

VISION ACCESS

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by

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

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From the Editor

Happy springtime! Yes, despite the challenges, losses and darker side of life with low vision, we can be happy. Studies have shown that even people with chronic health problems are often happier than people who do not face similar medical concerns and obstacles. I certainly hope that the information, personal sharing and support in the

pages of Vision Access will make it more possible for you to realize whatever it is that will make your life a good one for you.

Thanks to all who contributed articles and ideas to this issue of Vision Access. Please share your ideas and experiences with us. JMK, 4/2/05.

Organization News

From the Desk of the President:

Patricia Beattie

CCLVI's Upcoming Las Vegas Convention: Reaching Out to People of all Ages with Vision Loss

The leadership of CCLVI probably will be in Las Vegas for a week or more, but we hope that you will join us for at least some of the exciting program sessions we have planned. Our annual CCLVI convention is held in conjunction with the American Council of the Blind (ACB) which with its state and national special interest affiliates will be sponsoring tours, provocative and informative program sessions, and social events beginning with opening of the exhibit hall on Saturday, July 2.

If you haven't received your large print pre-registration packet via mail, contact the ACB National Office at (202) 467-5081 or 1-800-424-8666.

This year, we've been reaching out and some of our CCLVI program sessions are being co-sponsored by other organizations - including the Council of Families with Vision Loss, the National Alliance of Blind Students, and National Association of Parents of the Visually Impaired.

We get rolling on Sunday morning, July 3, with a co-sponsored session which has two major sessions. At 9 a.m., hear from a quartet of folks with vision loss who decided to "get involved". They include a woman who will tell us how she decided the question of how to present herself as a person with impaired vision - blind? Cane? Dog? Other? We'll also hear from a guy who sued the American Contract Bridge Association because they refused to adopt a deck of playing cards he designed which can be used by people with low vision. A visually impaired teacher will share her efforts to get her visually impaired students the appropriate educational services they need. Our fourth panelist will encourage us to try the martial art of tai chi to improve our balance - it worked so well for her, she's teaching it now in New York City.

On Sunday afternoon, First Vice President Bernice Kandarian will help you discover what's in the exhibit hall of particular interest to people with low vision, followed by our traditional "mixer" where Chairperson Carolyn Hathaway will serve great cheese, meats, and shrimp with beverages included in the price of admission. And we'll host conventioners from across the country and around the world at our opening "Welcome to Las Vegas Dance" featuring the ever-popular music of Gordon Kent for dancing and listening pleasure. (He'll be featured again at the close of the convention on Friday night with a "Fare Well to Vegas" dance.

There is more collaborative programming, however, earlier in the week, especially on Monday afternoon. We'll take a look at family members living with our vision loss and then tackle the problem of financing higher education for yourself, your kids or your grandkids. Our own scholarship winner, Lisa Boettcher, of the University of Missouri in St. Louis will share her extensive knowledge of where the money can be found for the basic college degree or - even more elusive - graduate study or research.

On Wednesday, we'll have a chance to try a little tai chi with Barbara Friedman, an instructor who herself has low vision, and then come together for our traditional CCLVI

model support group. We've invited Carlos Gourgey to facilitate this popular session again this year.

Coletta Davis is planning our annual Game Night on Wednesday to include "Battle of the Sexes", "The Price Is Right", snacks and a cash bar (Our dances also will have a cash bar). And our editor, Joyce Kleiber, has held up this issue of Vision Access in order to include more details of our convention plans. If you can't make it to Las Vegas for at least part of the activities July 2 through 9, watch for her informative reports in the next issue of Vision Access.

One-upsmanship By Bernice Kandarian

Thanks to all of you who renewed your CCLVI membership or joined for the first time! When the deadline for submission of the membership list to ACB arrived, we had one more member than we had last year. Some additional memberships trickled in after the deadline -- enough that we could have had an additional vote this summer at the ACB convention if they had been in sooner. There was a time when these stragglers would not have mattered, because we had enough members to "top out" on affiliate votes. At one time we had over two thousand members. If an affiliate has 625 or more, it receives 25 votes. Now we have only eleven votes. I would like to see us move back toward the twenty-five vote maximum. Thus, you are all officially deputized as membership representatives to bring in new members in time for next year's deadline February 15.

Meanwhile, if you want to change formats for Vision Access or if your contact information changes, please call me on the toll free number, 800 733-2258. Vision Access is available in large print, cassette or email.

Thank you!

News from CCLVI Chapters

Delaware Valley Council of Citizens with Low Vision.

We celebrated the holidays with a visit to a restaurant in Philadelphia's Chinatown. In April a representative of HumanWare, Carroll Stone, came to our meeting to demonstrate MyReader and other products.

