milleville. Both have low vision. Help Shape 2006 Convention Program

Do you have ideas, suggestions for next year's CCLVI Convention program? What would you find helpful? Interesting? Coletta Davis, Program Chairperson, would love to hear from you. Call Coletta at 714-630-8098, Fax: 714-666-2494, or write to her at 2879 East Alden Place, Anaheim, CA, 92806.

#### **CCLVI Chapter News**

#### **METRO CHAPTER NEWS**

Located at the nexus of the nation's theatre industry, it is not surprising that there are Chapter members who are involved in the performing arts in various ways.

Member Laurel Sanborn has appeared many times in walk-on roles in TV series. A glimpse of her could be seen in a Woody Allen movie, and she has performed in summer stock too. Chapter Member Peter Seymour has had several of his written pieces staged. A television commercial in which he was featured was cited in a news item in The Chicago Tribune. Chapter President Ken Stewart has been a cast member in several community theatre productions. He also wrote a one-act play presented a block from Times Square. That off-off-Broadway topical-humor piece about curb ramps had the politically incorrect title, "Gimps 4, Blinks 2".

And, the Metropolitan Council of Low Vision Individuals has never been prouder of itself than on July 21st, when the venerated New York Times published a review of a play produced by Laurel Sanborn's Performers Access Studio. The revival of Tom Stoppard's "The Real Inspector Hound" was the result of great work by many contributors of course, but most of all, the super-human efforts of Laurel and her husband Walter. Ken Stewart joined Laurel in the cast, and several more Chapter members added their laughter and applause in audiences throughout the twelve scheduled shows.

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

#### **National Capitol Citizens with Low Vision, NCCLV**

At our meeting in May, Day Al-Mohamed, Director of Advocacy and Governmental Affairs at the American Council of the Blind filled us in on what's "hot" in the legislative arena for folks with a visual disability. Topics discussed included descriptive video, assistive technology, voting, transportation, distance learning, electronic textbooks, and perhaps the most important of all - the Rehabilitation Services Administration downsizing.

Attendees learned that the future is in our hands and that now is the time to become active in the community. Together, we can make a difference by joining rallies and writing letters when we don't get our needs met.

For information about NCCLV call 703-645-8716 or email ncclv@yahoo.com

## More and Better Vision Access By Bernice Kandarian

From time to time, I have received comments through the 800 line regarding Vision Access. Your editor has made an effort to incorporate the good ideas embodied in these comments. For example, in this issue we are trying a different print font with larger point size and a bold face. Additionally, the membership voted at the 2005 convention to increase the frequency back to four issues per year, with deadlines of March 15, June 15, September 15 and December 15.

We look forward to your feedback on these changes and any other suggestions you may have about how to improve Vision Access. But what we look forward to the most are your future contributions to Vision Access. It is your magazine and it will thrive on your ideas expressed as articles.

#### In Memoriam

Note: If you attended the CCLVI program in Birmingham in 2004, you may remember that Dr. Smith spoke to us about "MyReader." His contributions have made a substantial difference in the lives of people with low vision. Blindness Industry Mourns Loss of Innovative Leader

CONCORD, CA (August 9, 2005) - HumanWare announced today, with deep sadness, the death of the company's founder and Chief Executive Officer, Dr Russell Smith, and his wife Marian who were killed on Sunday, August 7th in the crash of their Cessna 182. Russell and Marian, as they are known to most of the blindness industry, were avid fliers who had built their own private airstrip at their home in Aylesford, New Zealand. On Sunday while returning home together from Nelson, their aircraft crashed into the sea north of Christchurch.

"Russell devoted his entire working life to developing innovative technology for people who are blind or visually impaired," stated Philip Rance, President of HumanWare USA. "In his 30 years of service, he became an icon and was recognized, honored and admired throughout the world." Rance added, "His death, at age 60, is a huge loss to the blindness industry as a whole. Both he and Marian will be greatly missed by family, friends, and colleagues all over the world."

Dr. Smith graduated from University of Canterbury, Christchurch, New Zealand, with B.E.(Hons) in Electrical Engineering and went on to complete a Ph.D. degree in 1972. His doctoral research concerned new techniques for designing transducers and information displays for under-water sonar systems. He joined the Wormald International Group in 1975 to head a new division which would develop the SonicGuide sonar mobility aid for the blind. The benefit of Russell's earlier research in sonar techniques was instrumental in ensuring the successful launch of this innovative product on to the world blindness market. In 1976 Russell was appointed the first Manager of Wormald International Sensory Aids Ltd, which became Pulse Data International Ltd in January 1988 after a management buyout. In January 2005 Russell finalized a merger of the company with Canadian-based VisuAide, and the new combined company was renamed HumanWare Ltd.

