

VISION ACCESS

Volume 13, Number 1, Spring

Spring 2006

Copyright 2006

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 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, jmkleiber@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
www.cclvi.org

Contents

From the Editor.....	3
Organization News	
Come to Our Convention.....	5
CCLVI Chapter News.....	7
What Else for CCLVI?, By Joyce Kleiber.....	9
Quality of Life	
Tai Chi for People with Low Vision, By Barbara Friedman.....	10
Bioptic Driving Pro and Con, By Dr. Ikan C. Kleeerly.....	18
My Cup Runneth Over, By Jeff Weedle.....	24
Advocacy	
Advocate's Alley-Opening Doors When Opportunities Knock, By Ken Stewart.....	28
Science and Health	
Questions about Medicare Part D.....	30
Breakthroughs in Treating Macular Degeneration, An Interview with Thomas Ciulla, M.D., By Patrick Perry.....	37
Assistive Technology	
Freedom Scientific Announces New Portable Video Magnifier.....	46
Introducing the New Clarity Carrymate.....	48
New Talking Dictionary.....	49
Request for Contributions.....	50
Resources.....	51
CCLVI Membership Application and Renewal.....	52
CCLVI Officers and Directors.....	53

For address change or changes in publication format, please call 1 800 733 2258.

From the Editor

Last evening, I attended a program in which two leading psychologists in the Philadelphia area spoke about spirituality and mental health. Both said that it is important to honestly integrate all parts of ourselves, to accept the paradoxes-the strengths and the weaknesses, the loving and hating, to be ok with our mistakes. This makes it possible to live with a more open heart.

The psychologists said that traumas and everyday wounds lead us to close our hearts. Living with low vision usually involves many everyday wounds. An English teacher spotted me out-"See how close she has to hold the book!" I was unable to get a driver's license at age 16 when my friends and brothers learned to drive. When I tried to play on a baseball team, I couldn't see the ball as well as everyone else. And on and on. You can surely add to this list.

And so we may hide, hide the fact of our low vision, close off part of our heart, part of who we are. Then we are less free to be whole, to be spontaneous, to laugh, cry and respond, to tolerate ourselves and others.

Coming to a place of self-acceptance can be freeing. Then we are even more ready to cope with those everyday wounds.

In Vision Access and CCLVI we have a chance to be open and honest about our low vision with ourselves and with others. We can also make opportunities to work together to reduce frustrations. Read and respond to my article in this issue "What Else for CCLVI?" Consider sharing your thoughts and experiences in these pages. We'd love to hear from you. Thanks to all who contributed to this issue.

JMK, 3/11/06

Organization News Come to Our Convention

Here are some very good reasons to attend CCLVI's convention this summer in Jacksonville, Florida.

You will meet people from all parts of the U.S. who share the challenges of life with low vision.

You will hear Dr. James Nolan, Director of Special Projects and Research for Envision, describe his comprehensive, current research on driving with bioptic lenses. Dr. Nolan will tell us about legislative variations concerning driving with bioptic lenses in the 38 states that license driving with these lenses. Dr. Nolan has low vision. Hear about the experiences of a panel of drivers who use bioptic lenses.

Kermit the Frog says "It Ain't Easy Being Green!" Dr. Edwin Druding, psychologist and CCLVI board member, will lead panelists who will tell how they deal with, not being green, but with having low vision. How are the panelists' experiences the same or different from your own? Dr. Druding is also happily known to readers of VISION ACCESS as Dr. Ikan C. Kleerly. Come and meet him in person.

Learn about preparing for emergencies with your low vision in mind from Day Al Mohammed, ACB's Director of Advocacy and Governmental Affairs.

How do changes in the American's with Disabilities Act (ADA) affect issues that matter to people with low vision? Mitch Pomorantz, who is the ADA Compliance Officer for the City of Los Angeles will address this topic.

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

We will gather in Jacksonville, Florida from July 8 to 15, 2006. Call the Hyatt Regency Jacksonville-Riverfront at 1-800-223-1234 for reservations. The convention room rate is \$79 per night plus tax for up to four people per room.

CCLVI officers who attended the mid-winter meeting at this hotel tell us that the hotel is comfortable and that it is easy to get to meeting rooms and dining areas. The river walk across from the hotel has numerous restaurants. There are boats to take you across the river for shopping opportunities. And don't miss CCLVI's mixer, dances and game night.

We hope to see you in Jacksonville!

CCCLVI CHAPTER NEWS

Delaware Valley Council

One of our members, Carla McCollaum, has been vocal in advocating for voting machines that can be used by people with low vision. In Philadelphia such voting machine will be in every prescient in this spring's primary election. Carla is also advocating for measures that will increase pedestrian safety in Center City.

We are looking forward to our summer meeting with Gene Russo and his Connection through Dance. Gene teaches ballroom dancing to people who have impaired sight. His program is based in San Francisco, but when he comes to Philadelphia this July, he will offer a workshop in ballroom dancing and Salsa to members of our chapter.

Call 215-735-5888 for information about this chapter.

Metropolitan Council of Low Vision Individuals:

The Metropolitan Chapter membership includes folks from New York City, upstate New York and northern New Jersey. Currently, meetings are scheduled early on a weekday evening at Selis Manor on Manhattan's 23rd Street, very close to public transportation. The Chapter was again well represented at the second in an ongoing series of meetings at Yankee Stadium. The multi-disability assemblages are not there to watch a baseball game, but to watch over those who are now designing the facility which will replace "The House that Ruth (as in Babe Ruth) Built". They further articulated building, service, and employee behavior features which make sports facility attendance friendlier for people with vision impairments. The three Chapter members present also welcomed a new recruit to the Chapter's ranks from the participants.