For information about our chapter call 215-735-5888.

METROPOLITAN COUNCIL OF LOW VISION INDIVIDUALS

Installation of Accessible Pedestrian Signals continues to be a top advocacy priority of the Chapter. A demo unit from the Polara Company was once again displayed at the December Chapter meeting. And, the Metro Council took a leadership role in responding to the interest shown by the N.Y.C. Council's Transportation Committee. Following is the text of remarks submitted at a February 17th Committee public hearing in City Hall. "Intro. 19" was the name of the specific legislation the Committee was considering that day. Particularly significant was the wide spectrum of groups brought together by the Metro Council for this effort.

PUBLIC HEARING REMARKS- It is commendable that the City Council is attentive to the needs of pedestrians at street intersections. This particular proposal however, while quite well-intended, is flawed in several significant ways. It describes

obsolete technology. It identifies beneficiaries too narrowly. It misstates benefits. And finally, it goes too far into ministerial detail better drawn from federal regulation, industry 'Best Practice', and consultation between the Department of Transportation and stake-holders.

INTRO. 19

First and foremost, "audible" devices are no longer the best way to provide non-visual pedestrian information. The current technology, referred to generally as Accessible Pedestrian Signals ("APS"), provides WALK sign information in tactile as well as audible format. An APS can inform anyone who, for any reason, is not getting the visual information. And, it provides it with a minimum of intrusiveness into the streetscape. Its vibrating arrow also is a directional aid.

This latest generation of signal technology thereby assists not only the vision impaired population, but deaf-blind travelers, pedestrians who are momentarily blocked from the visual sign, and, those distracted or inattentive to the signalized conventions of the intersection. Areas of the world where these APS devices are already commonplace, like Canada, New Zealand, Scandinavia and Austria, find that they are useful to a wide variety of members of the general public.

On the other hand, while the beneficiaries are many, the benefits are not, contrary to Intro. Nineteen's text. Neither these signals, nor any pedestrian signals, tell people when it is "safe" to cross the street. Safety must be left to pedestrian judgment. No WALK signal, whether visual or non-visual, should ever be represented as a sign that a street crossing will be safe, only that it is authorized. The APS simply furnishes information, the status of the signal phase.

Intro. 19 requires priority to heavily traveled intersections, but in actuality, heavy pedestrian/vehicle usage reduces the need for signal information. Rather than specifying details of where APS's should be installed, and what they are like, legislation would be most helpful if it supports the Department of Transportation's efforts to- respect federal ADA Guidelines, 'Best Practices' in traffic engineering as expressed in the Manual on Uniform Traffic Control Devices ("MUTCD"), and, the products of consultations with pedestrian groups. DoT is now doing just that, and that is very encouraging. Also, formal Accessibility Guidelines under study and development at the U.S. Access Board since 2000, are likely to be finalized before the end of this year. In the meantime they, along with the MUTCD, clearly identify specific characteristics of acceptable pedestrian signals.

PEDESTRIAN CONSENSUS

On February 3rd in preparation for this public hearing, a variety of stake-holder organizations met to discuss this subject. There was unanimous agreement that-

- (1) Henceforth every newly signalized pedestrian crossing in the City of New York should receive the infrastructure necessary for the immediate or eventual installation of Accessible Pedestrian Signals,

- (2) Any pedestrian crossing already signalized, should receive Accessible Pedestrian Signal infrastructure when it is renovated, modified, or updated in any other way, and

- (3) The installation of Accessible Pedestrian Signals on City pedestrian crossing should move forward as rapidly as possible with no limitation set on numbers or target date.

The organizations represented at the February 3rd meeting were; the American Council of the Blind, the Council of Citizens with Low Vision International, the Disabilities Network of New York City, Lighthouse International, the National Federation of the Blind, the Queens Independent Living Center, and Transportation

Alternatives. Guide Dog Users, Inc. has also expressed enthusiastic support for Accessible Pedestrian Signals.

SOURCES OF OPPOSITION

While opposition to the presence of APS's on City streets has diminished in recent times, the specific objections heard in the past from those voices, should be acknowledged and answered. (a) "Loud buzzing or voice announcements are annoying to people who live or work nearby." The old audible devices depended upon widely projected and ambiguous sounds. Current technology is designed to be heard only within a few feet of each device. Indeed, that is how they convey only information about the adjacent specific crosswalk. And, the device responds to ambient noise levels, so it is even more quiet when the traffic noise is low. (b) "Audible announcements distract or interfere with listening to other important sounds like traffic movement". See above. Also, the preferred APS programming provides information without a spoken voice except when deliberately requested by a button push. (c) "It is expensive technology". With the appropriate infrastructure present, installations are quite modest in cost. Further, most of the cost of the devices can be funded from either of two federal programs. (d) "Audible signals are a symbol to the general public of the erroneous notion that blind people cannot travel independently." There is increasing evidence that a wide range of pedestrians gain helpful information when it is presented in alternate formats.