"Russell Smith was one of the fathers of our industry," notes Jim Halliday, President Emeritus of HumanWare USA. "In the 30 years since we

first meet, he has inspired and driven the development of an amazing list of technological firsts that have and will continue to create opportunities for people who are blind or visually impaired." He emphasizes, "Russell's legacy will live long after the rest of us are gone!"

Some of the "firsts" Smith's company have developed include:

Sonic Guide (1976) - the world's first sonar-based electronic travel aid.

Mowat Sensor (1978) - the world's first hand-held electronic travel aid.

Viewscan (1980) - the world's first portable, high contrast, large print reading system employing a hand-scan camera and a flat-panel display using 7,000 light pixels.

Viewscan Text System (1983) - the world's first portable, large print, word processing system.

Keynote (1986) - the world's first portable, talking word processor.

The Viewpoint VGA (1989) - the first video magnifier to support a split screen computer connection with an industry standard computer display.

SmartView (1995) - the world's first video magnifier to introduce built-in date, time, and calculator functions.

SmartView Xtra (1999) - the first video magnifiers to achieve "plug and play" capability with a wide range of PC display formats.

BrailleNote (2000) - the world's first true Braille PDA

myReader (2004) - the world's first low vision auto-reader

As well as being Chief Executive of the HumanWare Group, Russell was Chairman of the Board of the group's Europe, Australia, USA, and Canada subsidiary companies. Rance acknowledged, "Although we are a very solid company with teams in place to manage effectively well into the future, we will all miss Russell's inspiration and guidance, his tenacity, and his kind humanity. He and Marian will leave a huge void in all of our lives."

A memorial service will be held in the US to honor Dr. Russell Smith - Date and location to be advised.

CONTACT: Jonathan Mosen - 925-566-9265 - jonathan.mosen@humanware.com

#### About HumanWare

HumanWare designs and manufactures innovative technology for people who are blind or visually impaired. The company's products include integrated speech and Braille technology, a range of video magnifier solutions, screen reading software and speech synthesizers. Contact HumanWare at 175 Mason Circle Concord CA 94520

800.722.3393

www.humanware.com

## Quality of Life Living with a Spouse Who Is Blind By Dr. Ikan C. Kleerly

Some folks, both blind and sighted, have asked me what it is like to live with a spouse who is blind. My answer is that there is NO difference between living with a spouse who is blind or one who is sighted!

Living is a constant matter of adjustment. Blindness is but one of those matters that requires constant adjustment.

I had my first experience with blindness with my great grandfather. He developed cataracts which finally took his vision. I referred to him in my last article in Vision

Access, Vol. 12, No. 1. He lived to be 100 years old. He was hard headed and determined. These were qualities which probably helped him live so long.

Growing up in Philadelphia, I saw people who were blind standing on the sidewalks and playing the violin, accordion or the harmonica with a tin cup and with the word BLIND around their neck. Others just wore the sign.

There was a school for the children who were blind close to our town in New Jersey. I was amazed at how students who were blind got around the campus. Young people from our church would go to this school and sing. I was also amazed that students in this school also could sing, play in an orchestra and put on plays. Other than vision loss, they were just like us!

When I started college, I began to concentrate on special education. There were not many classes addressing that issue so I did research about special education.

While teaching at the college, I made special efforts to steer students who were blind and visually impaired into my class. I made accommodations for them long before the ADA required this.

One of those students, several years after leaving my classes, renewed our relationship. A year later, she was my spouse. She had been a single mom with six children at home. She attended college to seek a better life for herself and her children. She brought two preteens into my home when she moved in. She was very adamant about how much help she would accept from me. She also expected the girls to respect and to obey me. She expected me to inform her if she was inappropriately dressed with clashing colors or if she had a spot on her clothes. She insisted on managing her own finances. While she respected my recommendations for courses to take, she made her own selection. Studying was an arduous task and only rarely would she allow me to help her study or read to her. Many times her texts were not on tape but she persevered to the end using her 10x magnifier or her CCTV.

She graduated from the Phoenix College with High Distinction and from Arizona State University with Distinction.

If she is searching for something she has misplaced, she will inevitably find it before I do. In our counseling practice, someone will call on the phone and she will remember the name of the caller and their case history from many years back even though the caller may not give his or her name. She is a stickler for details and perfection. These abilities are necessary for her to maintain independence. I will have to back off of something that I had planned to do for her because she prefers to do it herself. This is important. I have observed spouses doing things for their mates who are blind which should be done by the individuals themselves.