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

National Capitol Citizens with Low Vision

In February, a group of us visited the new Air & Space Museum Udvar-Hazy Center which is located in Chantilly, Virginia. Paul Nyhus, our docent, treated us to over three hours of fascinating stories about the items that are on display along with their pilots, if applicable. He described the airplanes and other things that are on display in detail. A highlight for all of us was the hands on portion of the tour. Here, we were able to examine small scale versions of popular space ships and airplanes we had all seen and heard about. We got to see just how big the Enterprise and oncorde are. A few of us, using descriptive video headsets, also took in the movie Roving Mars at the IMAX theater.

This accessible tour was the first of its kind at the new museum. If you have an interest in this kind of event, we highly recommend you take the time to visit this museum.

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

What Else for CCLVI?

By Joyce Kleiber

As I looked at the "Contents" page of this magazine, I saw only two articles under the heading "Organization News." To me this is troubling.

CCLVI is the only organization by and for people with low vision. We have made efforts to reach individuals with information and support about leading a quality life despite their low vision. Ken Stewart and his Metropolitan Chapter and Carla McCollaum of the Delaware Valley Council engage in advocacy wherever the opportunity knocks! But have we, CCLVI, done enough to advocate for changes in areas that might make things easier for us and the millions of others in our country who live with low vision?

Could we ask people and companies doing product development to incorporate features that would be helpful to us? Could we promote larger, more readable print in everything from literature that comes with what we buy at pharmacies to telephone books? What do we need in order to make crossing a busy street less stressful?

As you think about your life, what things frustrate you most? Can we together begin to address these problems one at a time and advocate for change? I believe CCLVI members working together can and should advocate to bring about changes that matter to all of us.

Call CCLVI at 800-733-2258. Let us know your ideas about areas where we, together, might begin to do this important work. Let us know if you can give some of your time to this venture.

Quality of Life

Tai Chi for People with Low Vision

By Barbara Friedman

Tai chi helps to promote balance, relaxation, and resilience.

For those of us who deal with "attack trees" and "attack low fences", tai chi can help us to get out of the way of people and things more fluidly. This benefit comes from a generally increased ease of movement and from development of instincts and skills for how to move, where to move and which part of our body should be moving. Significantly, the more relaxed you are, the more you are able to use the vision you still have.

Tai chi is a very slow moving Chinese martial art. It is sometimes referred to as "meditation in motion". Tai chi can be studied as a martial art essential to which is an understanding of its medicinal purposes of promoting relaxation, physical balance, and clear thinking. The use of softness in movement can be surprisingly protective. Tai chi can also be studied just for these medicinal purposes. From whatever perspective is used, the body is entirely relaxed and the movements are flowing and beautiful.

In practicing tai chi, the important principles are: the power of relaxation, breathing and moving evenly, shifting of weight and therefore balance from one leg to the other, and the power of the waist for movement and strength.

Although tai chi is a very slow moving art, its practice can develop a lot of strength as well as ease of movement. I study American goju karate as well as tai chi. Since I started studying martial arts, there have been several periods of a few months each that my doctors asked that I not do active exercise. During those periods, I have maintained, with doctors' consent, my practice of tai chi. When I've been medically permitted to resume active exercise, I've always found that I can start doing karate again without missing a beat. This is because of the strength and flexibility that I maintained and developed by practicing tai chi.

I study and teach both empty-handed tai chi and tai chi double-edged sword. The movements of tai chi sword are different from those of empty-handed tai chi, but the benefits of relaxation and balance are the same. In tai chi sword there is an increased use of extension of the body and arms by the reach and use of the sword. There is no fighting or contact with other people. The sword I use has slightly rounded edges and is not designed to hurt anyone. It is made of metal but it is collapsible telescoping into itself. Long red tassels hang from the hilt.

Like empty-handed tai chi, the sword forms are also performed very slowly and in a stylized way. During those parts of the form where only one hand holds the sword, the non-sword hand is extended primarily for balance.

With or without the use of a sword, the practice of tai chi is also a wonderful way of understanding space. The skills and instincts developed from continual shifting of weight, the turning of the waist and the circular movements of all parts of the body, as well as shifting directions all are very helpful in learning how to avoid obstacles. These skills and instincts can also be helpful in learning to move through crowds or just getting out of the way of another person.

I came to the study of martial arts at a late age, primarily as a way of dealing with a combination of diminishing sight, loss of depth perception, and significant knee injuries. I had incurred the knee injuries before the loss of any major amount of sight. As a

result of all this, I was feeling neither stable nor safe in walking on stairs and dealing with changes of elevation. I was also getting to the point that I was not comfortable in walking on the street because I did not know how to respond effectively to seeing only partial bodies of the people coming toward me.

At that time, I was being treated by Dr. Joseph N. Trachtman, who helped me to reduce and virtually eliminate my nystagmus with biofeedback and vision training. Dr. Trachtman suggested that I start studying martial arts as a way to develop an internal sense of balance that was not dependent on sight.

Over the years, I had been exposed to martial arts through friends and I had thought about studying to improve my reflexes. As I started to lose some sight, the speed of my reflexes became an even more important issue. I liked the idea of a physical study that combined quickness of reflexes with the values of honor and responsibility.

By asking around to people I knew and people they knew, I was very fortunate to find Sensei Gerald Orange, a teacher who was willing and actually happy to work with me. I began studying tai chi and American goju karate with Sensei Orange in the Orange Inner Light Dojo in New York City.

Sensei Orange is a major martial artist and a teacher who is not limited to one way of teaching. He takes students as he finds them and brings out what they can do. He taught me how to learn and also inspired me as to how to teach. My knee injuries are still there, but I've learned the best ways to move safely and I continue to learn to do more and more. Through Sensei Orange I learned how to work with and beyond my knee problems. He does not see a difference as a limit but only an opportunity to do something in another way.

This study has been tremendously useful to me. This is particularly so because I have learned by training outdoors. Therefore it is a part of my training to be able to do tai chi comfortably in uneven terrain. This makes it easier for me to walk around in my ordinary life, including walking on snow and ice.