CITY COUNCIL ACTION URGED

The City Council's immediate and affirmative action with respect to Accessible Pedestrian Signals, is urged. The recent responsiveness of the Department of Transportation should be encouraged and assisted in every possible way.

Respectfully submitted,
Kenneth L. Stewart, President
Metropolitan Council of Low Vision Individuals

National Capitol Citizens with Low Vision

Skip Sharpe once again hosted our Holiday Party at the VFW Hall in Wheaton, MD complete with DJ and munchies. All Washington DC area ACB members are welcome so it is a great place to network. Those who attended had the chance to catch up with old friends and meet new ones.

In January, Rich Krafsig from HumanWare Group demonstrated myReader. MyReader is a new type of video magnification system that has the ability to take a digital photo of anything under the camera. Once the photo is taken, it can be magnified, enhanced, and displayed in numerous ways on the flat panel screen. Pages can be reformatted to allow for easier reading. We liked that it folds up making it much more transportable than other CCTV's. But the best part is that there is no XY table so you no longer have to worry about physically moving the document. Rich reported that studies have shown that myReader significantly increases reading comfort and reduces fatigue, allowing you to enjoy reading for extended periods. Anyone in the market for a new video magnifier must take a look at this!

For further information about our NCCLV Chapter, please call Barbara Milleville at 703-645-8716.

Scholarship Announced

The Barry and Velma Berkey Scholarship will be awarded annually to a blind or visually impaired full-time student attending George Mason University for the 2005-2006 academic year. The scholarship will be awarded to a student interested in one of the following academic careers: teaching, social work, music, journalism, or nursing.

Applicants must register for a full time course load (12 semester hours) for both the fall 2005 and spring 2006 semesters. Applicants must also have a "B" average whether a new incoming freshman, a returning student at GMU or transfer student. Applicants will also be required to provide an ophthalmologist certification of visual impairment. In order to be eligible, a candidate's vision must be 20/80 or less. Applicants must be US citizens. This scholarship is renewable if all above criteria are met. The deadline to apply for this scholarship is May 26, 2005. For more information, please contact Deborah Wyne at the George Mason University Disability Resource Center at (703)993-2474 or visit: <http://apollo.gmu.edu/finaid>. Under documents and forms for download you will find 2005-2006 George Mason University Scholarship Application.

Dr. Berkey is a life member of CCLVI.

Advocacy

New Medicare Provision May Affect Vision Rehabilitation

A provision in the Centers for Medicare and Medicaid Services (CMS) Physician Fee Schedule for 2005 directs that Medicare will not pay for services provided in a physician's office (i.e. "incident to" a physician's service) by "individuals who do not meet the existing qualification and training standards for therapists (with the exception of licensure)."

This ruling by CMS was intended to eliminate ostensibly unqualified individuals from providing 'therapy services' within a physician's office. The specific providers most commonly mentioned as targets of the rule are massage therapists and various forms of sports or athletic trainers.

However, in essence, this rule also means that vision rehabilitation professionals (VRPs) are not considered a 'qualified' provider, since VRP services fall under the existing therapy codes for reimbursement purposes.

The National Vision Rehabilitation Association (NVRA), the American Academy of Ophthalmology, the American Optometric Association, and congressional offices have been in communication with CMS at the highest levels to strongly oppose this administrative action. The rule is overly prescriptive and we believe it will have a harmful impact on access to quality vision rehabilitation services. We believe it is also patently disastrous public policy to implement a Congressionally-directed nationwide demonstration project, now in the final planning stages, which will expand the ability of ACVREP-certified VRPs to provide medically necessary services, while concurrently eliminating the ability of VRPs to work under an even more restrictive environment. The CMS Change Request: 3346 "New Requirements for Low Vision Rehabilitation Billing" for the vision rehabilitation demonstration is clear about the role of VRPs in providing services to Medicare beneficiaries:

"Vision rehabilitation services can be provided by a qualified physician.... a qualified occupational therapist ...or a vision rehabilitation professional who is certified

by the Academy for Certification of Vision Rehabilitation & Education Professionals (ACVREP)".

Please note that the CMS ruling will NOT have an impact on the demonstration, or the ability of VRPs in demonstration states to provide services in a doctor's office, clinic or other approved Medicare facility, as well as patients' home environs.