Buffet restaurants are an example of learning when to help and when to back off. It is not going to be a happy dinner when my spouse discovers that she has put vanilla pudding on her mashed potatoes when she thought it was gravy! At a luau in Hawaii, my spouse took a bunch of what she thought was tomatoes but which turned out to be raw fish. Buffets are times I might assist.

My spouse enjoys square dancing. I don't dance. However, I enjoy sewing as a pastime and have made over a dozen outfits for her. She enjoys going to Laughlin-a smaller version of Las Vegas. I don't. So she goes alone on the bus and has a great time. We both love to travel and experience new things. We have taken many cruises, traveled to many countries, but she cannot enjoy looking at the videos or pictures that we took. She enjoys the birds that come to our yard for their food. She enjoys hearing my description of these birds and hearing their songs.

Her adult children have but recently realized their mom is blind. They will take her to a restaurant and follow the hostess to a table while their mother stands helpless at the doorway.

Years ago my spouse traveled a lot. She would sit in the smoking section intentionally, because generally the gentleman seated beside her would offer to help her from the plane and then to recover her baggage.

Folks who are blind are no more dependent or independent than the general population. Some people who are perfectly sighted are more blind than my spouse.

What do you do when you meet someone who is blind? You ask if they need help. What do you do when you marry a person who is blind? You ask them if they need help. Same thing!

## It's About Time By Carlos Gourgey

I once had a very unpleasant experience with time. I was in a music class with a group of people playing Renaissance pieces, and was enjoying myself thoroughly. However, I had to leave strictly on time for another appointment at which I could not afford to be late. Since the classes often ran overtime, I had to check my watch several times to make sure I wouldn't miss my appointment. The teacher noticed me doing it - it was pretty hard to miss, since I need to hold the watch close to my eyes in order to see it. Unfortunately, he thought I was disrespecting him, took it very personally, and never forgave me. That was a shame, since I really liked the class and never meant to insult him.

Well, that's just one of the many embarrassments that come with low vision - but one perhaps easily controlled. I started experimenting with different timepieces. I already had one with a large dial, but even that is hard for me to check without being obvious.

I wanted to know what kinds of watches other people with low vision use. A favorite of many is the talking watch. (It seems that just about everything can talk these days. I'm still waiting for a talking bathtub that will call me before it starts to overflow.)

Some people in our online group shared their experience with watches. Here is one member's testimony:

#### Hi List

I recently bought a talking watch. It has a black face and white easy-to-read hands for me as a low partial. If I squint, I can still see the numbers. I can set it so it doesn't announce the time every hour. It also has an alarm on it with 3 alarm settings. I didn't like the gold band it came with, so I ordered one from a place nearby. I wanted a bracelet watch. Anyway, I like my watch, and well, when it gets time to replace the batteries, I'll either take it somewhere and have the jeweler do it, or do like one of my friends and get another one!

Like everything else with low vision, however, what works for one may not work for another. A different member wrote: Does anyone use a talking watch? I had to replace the batteries and it took three weeks for the jeweler to figure out how to do it! Has anyone had a similar experience?

I did try a talking watch and the same thing happened. It just stopped talking. I took it to a jeweler, and since the speech is powered by a separate battery not found in other watches, the jeweler didn't know what to do with it. I got that watch back several times and it still never talked. (Now if that would only work with politicians!)

So no more talking watch. But it was just as well, since for me the talking watch had one other disadvantage I could not overcome: I still could not check the time without anybody else noticing.

To solve this problem there is only one solution: the Braille watch. But aren't those strictly for blind people? Who cares? I'm legally blind, so it's not against the law for me to buy one. I got one at an ACB convention, and fell in love with it. The dial is large and very good for a low-vision user. And best of all, you don't even need vision to use it! Now I can check the time anywhere, anytime I want. I can check it at meetings without anyone finding out, and I can even check it in a dark movie theater where any vision-dependent watch would be useless. Actually, I don't go to movie theaters anymore, the commercials and noisy people have made the experience just too unpleasant. But that's not the point. What really matters is that I COULD check the time in a movie theater if I wanted to. The sheer possibility, even if never actualized, makes me feel powerful.

So now my Braille watch is the only one I use, except when I lose it, which happens much too often. (It would really be helpful if someone would invent an unlosable watch - that would certainly get my attention even if it didn't talk.) Fortunately my watch always faithfully resurfaces, just like my wife's guide dog. Except that the dog can't tell the time.

I extolled the virtues of the Braille watch to our online group, but was brought up short by a very legitimate concern that, since I happen to be male, I had not anticipated:Good point for a braille watch Carlos. I have a talking watch but I do not use it much. Working in a call center I cannot have it go off every hour and when I would check the time I felt like I was annoying people. I have a low vision watch and I just love it. I was actually thrilled to find it because for years I wore a man's watch so I could read it and now I actually have something that looks like a girl. It is not so clunky. I have thought of the braille watch option as well but have not done it because some of them are even smaller.