I ride the subway every day. When I first started studying martial arts, my knees were so unstable that I tried to avoid rush hour subways, so as to limit the possibility of getting knocked over or pushed to the side by crowds. After considerable work I can now stand my ground and make my way through any crowd. Also I sometimes ride standing without holding onto supporting bars.

When I had a major drop in sight a few years ago, I was able to make a lot of my adaptations to the sight change through my martial arts study. Today, although I have considerably less sight than when I started martial arts, I am much more comfortable walking on the street and in crowds than I was when I started studying.

I use this experience in my own teaching of empty-handed tai chi and tai chi double-edged sword. In 2002, the National Women's Martial Arts Federation invited me to teach a workshop on "Teaching Martial Arts to People with Visual Disabilities" at its annual meeting. The teaching of most martial artists is mostly by way of physical modeling. As a result most teachers and practitioners do not develop a big vocabulary of detailed verbal instruction for the work they do. Among other things I used a number of techniques to try to teach the participants what it is like to be a visually impaired person in a class. I also showed the participants how many techniques can be described in words.

As a student, I have not had problems in my own dojo [school]. When I've occasionally taken special workshops with teachers whom I don't know, I've almost always been the only person with low vision (or possibly the only one who speaks up about it). I generally tell the teacher first that I don't see well, and that it would be best for me to go to the front of the class and stay there. I also explain what I can and can't see in terms of positions and movements. In a large class, I sometimes use a

monocular, which helps in a limited way. I can't see the entire body of the person making the movements and the movement is frequently gone by the time I've grabbed a hold of it. However I somehow manage. People around me are usually helpful. Teachers seem to respond that if I'm willing to go through the trouble of trying to see enough with the monocular, they will go through the trouble of explaining to me what I'm not getting. Of course, like in most situations people with low vision encounter, there will always be times when you have to make it clear that someone telling you to move "here" or "there" may not mean anything to you.

It takes time to get a lot of the benefits of studying tai chi. However, the effort is worthwhile. The rewards are something to be treasured.

Contact Barbara Friedman by phone: (347) 668-6481 or by e-mail: barfriedma@att.net

Barbara Friedman taught "Introduction to Tai Chi" class at the 2005 ACB Convention in Las Vegas. She is a practicing attorney in New York City, focusing on copyright and employment law. In addition, she also teaches tai chi to individuals and groups, as well as workshops on "How to Move Well With Changing Vision" and "Sight and Sound Awareness".(c) 2006 Barbara S. Friedman

Bioptic Driving Pro and Con

By Dr. Ikan C. Kleerly

Several people that I have run into have asked for my opinion about BiOptic Driving. Actually, I didn't run into them with my car, I ran into them... well, you know what I mean. Arizona just issued the first drivers license to an applicant using BiOptic lenses. This follows a new law passed in January, 2006 allowing the use of BiOptic lenses for driving in the state of Arizona.

Before I confuse you with some of the terms about eye conditions which might be involved with the use of this device, let me confuse you with what is meant by BiOptic lenses.

Back in 1950 William Feinbloom, a Doctor of Optometry, developed lenses he referred to as BiOptic Lenses. He also coined the term "BTS" for BiOptic Telescopic System". This device is a small telescope mounted on the upper portion of the patient's glasses. This telescope has a magnification from two to five power and permits the user to resolve fine details in signs and other road situations. The telescopic lenses are NOT used constantly, but are glanced through momentarily for reference just as the regular driver glances at his rear and side view mirrors.

The BiOptic lens is used only for one or two seconds at a time, not continuously as one might imagine. It is a tool of reference such as the mirror system on the car. There is a warning on most right rearview mirrors indicating that objects may be closer than they appear through this mirror. Likewise the telescopic lens is used to identify a "blur" in the distance--to distinguish an asphalt repair in the roadway from a mini foreign car or a piece of tire that is lying ahead. (It may also be some illegal person who did not quite make it across the highway!)

BiOptic lenses are not for everyone. Experts in Low Vision caution prospective candidates that they must have a strong sense of responsibility in undertaking this kind of driving. They must be willing to voluntarily exercise good judgment by restricting their driving in situations they feel are unsafe. (Hmm, now if we can only get the drunk drivers to assume that same sense of responsibility.)

Some restrictions may be imposed by the issuing department, such as geographic or daylight only. Many other conditions are hazardous in and of themselves. These might include fog, rain, snow and ice. These are conditions that may cause the most expert drivers to have difficulty controlling their vehicles.

Studies have been conducted as early as 30 years ago to determine the minimum acuity necessary to drive safely. Some visual impairments are progressive such as wet macular degeneration whereas others are stable such as albinism which is a genetic condition. Ironically, states such as Arizona and many others issue a drivers license that is valid for 25 years! This is ridiculous! For example, I am 82 years old and have just renewed my license for another 5 years. Certainly, my vision will change within the next 5 years. Folks in Sun City refer to it as an "Aimer's" License! People who are impulsive, emotionally stable, overly aggressive, angry, inattentive, slow to react, substance abusers, risk takers, inexperienced young drivers and elderly are still awarded the license privilege. In my last article I mentioned a gentleman from California who appeared with his white cane at the Department of Motor Vehicles to renew his driver's license; the clerk issued him one without any question. Scarry!

Most licensing agencies want specific information on:

- Corrected and uncorrected visual acuity
- Peripheral visual field
- Stability of eye conditions
- Depth and color perception
- Eye-hand and neck coordination
- Contrast sensitivity, glare recovery and luminance.

A person with decreased central vision needs to be able to compensate for the scotomas. Scotomas are blind spots in the retina. Everyone has a blind spot which is the point at which the retinal nerves enter the optic nerve. This is slightly off from the fovea or point of central focus. You might remember the experiment that is often used with a line that has a break in the middle and an "X" on the end of the line. As you stare at the "X", your eye will make an adjustment so that the line appears to be solid. This is not to be confused with the "blind spot" that every driver experiences due to the rear view and side mirrors not identifying a vehicle near the left quarter panel of his car. (A parabolic mirror fixed on some left rear view mirrors does show that vehicle.) A person with these identified scotomas must compensate for those spots without compromising safety.