NVRA will continue to fight to amend this harmful policy, which likely will require legislative action. We encourage you to contact CMS to express your opposition, and to urge CMS to take immediate administrative action to clarify the rule to exempt ACVREP-certified VRPs. Please send your letter to: Dr. Mark McClellan, Administrator, CMS, 200 Independence Avenue, S.W, Room 314-G, Washington, DC 20201. Please be sure to send a bcc to NVRA:

Lorraine Lidoff, Executive Director, NVRA, 250 South Eastham Street, Eastham, MA 02642.

At the same time, as we pursue a legislative remedy, we will keep you abreast of all developments and hope that you may be able to reach out to your own ongressional members at the appropriate time to garner additional support for this effort.

Advocate for "Blind Justice", TV Series

To Pat Beattie, CCLVI President:

I am writing to ask if you're familiar with the Steven Bochco Production, BLIND JUSTICE. It airs TUESDAYS at 10 pm on ABC. At this point in time, ABC is not sure if they'll renew it for a 2nd season.

Please be so kind as to tell members of your organization about the poll that USA Today is running. Every year they take a poll of their readers about shows from various networks that may not be renewed. BLIND JUSTICE is one of those shows and we need people to let the executives at ABC know there is a large following for it.

There is a website, the address is: "life.usatoday.com". Once there you will find a section with the words: "SAVE OUR SHOW". Click on this and it'll take you to another screen. Once there, you will see a list of shows that have been picked up. However, on this screen is an opportunity to vote for your show. You must scan to the bottom of the screen and the option is in the last line of text, right above a graph which lists all the networks and the shows that will return for another season. Click on the text that offers a chance to vote.

This will take you to the screen where you can vote for a number of shows or just for BLIND JUSTICE. After voting, scroll down to the option to send in your vote. Make sure to wait for it to go through.

That's all there is to it. You have to be patient in going from one screen to the next because it may take a while. Please tell people to be persistent!!!

THANK YOU FOR YOUR SUPPORT!

Yemaya Royce

Advocate's Alley

By Ken Stewart

The Americans with Disabilities Act Accessibility Guidelines--ADAAG: What It Is and What It Isn't

After about four years of nagging, Grand Central Terminal installed accessible track platform signage. "Accessible", yes... Accessible?..., not really.

Grand Central Terminal certainly is grand. It is one of my favorite indoor public spaces in the world, an architectural masterpiece and a major transportation hub for a large commuter rail system. The track numbers reach up to the triple digits on two levels. I toured the facility with ten officials of the Railroad; they gave me and the statutory Advisory Committee staffer who accompanied me close attention. Many apparently reasonable ideas were considered for locating easy-to-find, easy-to-read, track number signs.

But when the new signage appeared, it was far from effective in either its appearance or its positioning. These new signs were very expensive-looking signs with the required braille component and raised lettering. However, there was weak visual contrast both internally and between the signs and their background wall surfaces. And worse yet, they were installed far down the platforms from the entry point to each platform. Travelers who are vision impaired must walk more than one hundred feet beyond their 'decision point' before learning which platform they are on.

My subsequent discussion with the Railroad's ADA Coordinator revealed an innocent belief that the A.D.A.A.G. guidelines were followed by the signage contractor. Indeed, the federal government's guidelines for transportation depots do not get very specific about siting signs. The recommendation is to place a sign on the nearest column to a passenger arrival area. But Grand Central Terminal has a huge high-roofed train shed with a paucity of vertical supports at the head of the platforms where almost all travelers approach their trains. So, while A.D.A.A.G. may have been followed to the letter, it certainly was not in spirit.

Be assured, our advocacy will continue. An attempt is being made to convince the Railroad that a few hours work by a couple of skilled maintenance workers could create very readable signage right at the head of each platform approach. Workers can simply reposition the big old black and white tin numbers that have been hanging a bit too high and in unpredictable spots for decades. And the necessary braille can be added to them. And, more completely modern accessible signage can be placed at doorways where the train shed is entered from the Terminal's main concourse. That is where the general public gets its information, from "train boards" with very high "plow" signs displaying each track number. These installations are original equipment, hallowed artifacts of Grand Central Terminal's heritage. Understandable, there is reluctance to alter their appearance significantly. Ways can be found though, once decision-makers advance beyond reliance on a set of generic prescriptions which cannot be expected to detail each site's individual solution.

A.D.A.A.G., the Americans with Disabilities Act Accessibility Guidelines, is a massive compendium of specifications for a very wide variety of features of the physical environment. Many many conscientious people (professional engineers, transportation experts, advocates for people with disabilities, as well as governmental types) labor long and hard to develop and update it. But, it does not answer every situation. In a few spots it may even cause unintended mischief.