I hadn't thought of it, but she's right: women's Braille watches are tiny and hard for low-vision people to read (let alone feel). If I were a woman, I'd still wear a man's Braille watch. But if I were a woman, I'd probably have some fashion sense that I'm totally lacking now. Which once again proves, when it comes to low vision, what works for one doesn't always work for another?

(If you use a computer and want to join our online support group for people with low vision, just write to Carlos at laflauta@hotmail.com.)

#### Marcie Answers Question about Medicare Prescription Coverage

Editor's Note: Dear Marcie is a service of the Medicare Rights Centerwww.medicarerights.org

#### Dear Marcie

I read an article on the new Medicare prescription drug plans that said most people will have to pay \$3,600 in out-of-pocket expenses along with a monthly premium. What expenses will Medicare cover and what will I be responsible for? Jay, Detroit, MI

#### Dear Jay,

You will have to pay a monthly premium, an annual deductible and varying amounts of coinsurance, depending on the total costs of the drugs you buy. At some point, you may have to pay the full cost of your covered drugs until you have spent

\$3,600 out of pocket for covered drugs. Then your costs will go down to only 5 percent of each prescription you fill ("catastrophic coverage"). Your Medicare private drug plan will keep track of your out-of-pocket expenses for you

If you buy a drug that is not on your plan's list of covered drugs (a formulary), or if you buy a drug from a pharmacy not in your plan's network, you will have to pay 100 percent of the cost and that amount will not count toward your \$3,6000 in out of pocket costs.

The 2003 Medicare law outlines the out-of-pocket costs for the basic Medicare prescription drug benefit. If you are in a plan offering the basic drug benefit in 2006, on top of the monthly premium (estimated to be \$37 in 2006), you will pay the following:

- \* The first \$250 of your drug costs each year (deductible);
- \* 25 percent of the cost of covered drugs between \$251 and \$2,250;
- \* 100 percent of the cost of covered drugs between \$2,251 and \$5,100; and
- \* 5 percent of the cost of covered drugs above \$5,101, or a copayment of \$2 for covered generics and \$5 for covered brand-name drugs-whichever is greater (catastrophic coverage).

Keep in mind that you may never see a plan exactly like the one outlined above. The Medicare private drug plans will announce their coverage packages and costs in the fall. The plans can create their own cost-sharing formula as long as the overall package is at least as good as the one outlined in the law. However, in every plan you must spend \$3,600 (in 2006) out of pocket for covered drugs before your out-of-pocket costs are reduced substantially (catastrophic coverage).

State pharmaceutical assistance programs, registered charities, and pharmaceutical manufacturer patient assistance programs are the only agencies that can help you pay part or all of that \$3,600. (Extra help paying for out-of-pocket expenses is available for those who qualify. See Resources below to apply online with Social Security.

Your premiums, deductible and out-of-pocket costs likely will go up every year.

#### Marcie

#### Resources

To apply online for "extra help" paying for the new Medicare prescription drug benefit, visit www.socialsecurity.gov

Visit the web site for The Access Project for a state-by-state listing of AIDS Drug Assistance Programs around the country, along with detailed information about program contacts, eligibility, enrollment, formularies and DARE consortiums.

Consumers and providers can access information about public and private pharmaceutical patient assistance programs online at RxAssist, including details regarding Rx Outreach, a no-fee program that provides qualified low-income individuals and families with access to generic versions of brand- name medications.

Call your State Health Insurance Assistance Program for more information on Medicare benefits, rights and options. Call Social Security at 800-722-1213 for questions about enrolling in Medicare.

### **Learn About Blindness, the Interactive Way**

If learning about blindness is new to you, The Hadley School for the Blind has a course for you and it's just a mouse-click away.

"Blindness Basics," is an interactive, tuition-free Web course that allows a person to apply knowledge of the blindness field to real-life situations. The course is open to students in the Professional Education Program and acts as an orientation for anyone working within a blindness organization.

This accessible e-learning course presents important information about blindness in various formats. In Lesson 1, many misconceptions about blindness are addressed, in addition to successful techniques for interacting with visually impaired people. Computer simulations give students the opportunity to decide what words or actions are appropriate in various situations. Lesson 2 presents the history, relevant laws and attributes of the service delivery and educational systems of the blindness field, through radio interviews. Magazine articles in Lesson 3 explain the stages of adjustment and common causes of visual impairment, as well as the characteristics of deafblindness. Finally in Lesson 4, journal articles present how a person who is visually impaired can become self-sufficient and regain newfound hope for the road ahead.