Licensing agencies generally evaluate an applicant's ability in speed control, shifting and braking, depth and special perception, steering, use of mirrors, backing up, parking, knowledge of the highway rules and certainly driving courtesy.

Drivers using BiOptic aids must use non-visual cues, keep their eyes moving and alert, check mirrors, anticipate what other drivers will or will not do, be aware and communicate their intentions, follow safely, be cognizant of speed and road conditions, be aware of last resort escape routes, choose a less demanding route and know where they are going, check over their shoulder and all mirrors before changing lanes, look behind as they back up. Even a small child may not be seen from any view regardless whether drivers are fully sighted or using BiOptics.

California began issuing bioptic drivers licenses in 1971. New York followed in 1977. The federal Department of Transportation issued new laws eliminating discrimination of the visually impaired. Indiana joined the group in 1986. Currently there are 34 of 51 legal jurisdictions that allow bioptic driving. Now we can add Arizona.

Indiana seems to have set the standards for bioptic drivers. First, 95 percent of the driving must be through the carrier lens. That is the regular glasses fitted for the

individual upon which the bioptic lens is mounted. Second, objects appear larger and therefore closer through telescopes so users need to demonstrate to specialists their agility in using the lenses. Third, the individual must be able to multitask, able to see through the telescope while still viewing both sides in the peripheral. Fourth, the movements in the telescope can appear jumpy so it takes some adjustment to cope with that issue.

BiOptics range in power from 2x to 5.5x. Some states permit only the lower power, although Indiana permits a special 5.5 under special conditions. The potential driver with bioptics undergoes specialized training to spot stationary objects when he is stationary, moving objects when he is stationary and when he is moving and moving objects when he is moving. He also needs to adjust to the differing rates of movements whether in the same or opposite direction as his travel and the rates of travel as traffic approaches or crosses his route of travel.

Some day I may invest in those things. But for now I will continue to have my wife sitting on the hood and shouting back directions to me.

The above article and the following article were first published in Dialogue Magazine, January-February, 2006. Dialogue is published by Blindskills, Inc., P.O. Box 5181, Salem, OR 97304-0181; Phone: 800-860-4224; E-mail: info@blindskills.com; Web site: www.blindskills.com. For a free sample copy of Dialogue or information about other publications offered by Blindskills, Inc. contact the office directly.

My Cup Runneth Over **By Jeff Weddle**

Reprinted with permission from Dialogue Magazine.

The wedding was fine, and by "fine" I mean, short. Afterwards, we all headed across town to a swanky hotel for the reception.

Tables were decorated around the outside of the dance floor and we took our seats expectantly awaiting our free food--the main reason people go to receptions. The only visible edibles, however, were rolls.

I ate a few. The rolls were pretty good but they were making me thirsty. "I need a drink," I said to my wife. Just then, the lights in the room dimmed as everyone was seated and ready to eat.

"I think you have to go up and get your own drinks here," she answered. Oh no! I'm pretty sure no one saw the look of panic that ripped across my face and I'm quite confident no one heard my heart beating, but I felt it. I thought the dance music had started.

"Want to go get one?"

"Um, I don't know. I guess I'm not that thirsty all of a sudden." That was smooth, dodged that bullet, but the inevitable came about 20 minutes later.

"Jeff, I'm thirsty. Let's go get some drinks."

"Why don't you go?" I suggested deftly. "Grab me a soda while you're up there."

"What? Just come up with me."

This was silly. Why was I afraid to go up and get a drink? Suck it up big man, I told myself. I got up, put one foot in front of the other and followed my wife up to the drink table.

Horror of horrors! All the drinks were in coffee-pot-style containers with the tricky lids. The kind where you don't know if you're supposed to twist, push, pop or just tip to get the drink to come out. Even worse, they had little tiny signs by each pot telling us what was in it. With the lights dim, they all looked very exotic to me.

I tentatively grabbed one that looked soda-like and tipped it. Nothing happened. I pressed the top and still nothing. My palms began to get sweaty--huge lines were forming behind me--I started freaking out. I twisted the top off and tipped the pot. Oh come on! What, is this thing engineered by NASA? Then something gave and the drink came forth, it filled my cup, two sugar bowls and soaked a few hundred festive napkins.

"Ah, that's how that works," I nervously laughed to the frowning woman behind me.

"No, actually, you twist it to the right like so and it comes right out."

"Oh, sure enough, they should put directions on these things."

"Actually, they did," she explained as she pointed to directions, which still remained invisible to me.

After navigating the series of trip wires and booby traps (otherwise known as chairs) I sat down next to my wife, or at least, a woman who looked strikingly similar to my wife.

"Oh there you are. What took so long?"

"Some dumb guy up there was spilling drinks all over," I scoffed.

"What did you get to drink?"

"Just this stuff here," I said.

"You don't even like pineapple kiwi punch."

Oh good Lord. "Well, like I said, I'm not that thirsty."

Later that night I explained to my wife the anxiety I have about pouring drinks in public. She had no idea, and this is my wife! There probably isn't a person who knows me better than my wife, but even she can't read my mind!

One of the problems blind folks have is that people who can see have no idea just how difficult life can be when you can't see well. People who can see take it for granted. They don't think twice about pouring a drink. They aren't being rude, they just never consider it.

If you need someone's help you have to tell them. Ever since then my wife has asked if I would like her to get the drinks. Wonderful! She never would have known this if I hadn't told her.

Weddings are still painful, but at least now I can have a drink I actually like. People can use dry napkins now too, which is an added joy.