My personal view is that the ADAAG's continuing to specify text signage in raised lettering, has the effect of excusing text signage which is too small. The Guidelines permit lettering only two inches high in the mistaken (in my opinion) belief that people who have impaired sight read raised letter text on signs. I have yet to meet any who

do. We do find raised numerals at hotel room doors in dimly lit corridors helpful, but not multiple word sign messages.

I am also disappointed that the latest edition of ADAAG still fails to address the need for high visibility markings on stair treads. Difficulty negotiating stairways is the most common single complaint I hear from pedestrians with low vision.

Another omission in ADAAG from the perspective of people with low vision was pointed out to me by a staff member of the U.S. Access Board, the federal agency which leads the governmental effort to establish effective accessibility standards. The omission is escalator design. It concerns the de-stabilizing effect of the separating treads as the escalator ride begins, either upward or downward. Personally I usually have no trouble shifting my feet slightly so that neither foot is attempting to straddle two separating treads. I take firm hold of the moving hand rail and use my reflexes and agility to keep myself safe on escalators. I never have sufficient visual clues to anticipate where the tread separations will occur. Others who are not so fortunate would be greatly assisted, I think, if there is a future ADAAG standard calling for both a bold visual and a tactual leading edge on each escalator tread, so that fancy footwork is not a prerequisite for a pleasant ride.

I recall only one escalator problem I faced. This occurred when I approached a bank of four side-by-side; up and down escalators with a lower floor and an upper floor. I wanted to go up but found myself moving down. Luckily there was no one getting on behind me so I was able to race the descending treads in reverse and recover my previous floor!

Quality of Life Should People with Low Vision Use "No Vision" Aids? By Carlos Gourgey

One topic we have discussed often is the use of aids normally associated with people who are totally blind. The most important of these are canes and guide dogs. Many people who are not blind use both. For those who retain some vision, are the advantages greater than the disadvantages?

Here are some comments from our group:

A number of years ago I wondered why a partially sighted university student of mine, who could read small print with her low vision aid, used a dog. The answer was that the information she got when traveling was so faulty, that she was more confident and felt safer crossing streets with her eyes closed and letting the dog do the work.

Since then I have met numerous people who are partially sighted who use dogs. A dog isn't for everyone, but most who chose to have a dog, benefit.

I don't need a cane for mobility reasons for the most part. I have one and while I've found it to be an instant identifier that you are blind, there can be problems with the sighted community when you fold it up and walk away. For me, I've come to the realization (in the last year!) that there is a time and place to use it and I don't hesitate to do so if it allows me to do the things I want to do.

Thus even if one is not totally blind, aids that blind people normally use can be helpful in complementing the little vision one may still have. It is important, however, to use these aids properly.

While a guide dog may be right for you it may not be for someone else. I am not against partials using guide dogs provided that they allow the dog to guide them and do not become the dogs guide. I have seen high partials who end up leading the dog and to me this is a severe abuse of the training the dogs receive. It can be a total waste as over time the dogs lose what they have had in the way of training.

One common concern about using these aids has to do with the social consequences. Choosing to use a cane or a dog does affect our relations with others, whether we like it or not. Some members noted certain advantages:

A lot of people tell me that I'd be better off with a dog than a cane. Maybe so, but I prefer to use a cane because I prefer not to have the added responsibility of a dog, and I'm afraid of most dogs except for people's guide dogs. I have to admit that when even they get feisty, I get nervous. I admit, though, that I would be more socially accepted if I used a guide dog than a cane.

I notice that when I'm with my friend Donna with the dog. I went to church with her, and everyone talked about the dog, a real ice-breaker if you will. I have even thought of getting a dog for protection and social acceptance alone, but decided that I'd have to have better reasons than that to do this. I also admit that it's easier to find a door with a dog because I've seen friends command their dogs to find the door, but the dog owner does need to know where he or she is going in order to tell the dog what to do.

Yes, I am partially sighted. I am blind in one eye and legally blind in the other. I primarily use my dog for help with depth perception issues. A side benefit is that it makes my disability visible so people don't, for instance, wave at me and expect me to know who they are. My dog also makes my life easier when I go to the market. The clerks don't just say something like "It is on aisle 7." They instead show me where something is.

There are many times when people have thought I was really rude when I didn't acknowledge them when they waved at me - etc. Most of the time I have a chance to explain to them later that I couldn't see them from a distance, but sometimes a person will avoid me thinking I don't want to talk to them. I have also made the mistake of waving at people I don't know. It can be embarrassing. I now have a service dog that wears a guide dog harness. She makes life a lot easier for me because I don't have to keep explaining myself when I have her with me.