"The interactive aspects of this course help students make the information their own in an enjoyable way," said George Abbott, Hadley's Dean of Educational Programs and Instruction. "Anyone who works in a school, agency or other organization involved with people who are visually impaired can benefit from this course."

If you have any questions, please contact Student Services, as follows: United States, Canada and Puerto Rico: (toll-free number) (800) 526-9909 All others: (847) 446-8111 Hearing Impaired: 847.441.8111 (TTY)

Fax: (847) 446-0855

Email: student\_services@hadley.edu

#### Website Directs People with Disabilities in Coping with Emergencies

The U.S. Department of Transportation today launched a new web site containing information to help ensure safe and secure transportation for people with disabilities in the event of a disaster or emergency.

The new site includes advice on emergency preparedness, transportation accessibility, and evacuation methods for certain modes of transportation, such as rail and transit systems. Disabled individuals can learn how to react in situations ranging from evacuations of mass transit systems to being trapped in a car during a blizzard or hurricane.

The site also includes links to Department of Homeland Security web pages that provide information on preparing for specific emergencies, including natural disasters such as severe weather, fire and earthquakes, as well as man-made disasters such as spills of hazardous materials. In addition, the site also provides information for transportation providers on how to respond to the unique needs of people with disabilities during an emergency.

The new site was developed in response to an executive order issued by President Bush on July 22, 2004, which directed federal agencies to support safety and security for individuals with disabilities during natural and man-made disasters.

The web address for the new site is <a href="http://www.dotcr.ost.dot.gov/asp/emergencyprep.asp">http://www.dotcr.ost.dot.gov/asp/emergencyprep.asp</a>.

#### **Low Vision Conference**

Discovery 2005, The Low Vision Conference, will take place in Chicago, IL from November 3 to 5. Here is a small sample of meeting topics: Keynote address: "What You Need to Know About Treatment Strategies for Retinal Diseases", "The Impact of the ADA Legal Decision on Employment Opportunities for Those Who Are Visually Impaired", "Internet Search Strategies: Finding What You Are Looking For", "Going Places Alone and with Others, You Can Do It All", "Connecting to the Sighted World Through the Arts and Other Media", "Making Your Home More Livable: Environmental Modifications to Enhance Low Vision", "The Psychology and Reality of Low Vision". For a complete program listing and for registration information go to www. Deicke.org.

This conference will offer a comprehensive perspective on low vision and vision rehabilitation. Planners, a coalition of nonprofit and governmental agencies, have designed this event to bring together people with vision impairments of all ages, their families, educators, doctors, rehabilitation professionals and vendors.

For lodging call the Holiday Inn Mart Plaza at 312-836-5000 .Questions? Call the Deicke Center 630690-7115. Ask for Leah Gerlach, Chairperson.

#### **Advocacy**

Advocate's Alley By Ken Stewart F.A.R. Sighted Design

The metaphorical "800-Pound Gorilla" sat wherever it wanted, but it listened to me! With respect to transportation in Metropolitan New York, that gorilla is the Port Authority of New York & New Jersey. Its Director of Governmental Relations came to meet with representatives of our neighborhood's Community Board Transportation Committee, and she did sit where she pleased. But she was quite receptive to my input which was supported by my fellow committee members. My input concerned the color selection of additional sign stanchions. The Port Authority was trying hard to be considerate of our residential area. Many approach lanes pass through our neighborhood to connect with the Lincoln Tunnel. We quickly agreed on a choice of color. This color choice will be easy to see by pedestrians who are visually impaired. Also it will not be offensive to residents who don't want any more reminders than absolutely necessary of the high volume of traffic moving past their apartment windows at all hours.

That was certainly only a minor advocacy achievement. However it offered a much greater opportunity. After our meeting, the Port Authority Rep and I chatted. She was receptive to my proposal to develop a set of guidelines for low vision-friendly transportation centers. Such standards are very timely because the Authority is now designing a facility to replace the rapid transit station which was located beneath the World Trade Center towers. Also he City is planning a major transit center which will link several subway lines.

The Governmental Relations Director was pleased to hear me tick off the favorable features of their midtown bus terminal. Incidentally, this is the busiest bus station in the entire world. My list, compiled from discussions with other low vision travelers and from my own experiences, includes: very large illuminated yellow-on-black gate numbers, floor design patterns which present conspicuous right angle patterns for directionality, evenly distributed corridor lighting, a dramatic change in floor color

indicating a short set of steps in an unexpected area like a wide concourse, and visually contrasting features in the public rest rooms to precisely highlight plumbing fixtures.