The above article was first published in Dialogue Magazine, January-February, 2006. Dialogue is published by Blindskills, Inc., P.O. Box 5181, Salem, OR 97304-0181; Phone: 800-860-4224; E-mail: info@blindskills.com; Web site: www.blindskills.com. For a free sample copy of Dialogue or information about other publications offered by Blindskills, Inc. contact the office directly.

Advocacy

Advocate's Alley--Opening Doors When Opportunities Knock

By Ken Stewart

In an article I recently prepared for Dialogue Magazine, I speculated that the nicely contrasting black color of the bicycle racks appearing on Manhattan sidewalks may have been influenced by my input years ago. As naive or grandiose as that thinking may be, it does continue to motivate me.

In just nine calendar days, I responded to a total of six separate opportunities to advance advocacy causes.

On Monday, I conducted a session at the Annual Meeting of the Association of Towns of the State of New York. With local governmental officials, we discussed ways of "reasonably" accommodating the special needs of people with disabilities related to programs, services and facilities. A combination of incidental factors brought only a handful of the 2,500 attendees to my session, but I am hopeful that a precedent has been set and that next year we'll do it bigger and better.

For the rest of that day and the next, I tried to educate local officials through one-to-one conversations--like the one with an upstate Town Assessor, a tablemate at the conference breakfast.

The following day I took the microphone at a public forum to both compliment and encourage the President of the Long Island Railroad. I cited many things the busiest commuter railroad in the country does to aid travelers who depend on audible information. And, he was receptive to my request that on-board announcements include identification of the specific platform number on which the train is terminating. The approach which I 'acronymize' as "TATL-Tales", for Terminal Arrival Track Location, is already being instituted on the L.I.R.R.'s sister rail lines which operate northward out of Grand Central Terminal.

The very next day I pontificated on several issues at the monthly meeting of the Transit Riders Council which is a statutory body representing consumer interests to New York City's subway and bus system. From that meeting, I headed directly to the Federal Courthouse where civil litigation is creeping forward on the non-compliance by bus operators announcing stops. After the suit was filed in 2003, the Transit Authority's statistics show compliance has risen from under 40% to about 55%.

After several intervening days pursuing professional responsibilities as an arbitrator for the securities industry and as a hearing officer for public school districts, I had one more opportunity to spout the perspective of people with low vision who use public transportation. While attending the annual Transportation Leadership Awards ceremony at New York University, I talked with a member of one of the private consulting firms which do design work for governmental agencies. Typically, these professional engineers reveal little awareness of what makes a county road or an urban intersection more or less usable by a pedestrian with limited vision. But, they are also typically "all ears".

Science and Health

Questions about Medicare Part D

Medicare Part D has raised many questions. Some of these are: Which plan will cover the medications I use? What can I do if a newly prescribed medication is not on my Medicare private drug plan's formulary? Is there any way to lower the cost of my co-payments? What is the best time of the month to enroll in Medicare Part D? These questions were submitted to the Medicare Rights Center. Here are the answers.

Which plan will cover the medication I use? Medicare private drug plans are not required to confirm coverage of specific medications over the phone. Plans must post a current, shortened list of covered drugs (formulary) on their web site--updated at least monthly--and must mail their abridged formulary to anyone who requests it.

The abridged formulary must include at least two drugs in each drug class, even if the plan covers more. Formulary information must also indicate if the plan places certain restrictions on coverage of particular drugs, such as prior authorization, step therapy and dosage limits, but it does not have to explain how these restrictions work.

Only currently enrolled members have the right to get the entire formulary mailed to them upon request.

In addition to formulary information, plans must provide information to their members and prospective enrollees about their service areas, benefits offered under the plan, cost-sharing amounts (the amount they will charge you), transition policies, pharmacy network, appeals and grievances, and any other aspect of coverage.

This information must be provided in writing at the time of enrollment and annually after that, and it must also be available in writing upon request and on the plan's web site. The plan must also operate a toll-free number during business hours and be able to give you this information. In addition, plans and pharmacists are required to tell you if you could save money by using a generic drug.

What can you do if a newly prescribed medication is not on your Medicare private drug plan's formulary?

There are a couple things that you can do. First, you should ask your doctor if any of the drugs covered by the plan would work for you. If so, ask for a new prescription for that drug.

Second, if your doctor feels that only the drug originally prescribed will work for you, you should file an exception request.

You have the right to an exception to the plan's formulary (list of covered drugs) when

- 1) your doctor prescribes a drug not on your plan's formulary because your doctor believes the drugs on the plan's formulary will not work for you or
- 2) you are using a drug covered by your plan, but that drug is removed from your plan's formulary for reasons other than safety.

You generally cannot file an exception request at the pharmacy. You must call your Medicare private drug plan directly to request an exception. (You, someone you appoint, your legal representative or your prescribing doctor can file an exception for you.)

Your doctor will have to submit an oral or written statement certifying that the drug prescribed is medically necessary because other drugs are not as effective or may be harmful for you.

Generally, plans must grant these requests when they determine that it is medically appropriate to do so. Plans must respond to your request in writing within 72 hours or sooner if your health requires quicker attention.

You can also ask for a faster response (an expedited request) when your "life, health or ability to regain maximum function" is in jeopardy. (Plans must expedite exceptions if your doctor certifies that such action is necessary for your health.) Plans must respond to expedited requests within 24 hours or sooner if your health requires such immediate attention.

If a plan grants your request, it determines what your co-payment will be for that drug. The plan must continue to cover refills at that co-payment for the rest of the calendar year as long as the doctor continues to prescribe that drug, and it continues to be safe. It is up to the plan to decide whether you have to file a new exception request for that drug the next calendar year (if you renew membership.)

If your Medicare private health plan denies your exception request, you can appeal the plan's decision to Medicare. Notes:

You cannot ask for an exception for drugs specifically excluded from Medicare coverage by law.

You can request an exception to get a lower co-payment for a drug assigned to a higher-cost tier that is already included in your drug plan's formulary. But if you had to request an exception to get your plan to cover your prescription, you cannot then file a second exception to get a lower co-payment for that drug.