I have noticed the same thing in travels with my wife. I use a cane; she is totally blind and uses a dog. When I'm with her, we always get better attention in stores, buses, etc. (Well, it might not be the dog, but rather the fact that she's more attractive than I am.)

It's not all positive, however. Some members have found the cane or the dog can be a social disadvantage:

One time I went to a singles dance, and felt quite self conscious because I was supposed to see the name tags on people to ask them to dance. I didn't use my cane because I felt too self conscious. A few years later, the man I met at singles who I lived with for a few years, admittedly told me when I told him that I thought he hated when I used my cane because it made it look like he was a bad guy for not helping me. I then asked him whether he would have asked me to dance at the singles club if I had my cane with me, and he said that he probably wouldn't have. Well, thank God he was NOT Mr. Right anyway. He turned out to be a sheister and a user, so you single people, don't settle for less than you deserve, and guess what....I still have to learn that too, but I can proudly say that I will never date someone who doesn't respect me for who I am.

On second thought, maybe the cane can be a good screening device!

One concern many low-vision people have is how the aids we use affect the way others perceive us. We have little control over that, unfortunately. Something that happened to one group member makes this very clear:

As far as everything else goes I see the pros and cons of having a dog, using a cane, etc. that everyone has expressed. I definitely do not think I would be ready to have a dog, and honestly I feel like the only thing a cane would do is show people I have an impairment, but it wouldn't help me navigate. I don't know though.

But one thing that is really upsetting me is something that happened this weekend. I can't seem to get it off of my mind and I keep getting sad about it.

I was at the beach in a house with a lot of people I did not know (the ones I did know are aware of my impairment). So I was talking to some of the ones I didn't really know and asked what movie they were watching. One guy said "Jurassic park for f***ing blind people" to which I said "what?" He then went on to say "yeah it is so stupid, they have these audio captions when no one is talking to help blind people"...so I said "well I am legally blind and those actually help me a lot." Well to make a very long story short everyone started joking about it even after I said my thing and it was very uncomfortable. Then one of my friends who knows about my vision came out and heard and stood up for me and when she said something one other guy sarcastically said "yeah we know, we know, she has macular degeneration." But why wouldn't they stop making fun of the captioning. It is as if no one understands.

In my opinion, what happened to you at the beach house goes beyond rudeness. It is mindless cruelty. That they continued to ridicule the captions after you explained your condition is inexcusable. Such behavior needs to be recognized for what it is, so that you need no longer take it to heart. When you call it by its name, you can see that what those people did degraded them, not you.

Because of other people's attitudes, and especially if we have been disabled at an early age, our self-esteem can take a big hit. I think we can counter that by allowing

ourselves to be justifiably proud that we survive struggling with obstacles to the kind of life that others take for granted.

We can go crazy worrying about what others, or even society as a whole, think of us. Once on a New York street a woman yelled at me because I was using a cane but seemed able to look at something. She discovered very quickly that wasn't a good idea.

As people with low vision our needs are different from those who are totally blind, but no less real. We should not feel intimidated just because blind people's needs are better known. Maybe some day people will expect to see someone with low vision carrying a cane but still wearing glasses or even a monocular, using that low vision when necessary. We ourselves can bring that day closer, by using whatever aids we need, whenever and wherever we need them.

All you need to join our group is a computer and access to email. If you would like to join, please write to me at laflauta@hotmail.com.

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Sbcglobal.net DSL Offers Free Tech Support to People with Low Vision By Carolyn Hathaway

I just went on line with sbcglobal.net DSL and had to call their tech support. The first few times I called they weren't much help. But then I talked to someone in Dallas and he told me that since I was blind I was eligible to receive tech support in my home free of charge from Southern Bell Co. They had someone out the next day and fixed

my problem. The next time I called tech, the person I talked to who was not in the U.S. didn't know what I was talking about when I said I was entitled to tech support in my home without charge. He wanted me to get a sighted friend in to help me. When he checked with his supervisor he found out I was correct and a tech support person was sent out to my home. He gave me the number of my local support supervisor to call in the future. If you call tech support for sbcglobal.net and get the run around, insist that you are entitled to free service in your home. I hope that this will help people who have sbcglobal.net.

The Shopping Experience For People Who Are Partially Sighted By Dr. Sam Genensky, First President of CCLVI

Editor's Note: The following article is based on Dr. Genensky's Presentation to the October, 2004 California Council of Citizen's with Low Vision Convention.

People who are partially sighted need, in general, assistance to determine what is for sale. They may also be unable to visually locate a clerk with whom they can do business. Here it is appropriate for people who are visually impaired to speak up and ask if anyone is available to help them.