The "Gorilla" and I agreed that the guidelines for transportation centers could include photos as well as explanatory text. These photos could illustrate a few things not to do. For example, a floor pattern with dark spots could conceal a janitor's mop bucket or a suitcase!

I have at times categorized those things which need to be thoughtfully designed by architects and interior decorators- those features which they want us travelers to: Find, Avoid, or Read. Hence, "F.A.R.-sighted" design.

#### **Travel**

## Armchair Traveler By Jane Kardas

Have you dreamed about a visit to New York City? Do you feel your disability would be in the way? Well come along with me and let me share with you the possibilities of such a trip! This will just be a slice of the Big Apple! I can tell you as a woman living in a small town with a population of 15,000, that a trip to New York City is quite a thrill. Such a trip offers many choices of fabulous places to visit! I was especially impressed with a walk across the Brooklyn Bridge on New Year's day with a very special someone, Ellis Island, the Staten Island Ferry, and the Empire State Building by night offers a spectacular view for those of you with enough vision. A new find I highly recommend is the Museum of Modern Art, located in Manhattan. I will share with you the opportunities available there for people with vision disabilities as well as those with hearing and mobility loss.

As stated in the Museum's brochure, "Touch Tours allow the blind and partially sighted visitors to experience a selection of sculptures, paintings, and design objects from the collection. These tours take place in the Museum's galleries and Sculpture Garden. They are available to individuals or groups by appointment".

With such an appointment four of us enjoyed a hands-on demonstration of the sculptures. We wore plastic gloves. A docent added explanations and clarified our impressions as needed. This was a fabulous opportunity. If you are considering a trip to New York City I highly recommend the Museum of Modern Art. And in case you say you've been there before, let me tell you that the museum has been totally remodeled by a famous Japanese architect, Yoshio Taniguchi. So, as you might surmise it is a clean palette, quite modern, in the Japanese tradition.

The Museum's brochure states, "A new audio program for blind and partially sighted visitors as well as the general public is available inside the museum at the audio program desks. Developed with Acoustiguide in consultation with an advisory board of people with sight loss, this audio program provides vivid and detailed descriptions of key works from the Museum's collections. Expert commentary, musical accompaniment, and historical references enhance the experience. The cost is five dollars for visitors and four dollars and fifty cents for members. Transcripts of this and all Museum audio programs are available in regular and large print upon request".

In case I haven't caught your interest yet, perhaps the option of Art inSight might interest you. Also stated in the Museum's brochure, "Art inSight, a new program for blind and partially sighted adults, is held monthly in the Museum galleries. This program highlights specific themes, artists, and exhibitions, engaging participants

through extensive verbal description". For those of you with special mobility needs, wheelchairs and walkers are available on a first-come-first-served basis.

Now I bet you're wondering how you're going to get around to see the rest of the city. After all, you want to make the best of your experience; it may be a one-time opportunity. So let me tell you about a not-for-profit organization--the Big Apple Greeter. These Greeters assist people with disabilities during their visit. They offer up to a four hour tour around the five boroughs and come armed with free passes for the subway and bus system; a four hour walking tour may be too much. This organization attempts to match visitors with greeters.

So now tell me, what's not to love about the Big Apple? This slice, I can guarantee, will only leave you yearning to return for more. For further details on the Museum of Modern Art call (212) 708-9864, (212) 247-1230 (TTY) or e-mail accessprograms@moma.org. For information on the Big Apple Greeter call (212) 669-3602 or go to their website at <a href="https://www.bigapplegreeter.com">www.bigapplegreeter.com</a>.

#### The Road to Success Is Paved with Snow

Join over 300 active adults for a cross-country skiing vacation at the 31st annual Ski for Light International Week, January 29 - February 5, 2006 in Granby, Colorado USA. Participants will stay at the Inn at Silver Creek and ski each day at nearby Snow Mountain Ranch.

Ski for Light pairs visually impaired skiers with sighted instructor/guides. The program attracts beginners to advanced competitors.

Skiers set the pace, asking their guides to assist with skills, technique, endurance or simply enjoying the outdoors.

The total cost for the week, including all meals and ground transfers is: \$850USD single-occupancy, \$725USD per person double-occupancy, and \$600USD per person triple-occupancy. Skis, boots and poles will be provided to first-time participants free of charge. Transportation from home to and from Denver is your responsibility.

Interested? Contact Lynda Boose at 1-906-370-7541 or lynda@sfl.org Apply online at http://www.sfl.org The application deadline is November 1, 2005.

#### **Hotline Helps Air Travelers with Disability Related Problems**

There is an aviation consumer disability toll-free hotline. Call the hotline if you experience disability-related air service problems. The toll-free number for the hotline is 1-800-778-4838 (voice) or 1-800-455-9880 (TTY). The Aviation Enforcement Office is committed to improving the quality of air transportation for people with disabilities and believes that if travelers use the toll-free hotline this hotline can be a major step towards accomplishing this goal.