You can request an exception to other coverage restrictions, such as dose and dosage limitations, substitution requirements and step therapy.

Is there any way to lower the cost of my co-payments? Yes there are a number of things you can do to try to lower this cost. One option is to try mail order if your drug plan allows that. Mail order can often be cheaper than buying at the local pharmacy.

You should also talk to your doctor. He can ask if there are generic or cheaper brand-name versions of the drugs you are taking that are covered by your plan. That could lower your out-of-pocket costs a lot.

If your doctor believes no other covered drug will work for you, you have the right to ask your Medicare private drug plan to lower your co-payment for that drug. You can also do this if the co-payment is suddenly raised for any covered drug you have been using.

By asking to lower the co-payment, you are asking the plan to change the "tier" that the drug is assigned to in the plan's list of covered drugs (formulary). Most plans have different cost-sharing tiers. Lower tiers have lower out-of-pocket costs and usually include generic versions of the drugs. Higher-tier drugs will cost you more because they generally include the more expensive brand-name drugs.

You can ask your plan to lower your co-payment by filing an exception request. This works in much the same way as a request to have the plan cover a drug that is not on its formulary. For more information about how to ask for a lower co-payment, check your individual plan—each plan will create its own process. In all plans, however, you will need your doctor to certify that only that drug will work for you.

What is the best time of the month to enroll in Medicare Part D?

Generally if people with Medicare enroll in a Medicare drug plan at the beginning of the month, they will be able to get the most out of their coverage, from the first day it is effective. Enrollments early in the month give Medicare and drug plans time to update their systems and mail membership cards, acknowledgement letters, and welcome packages to enrollees before their coverage becomes effective. In these cases, if people with Medicare go to the pharmacy on the first day of coverage, they can get their prescriptions quickly and accurately.

Enrollments later in the month make it far less likely that all of the information needed to file the claim correctly will be available at the pharmacy or the plan. People who enroll late in the month and need to fill prescriptions but have not yet received a membership card should take to the pharmacy whatever documents they have received from Medicare Part D or a welcome letter from the insurer.

Breakthroughs in Treating Macular Degeneration

An interview with Thomas Ciulla, M.D.

By Patrick Perry.

Reprinted with permission from Saturday Evening Post January/ February 2005,
www.saturdayeveningpost.org

"I didn't know what was happening," recalls 75-year-old June Simmons, who first noticed symptoms of age-related macular degeneration (AMD) in 2000. "Everything began to look funny, people weren't straight, appearing at odd angles, and cars had curves where there really weren't any."

During a trip to Wal-Mart, she dropped into the optical department. "I thought perhaps I just needed stronger glasses," the outgoing and active senior recalls. "But the optometrist thought I had macular degeneration in my left eye, so he referred me to a retinal specialist."

The specialist confirmed the diagnosis, suggesting that June undergo photodynamic therapy (PDT), which she underwent in her hometown of Springfield, Illinois.

Unfortunately, June soon began noticing changes in her right eye.

"I came home on Friday night and everything was fine," Simmons says. "But on Saturday morning, I got up and picked up the newspaper and didn't know what was going on. Overnight, I was unable to read. So I returned to my ophthalmologist and underwent more PDT treatments."

The computer-savvy senior began to resign herself to the possibility that she might eventually lose her sight. An avid reader and amateur artist, June sank into depression, hiding her tears from family members.

By chance, she was listening to the television when she heard about a new trial for AMD.

"Dan Rather was on television, talking about the new trials for macular degeneration, so I got on my computer and went to clinicaltrials.gov to find the companies involved in trials," she relates. "That is how I first learned of Dr. Thomas Ciulla and the Midwest Eye Clinic, which was one of the trial sites listed. I immediately called and talked to the coordinator, who told me to come to Indianapolis."

After initial examinations and follow-up visits, Dr. Ciulla admitted June to the trial. She received the first treatment in October 2003. Because the trial was blinded, the patient does not know if the active agent was used. June, however, reports significant improvement in her vision.

"Before I went into the study, I saw a low-vision specialist. At that time, my vision was 20/300," Simmons remembers. "Last month, it was 20/32. I still can't believe it." She has resumed driving and reading her favorite mystery novels.

June is one of many patients enrolled in ongoing trials of emerging and promising new treatments for macular degeneration. An unpredictable disease that destroys the macula, age-related macular degeneration affects more than 13 million adults and remains the leading cause of blindness in the United States. Until recently, few effective treatments were available.

To learn more about promising treatment options under investigation, the Post spoke with ophthalmologist Dr. Thomas A. Ciulla, an investigator in the ongoing trials and a highly regarded expert and author on AMD.

Post: What is the difference between normal aging of the eyes, with progressive difficulty in reading, and AMD?

Dr. Ciulla: Macular degeneration is a very specific condition in which we see the formation of yellow deposits, called drusen, under the retina and changes in the pigment cells that nourish the retina. Patients with aging eyes may not see well for many reasons, including cataracts. While AMD obviously can occur as we age, growing older does not automatically mean that one will develop AMD.

Post: What breakthroughs do you see that will offer hope to people with AMD?

Dr. Ciulla: We're on the cusp of many exciting breakthroughs with a host of new drugs on the horizon. Previously, we used treatments that were "destructive" to treat AMD. For example, we would laser a patient's retina to stop wet macular degeneration from progressing to the center of the retina. Laser is a fancy way of cauterizing or destroying tissue. Often, laser causes a blinding scar, and in at least half the patients it didn't work; blood vessels would continue to grow, sometimes more vigorously. Recently we've learned that certain growth factors, such as vascular endothelial growth

factor (VEGF), are responsible for new blood vessels under the retina. We're now developing several drugs that target VEGF to prevent blood vessels from growing or expanding. Within the next few years, several drugs will hopefully be approved and available for general use, including three new drugs currently in phase III trials, as well as other drugs that are in earlier phases of trial.