It also is advisable for visually impaired customers to inform shopkeepers that they have trouble seeing. If this is done shopkeepers know that they are dealing with people who need assistance because they have little or no useable eyesight. In almost every case clerks will try to be helpful

When people who are visually impaired inquire as to whether someone is available to help them and a clerk is available, that person should say something to the effect of, "May I help you." And if customers who are visually disabled show confusion as to where the voice is coming from, clerks should announce where they are located or better yet, come over to customers who are visually disabled and advise them that they are close by and available to assist them

Using a white cane or a guide dog in a shop is permitted, and the presence of either visually alerts shopkeepers to the fact that customers need help because of their limited eyesight.

There are instances where maneuvering through a shop with a white cane or a guide dog, even if sanctioned by law, is not advisable, e.g. in a shop which has glassware on tables or other supporting surfaces that, if bumped into, may cause the glassware to fall and break. Another example is a store within which the display counters, shelves and display tables are crowded into a very small space that constitutes a challenge to even the non-disabled community when its members attempt to navigate through the store.

People who work in stores are required by the Americans with Disabilities Act (ADA) to tell customers who are severely visually impaired what the store has for sale and to show them items that are of interest to them, so that they can decide whether or not to purchase the items.

What follows was excerpted from a conversation I had with a functionally blind friend and colleague at the Center for the Partially Sighted.

Communication Issues

Living in a large metropolitan area like Los Angeles, my friend runs into some very formidable language barriers, i.e. she has to deal with people whose primary language is not English. She pointed out that when she encounters such people, she has

trouble trying to convey to them what she wants and then in return, trying to understand what these people say to her. She runs into this problem in stores like Target as well as at grocery stores.

Another formidable problem she faces is dealing with people who are wanting relative to literacy. For instance, before she goes shopping, she takes the time to make a typewritten list of what she needs and she gives this list to the salesperson in the store. All too often, she finds that the person to whom she gave the list is unable to read what she has written. She went on to say, "You might think that putting down what you want on paper and giving it to the person with whom you want to deal will solve the communication problem, but unfortunately you run into all too many people who simply can't read." This is becoming more common these days, especially when you are shopping in grocery stores. The person you are obliged to deal with may be a one who stocks the shelves or may have another low level job.

Not only does she run into people who can't read or who have very poor command of the English language; clerks may have some idea of what she might want, but they still are not able to find something on the shelves, because they can't read the labels on the products. Since she is a caring person, she doesn't want to be unkind, but at the same time she wants to locate the items she wants to purchase and go out of the store as quickly as possible.

Access to What You Are Trying to Purchase

In a grocery store chances are that my friend will find someone to help her, but she may have to ask for help, and chances are she will receive the help (but here again language may be a problem). However, if she goes to big stores like Costco's, she may have trouble finding someone to help her probably because these large stores don't have as much manpower as they had in the past. Other stores in which finding help has proven to be a problem for her include Mervyn's, J.C. Penny's, and any of the other big department stores. In various stores her guide dog may be able to locate a counter, and sometimes when this occurs, a person clerk may be behind the counter, but she can't count on someone being behind the counter. She intimated that a guide dog might prove more helpful than a cane in a store environment.

Because of the uncertainty of finding help in lower scale stores, my friend is more likely to go to a higher end store such as a boutique or a Nordstrom's. She pointed out that she pays for the higher probability of getting service, but she is also more likely to find what she is looking for. The bigger stores are geared around customer service. In stores like Nordstrom's clerks take her to the section of the store she is looking for; she has found that on occasion Nordstrom personnel will take her to another store to purchase an item they don't carry or which may currently be out of stock. She feels that she and others who are visually impaired don't have the ability to shop for inexpensive items. This is because, visually speaking, she doesn't have access to many stores that sell less expensive items.

The woman I interviewed had been fully sighted earlier in life, and hence she is very much aware that she can no longer browse by herself. Further, the people who give her help in the store are not usually available to go browsing with her.

When she goes into stores and asks what kind of store she is in and then asks, if appropriate, what is on sale, clerks will tell her what is on sale if they know their inventory. If this type of encounter lasts a considerable time, my friend feels she is obligated to purchase something.

Since she doesn't drive, she has to haul whatever she has purchased out of the store into a cab or other public access vehicle and take it out of the vehicle and bring it into her home. This limits the amount and size of the merchandise that she can

purchase on a trip and sometimes involves making additional trips to purchase and take home what she needs.

Sometimes she finds it is helpful to purchase items via a mail-order service. She feels that visual impairment is expensive and very time consuming. She stated that she believes that people who are visually impaired don't have the ability to run into a store, spot what they want, pay for it, and then run out of the store.

When going shopping by herself she picks times when she anticipates that the stores she wishes to shop in will not be crowded; then the clerks will have time to help her. Thus she shops early in the morning, in the middle of the day, and not on weekends.