#### Science and Health

Anti-Inflammatory Drugs May Prevent Age-Related Macular Degeneration Reprinted with permission from VisionConnection (www.visionconnection.org). Copyright 2005 Lighthouse International. All rights reserved.

VANCOUVER, Canada, June 10 -- Rheumatoid arthritis patients treated with non-steroidal anti-inflammatory drugs (NSAIDs) are 10 times less likely to develop agerelated macular degeneration (AMD), researchers at the University of British Columbia (UBC) and University of Saskatchewan (U of S) have found. The study, recently published in Neurobiology of Aging, is a joint effort of neurologist Dr. Patrick McGeer, a UBC professor emeritus in the Kinsmen Laboratory of Neurological Research, and Dr. John Sibley, a U of S professor of medicine and head of the division of rheumatology. The scientists reviewed 993 rheumatoid arthritis patients in Saskatchewan 65 years or older who, on average, had been living with the condition since age 51. Only three had developed AMD, where about 30 cases could be expected in a similarly-aged group from the general populace. People with rheumatoid arthritis, says Sibley, "have been followed closely for more than 40 years with particular attention paid to retinal changes because medication widely used for rheumatoid arthritis can create visual problems.

It is already accepted that NSAIDs reduce the incidence of bowel cancer. Fifteen years ago, McGeer and Sibley found the first of a growing body of evidence that NSAIDs may also help reduce the incidence of Alzheimer's. However, Sibley says this is the first time a link has been identified between anti-inflammatories and macular degeneration. "Age-related macular degeneration is like Alzheimer's disease of the eye, with retinal deposits called drusen acting like amyloid deposits in the brain found in Alzheimer's," says McGreer.

The researchers emphasize that further study is required to confirm their findings, but if they are corroborated, anti-inflammatories would be the first treatment tried for AMD. Related questions such as optimum dosage and when to begin treatment still need to be answered. Also, since NSAIDs can have side effects such as stomach upset, ulcers and stress on the kidneys, they are not appropriate for everyone and criteria for high-risk patients who would benefit from their use will need to be defined.

# Macular Degeneration By Dr. Ikan C. Kleerly

It was an extremely fast-paced week in July. I was privileged to be one of the almost 1700 people in Las Vegas at the 44th Annual convention of the American Council of the Blind. Add to this number of people a couple hundred guide dogs and you will get the picture. Most of those people were in line in front of me every time I went to eat. Meetings might start before 7am and still be going past midnight. I was so busy that I didn't even have time to lose my money at the slots. CCLVI was highly visible with meetings and social affairs. I immediately realized that there was more than a generation gap when I heard the music at the social events. (What happened to Guy Lombardo?) (As another parenthesis, this author was elected to the board of CCLVI for a four year term. That's what I get for being outside the door at the wrong time!)

Speaking of generation gap, there are a lot of things we lose as we get older. I won't ask if you have taken inventory, but certainly the eyes have it. This condition is called Macular Degeneration. (But please do not refer to folks as "degenerates").

Macular degeneration is most often related to aging. There is a form of juvenile degeneration also. This form will not be addressed at this time. After the age of 50 people begin to notice some changes in their eyesight. There appears to be a heredity factor involved; it may run in the family. The first noticeable effects are spots that appear. These are referred to as "drusen".

The eye is like a camera, the retina, a thin layer of cells at the rear of the eyeball is like the film of the camera. The macula, the center portion of the retina, is the area of greatest focus. When spots or drusen appear, vision may not be seriously affected. Spots or drusen are more annoying than anything. Only a small percentage of people with drusen develop severe macular degeneration. Age Related Macular Degeneration (AMD) generally develops in one eye than later may affect the other. A person can check for AMD with the Amsler Grid. This is a grid of black lines about 1/8"wide on a white background. If the person has AMD the lines appear not to be parallel. Sometimes an ophthalmologist or optometrist may have this grid available free for the asking.

One of the most noticeable effects of AMD is to cause difficulty with reading or and other tasks requiring close up vision. Changes in distance vision are generally less noticeable in the beginning stage. In the distance, it may seem that edges of buildings are not vertical or that telephone poles are bent. There may be a noticeable difference in colors or sizes as these are seen by each eye. If you become aware that you vision changes in any of these ways, it is imperative that you see an ophthalmologist for a diagnosis. Remember, optometrists will probably sell you a new pair of glasses. They are usually not experts in diseases of the eye.