One drug in phase III trials made by Genentec is called Lucentis (ranibizumab), an antibody fragment injected in the eye that is designed to bind to and inhibit VEGF.

Another medication in phase III trials is Macugen from Eyetech and Pfizer. Macugen is an anti-VEGF compound that binds to and thus inhibits the activity of VEGF when injected in the eye.

Finally, Retaane (anecortave acetate) made by Alcon, also in phase III trials, is a novel steroid derivative that is injected around the eye.

In addition to these exciting drugs, we continue to study the role of radiation to potentially decrease the growth of abnormal blood vessels, and clinical trials in the area continue.

I suspect new medications, including Lucentis, Macugen, and Retaane, will be approved within the next two years.

Currently, if patients present with blood vessels already in or very close to the center, we use a treatment called photodynamic therapy (PDT), which involves a drug called Visudyne (verteporfin). In a retina specialist's office, Visudyne is infused much like intravenous therapy. Several minutes after infusion, the drug is activated in the eye using a low-energy laser. The activated dye will then close leaky blood vessels. Many patients will need to be re-treated every three months or so. From studies, we know that patients on average will need three treatments during the first year, two in the second year, and one in the third year. Again, the treatment does not restore vision, but it slows progression of AMD.

Today, a drug called triamcinolone acetonide is available. Although not yet approved for the eye, the steroid is the same drug that orthopedic surgeons inject into patients with joint inflammation.

We have learned that we can inject the drug into the eye, and it will stop or delay the progression of AMD. Several studies are looking at triamcinolone injected in the eye as an adjunctive treatment to PDT with Visudyne. I currently offer the treatment to my patients, and it works fairly well. Although no large randomized prospective trial has yet been conducted, one will take place shortly.

Post: Have other patients in clinical trials reported positive results?

Dr. Ciulla: We are involved in several clinical trials with these new drugs that usually involve injection in or around the eye. The studies are double-blind, so I do not know who is receiving the active drug agent. Several patients experienced incredible improvement in or stabilization of vision, and I'm hopeful that these patients are getting the active agent. Some have come into my office ecstatic, thanking me profusely for the benefits. Several of these patients have lost vision in one eye from wet AMD, so they have already experienced vision loss. Obviously they are frightened

because if AMD affects their good eye, they lose virtually all independence.

Post: How can people enroll in trials?

Dr. Ciulla: If interested in learning about the trials, visit www.clinicaltrials.gov, or these company Web sites: Alcon (alconlabs.com) for Retaane; Genentec (genentech.com) for Lucentis; and Eyetech (eyetech.com) for Macugen.

Post: Can these new drugs be used to treat other eye disorders, such as retinal vein occlusions?

Dr. Ciulla: VEGF is potentially the key growth factor in macular degeneration because it mediates the growth of abnormal blood vessels. Many other eye diseases involve abnormal blood vessel growth in and under the retina. Diabetic retinopathy, for example, involves the growth of blood vessels not under the retina, as is the case in AMD, but on the surface of the retina and into the vitreous cavity. When blood vessels are pulled, they can tear. As they tear, blood is released into the vitreous cavity, and many diabetics will have hemorrhage into the eye. These drugs may be beneficial for diabetic retinopathy.

Post: Could you discuss novel methods of drug delivery?

Dr. Ciulla: Many drugs are delivered locally, either in or around the eye. This is a very important advance in ophthalmology for retinal diseases because many drugs have a variety of toxicities. Steroids, for example, pose many side effects. By injecting steroids in or around the eye, we avoid many potential systemic side effects.

Also under investigation is a sustained-release delivery device implanted in the eye that will release a drug over many months and potentially years. If successful, patients with AMD may only need to undergo one or two procedures during their lifetime.

Post: Are injections in and around the eye painful?

Dr. Ciulla: Injections are minimally painful, if at all. Every precaution is taken to insure that the eye is appropriately sterilized and anesthetized prior to the procedure.

Post: What is the benefit to the early detection of AMD?

Dr. Ciulla: Previously, early diagnosis may not have mattered much because we had such a limited number of treatments that did not work well. Now we have a number of new treatments, and it's very important to diagnose and treat patients before central scarring occurs. Scarring may lead to irreversible central loss of vision. We can potentially use laser treatments, photodynamic therapy, or consider them for enrollment into one of our ongoing trials.

In addition, we want to diagnose patients with non-exudative, or dry, AMD early to educate patients on how to modify risk factors, such as smoking, hypertension, obesity, light exposure, and so forth.

Post: Does AMD tend to occur in both eyes?

Dr. Ciulla: Macular degeneration is generally a bilateral condition. Patients may develop drusen in both eyes initially, but one eye may be worse than the other. Subsequently, one eye can progress to the wet form of the disease. Years later, the other eye can perhaps progress to the wet form of the disease as well.

Post: Is this an exciting time for you as a specialist in macular degeneration?

Dr. Ciulla: This is a very exciting time for retinal research. When I started eight years ago, retinal and vitreous diseases were largely surgical disorders. Many of these diseases had poor prognoses, and many patients lost vision regardless of what we did.

Now we're on the horizon of a very exciting time with many novel drugs to potentially treat AMD, diabetic retinopathy, and venous occlusions--among the leading irreversible causes of blindness.

Assistive Technology Freedom Scientific Announces New Portable Video Magnifier

Freedom Scientific announced the new OPAL ultra-portable video magnifier. This new product offers powerful features for low vision users on-the-go.

The OPAL contains a small camera and displays images on a brightly lit four-inch screen. The magnification level can be varied from 3x to 6.4x with a sliding fingertip control while the unit rests firmly on a document. The ultra-portable design allows the OPAL to be easily slipped into a coat pocket or purse so it is ready for use at any time. Use the OPAL to verify a prescription at the pharmacy, read the menu at a restaurant, fill out a check at the bank, read item labels at the grocery store, and much more.

Like the TOPAZ desktop video magnifier, the OPAL features simple, ergonomic controls. Simply turn it on with a push of a button, place it on an object or document, and use the zoom slider to adjust the magnification for the best reading comfort. A single button can switch between seven different viewing modes - indoor and outdoor full color modes and five contrast modes for reading text.

One of the unique features of the OPAL that really sets it apart is the ability to connect it to a TV or computer to take advantage of the additional magnification afforded by the larger screen - up to 32 times on a 20-inch TV.

The OPAL is priced at \$795 and will be available for purchase in March. For more information including specifications, contact Freedom Scientific at 800-444-4443 or 727-803-8000. <http://www.freedomscientific.com/>

Introducing the Clarity Carrymate!

Clarity announces the release of their most portable video magnifier. See <http://clarityusa.com/carrymate.html>

This ultimate portable video magnifier is able to fit any lifestyle. The self contained system offers more than 6.5 hours of battery life with over 11 inches of viewing space and only weighs 10 pounds.

The Carrymate is an ideal compact design that will fit easily into any work space from a desktop to a countertop. The internal rechargeable battery powers the product for over 6.5 hours. You just turn on the Carrymate and its ready when you need it anywhere anytime.

If you need magnification to match your active lifestyle then the Carrymate is the system for you. The system boasts an 11.3" viewing screen, self contained battery, and high powered camera. You can use the carrying case or the attached handle for your traveling convenience.

Like all Clarity products, the Carrymate is backed by their lifetime warranty (one year for internal batteries) and our excellent customer service. Every Clarity system is individually handcrafted in the USA.

Please contact Clarity or your local Clarity representative for more information or an in-home demonstration. To locate your local Clarity representative visit www.clarityusa.com. Douglas Gerry, Sales Director, Clarity, Voice: 775.782.5611 Ext 207, Fax: 775.783.0966, www.clarityusa.com

New Talking Dictionary

Talking Dictionary is a speech enabled 250,000 word English dictionary and thesaurus. Talking Dictionary has been designed for use by the non sighted person. All of the controls are easily remembered keyboard shortcuts and it is a very fast and easy to use program.

Talking Dictionary is designed to be used as a stand alone program. What this means is that you do not need any kind of screen reading software or anything else to use this program. Your PC must run Windows 95 or greater and you must have a sound card or speakers. Talking Dictionary has been tested on Windows 95, 98, 98 SE, Windows Millennium Edition, Windows 2000 and Windows XP.

Talking Dictionary has many features, such as a powerful spell checker and the ability to quickly scroll through various word definitions and synonyms.

The dictionary also comes complete with a "getting started" tutorial which gives you examples of using the dictionary. Comprehensive help is also built into the product.

This highly versatile encyclopedic talking dictionary retails at \$39.00, a price inclusive of postage and handling. This dictionary may be purchased through <http://rwfts.com>

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

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

Clarity
www.clarityusa.com.
Douglas Gerry, Sales Director,
775.782.5611 Ext 207

Dialogue Magazine
Blindskills, Inc.,
P.O. Box 5181, Salem, OR 97304
800-860-4224
info@blindskills.com www.blindskills.com

Freedom Scientific
800-444-4443
www.freedomscientific.com

RWF Talking Software
www.rwfts.com

Council of Citizens with Low Vision International
An Affiliate of the American Council of the Blind
2006 Membership Application

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 _____

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

703 642-1909 h

703 578-6513 w

703 671-9053 fax

pbeattie@nib.org

1st Vice President Bernice Kandarian (04-06, 2nd term)

2211 Latham Street, #120

Mountain View, CA 94040-1652

650 969-1688 h

bernice@tsoft.net

2nd Vice President Coletta Davis (04-06, 1st term)

2879 East Alden Place

Anaheim, CA 92806-4401

714 630-8098 h

714 666-2494 fax

coletta@fea.net

Secretary Carolyn Hathaway (04-06 1st term)

4831 Dueber Avenue SW

Canton, OH 44706-4296

330 484-3807

carolynmu@sbcglobal.net

Treasurer Mike Godino (04-06, 1st term)

104 Tilrose Avenue

Malverne, NY 11565-2024

516 887-1336 h
mikeg125@optonline.net

Past President Ken Stewart (02-??)
34 Points of View
Warwick, NY 10990-2431
845 986-2955 h
212 664-1038 h (mid-week)
cclvi@yahoo.com

Directors

Lisa Boettcher (04-07, 1st term)
3608 South Blue Cedar Lane
Columbia, MO 65203-6614
573 445-5544
lwb6c9@mizzou.edu

William Burgunder (*05-06 partial term)
623 Berkshire Ave
Pittsburgh, PA 15226-2041
412 531-6876
waburgunder@earthlink.net

Kathy Casey (*05-08 1st term)
1 Twiller Street
Albany, NY 12209-2127
518 462-9487 h
kcasey03@nycap.rr.com

Edwin Druding (05-08 1st term)
7628 N 49th Ave
Glendale, AZ 85301-1512
623 937-1211
drdruding@cox.net

John Horst (05-08, 1st term)
249 Holly St
Elizabethtown, PA 17022-1621
717 367-6328
pcb1@paonline.com
jjkhor95@epix.net

Jane Kardas (*03-06, 2nd term)
810 Maple Avenue
Ukiah, CA 95482
707 468-5510 h/fax
janecalvert35@yahoo.com

Barbara Milleville (04-07, 1st term)
2712 Livingstone Lane #103
Vienna, VA 22180-7264
703 645-8716 h

bmilleville@mindspring.com

Fred Scheigert (04-07, 3rd term)
123 South Pitt Street
Alexandria Virginia, 22314-3111
703=5491458h
fredScheigert@comcast.net

WEINGER, JERRY (03-06, 1st term)
CHERRY HILL, NJ 08003-5123
215-735-5888h
jnweinger@comcast.net