There are three types of AMD--wet, dry and pigment epithelial detachment (PED). Only the ophthalmologist can determine which type is present in your eye. It is important that you know which one of these types you may have. It is even possible to have one type of AMD in one eye and a different kind in the other eye. Dry AMD occurs in 85 to 90% of the cases while wet AMD is about 10% and PED only 5%. In the dry form, the macula thins out and actually stops working. Whereas there is no medical treatment or cure for dry AMD, glasses may help for reading. Another pair of glasses may be useful for long distance vision. People with AMD can also be taught how to use their peripheral vision to greater advantage. Patient also should be aware that the dry form can change to the wet form of AMD. These are reasons for monitoring the condition with the Amsler grid. The wet type causes more damage than the dry type.

Recently there has been some research in the implanting of a telescopic lens in the eye which is focused on a healthy portion of the retina and gives promise for improved vision.

In the wet type of AMD, abnormal blood vessels grow under the retina like roots under a sidewalk. They cause the retina to lift up away from the choroids layer. The blood vessels leak fluid and can be repaired with laser treatment. A procedure called fluorescein angiography may be recommended for monitoring the wet type. A dye is injected into a vein in the arm and a special camera takes a series of pictures of the retina. These pictures are kept and compared to changes in future tests.

What can you do to prevent AMD? First, choose your genetic makeup before birth. Since that is impossible at this time, prevention and proper care will help slow the disease process. Zinc has been recommended as have dietary supplements that contain carotene. Recent research establishes that smoking and use of alcohol promote more rapid deterioration of macular cells. People who have quit these substances have shown a decrease in the progression of the condition. Many foods such as carrots and green vegetables contain the ingredients for an eye healthy diet. I do not advise my patients to chew on a garbage can to get their zinc. Beside

that, most of the containers are plastic anyway!

In the next issue Dr. Ikan C. Kleerly will address "Black Eyes" since his wife found out where he was when he was not in those meetings!

## **Request for Contributions**

CCLVI gratefully accepts contributions from readers and members to help pay for the costs of publishing VISION ACCESS, the costs related to our 800 line and Project Insight, and for funding the Carl E. Foley and Fred Scheigert Scholarships. Please send contributions to CCLVI Treasurer, Mike Godino, 104 Tilrose Avenue, Malverne, NY, 11565-2040. Our Tax ID number is 52 1317 540.

#### Resources

Air Travelers Disability Hotline 800-778-4838 800-455-9880 (TTY).

Big Apple Greeter (212) 669-3602 www.bigapplegreeter.com.

**CCLVI Chapters** 

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

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

Metropolitan Council of Low Vision Individuals 845-986-2955

National Capitol Citizens with Low Vision 703-645-8716 ncclv@yahoo.com

CCLVI Scholarships Janis Stanger, 1239 North American Beauty Drive, Salt Lake City, Utah 84116.

Discover 2005 Low Vision Conference Deicke Center Phone: 630-690-7115 Leah Gerlach, Conference Chairperson

Emergency Information www.dotcr.ost.dot.gov/asp/emergencyprep.asp

Foundation for Blind Children 602-331-1470 www.the-fbc.org

Hadley School United States, Canada and Puerto Rico: (toll-free number) (800) 526-9909 All others: (847) 446-8111

Hearing Impaired: 847.441.8111 (TTY)

Fax: (847) 446-0855

Email: student\_services@hadley.edu

HumanWare 175 Mason Circle Concord, CA 94520 800.722.3393 www.humanware.com

Medicare Rights Center www.medicarerights.org Museum of Modern Art (212) 708-9864, (212) 247-1230 (TTY) e-mail accessprograms@moma.org

National Association of Parents of the Visually Impaired 800-562-6265

Ski for Light Lynda Boose 906-370-7541 lynda@sfl.org www.sfl.org

VisionConnection (www.visionconnection.org). wgps laflauta@hotmail.com.

Council of Citizens with Low Vision International An Affiliate of the American Council of the Blind 2005 Membership Application Name \_\_\_\_ Address\_\_\_\_\_ City\_\_\_\_\_ State \_\_\_\_ Zip Code \_\_\_\_\_ Country \_\_\_\_\_Phone \_\_\_\_\_ E-Mail \_\_\_\_ -----Membership Status: I am:

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\_\_\_ 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\_\_\_\_\_ Malverne, NY 11565-2024 Ph; 800-733-2258 http://www.cclvi.org Council of Citizens With Low Vision International 1155 15th Street NW. Suite 1004 Washington, DC 20005 (800) 733-2258 http://www.cclvi.org Officers and Directors 2005-2006 President Patricia Beattie (04-06, 2nd term) 906 North Chambliss Street Alexandria, VA 22312-3005

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