She feels that shopping is a very humbling experience for people who are visually impaired. She pointed out that sometimes when using a cane, the situation can be miserable; she doesn't know what sort of obstacles she will encounter at various levels above the floor. If, for example, there are obstacles in a store at shoulder level neither a cane nor a dog will be able to detect them, and she may end up running into such obstacles. If she enters a store with a cane or a guide dog, the cane or the guide dog will alert most people to the fact that she has trouble seeing. If she goes into a store as a partially sighted person without using a cane or a guide dog, people in the store may not sense that she has trouble seeing. Then she lets the store personnel know that she has trouble seeing and is in need of assistance.

There have been times when she walked into a store and no one responded to her request for help or acknowledge her presence. In those instances, she decides to leave the store, under the assumption that people in the store were not interested in her business.

She sometimes ends up talking to someone who is not a store employee and may ask the person where she can obtain assistance or what kind of a store she is in. She feels that being polite is always in order, but she also feels that she must assert herself when the situation requires this of her. She finds that people from whom she asks assistance are almost always kind and considerate. She also finds that younger people in a store do not give her as much help as do people who are older. This, she feels, is probably due to the fact that the younger people have not had as much experience as older people.

Relative to Dealing with People with Disabilities

She finds mall shopping to be very pleasant, but all bets are off if the mall is very busy, e.g. in the weeks and days before Christmas.

Before she goes into "a new place" she calls ahead and tries to obtain information about the location of the place and what maneuvering problems she might encounter. She doesn't just dash out to a place without knowing something about it. She feels that shoppers who are visually impaired tend to be "destination oriented". It is not likely that she will just go to a shopping area such as Old Town Pasadena or the Promenade in Santa Monica. She will go to such places if she has a specific destination in the shopping area.

People who don't know her do not tend to hang around with her. That is not so bad as she doesn't want strangers hanging around her for long periods of time, but on occasion she will ask strangers for specific information such as, "Is this J.C. Penny's?" or "What do they sell in this store?" Thus it again can be seen that browsing about is not possible for people with limited sight.

When going shopping with a fully sighted friend, she tends to receive less service from store personnel. If she goes into the same store on another occasion by herself

and with her guide dog or a cane, she gets lots of assistance. In general, going to a store or a shopping center having a sighted friend with you can prove very helpful, but in a small store, it is best to be on your own.

She stated that when she is with fully sighted people, clerks will tend to speak to the sighted person and not to her; she feels that this occurs because people who are visually impaired may be unable to make eye contact. People who are sighted will use eye contact as a signal that they are attending to you. When people who are visually impaired don't respond like a fully sighted person, clerks may be bewildered and don't know what to do. She recalled going out to dinner with a friend who, in the course of his work carries his name on his shirt. The waitress asked "What would you like to have, Randy?" Randy is blind, but the presence of his name put the waitress at ease even though Randy and she could not make eye contact.

The presence of more sophisticated ways of dealing with money, such as the use of ATMs and debit cards, is making life more difficult for people who are visually impaired. If they have to deal with such mechanisms, they find that they must rely more and more on doing so via a fully sighted person.

Living Well with Macular Degeneration

Have you or has someone you know been recently diagnosed with age-related macular degeneration (AMD)? You may wonder how AMD will impact your life or that of your loved one. The Hadley School for the Blind's new, tuition-free, distance education course "Macular Degeneration" explains the diagnosis and shows how people with AMD can continue everyday activities with limited vision.

The course covers various aspects of AMD. It not only compares 20/20 vision with AMD's symptoms and progression, but also lists risk factors for the condition. In addition, the diagnosis is discussed in light of the doctor-patient relationship. Ways to maximize vision and continue activities are suggested. Finally, the emotional impact of AMD is explored.

"AMD, by itself, does not signify blindness," says instructor Don Golembiewski. "Informing yourself about the disease and the many resources available can help immensely in the rehabilitation process." This course is currently available in large print and will later be available on audiocassette. It is open to students in the Adult Continuing Education and High School Programs as well as those enrolled in the Family Education Program. At a later date, an online version of the course will be offered to students in the Professional Education Program.

So why not enroll in this course to learn more about this condition? To do so, contact Student Services.

Founded in 1920, The Hadley School for the Blind is one of the largest, worldwide educators of persons who are visually impaired. Hadley offers more than 90 tuition-free courses to eligible students. The school's 10,000 annual students come from all corners of the United States and more than 90 countries. Courses are available to students who are visually impaired, family members and professionals. Visit us on the Web at www.hadley.edu.

Contact Student Services, as follows:

United States, Canada and Puerto Rico: (toll-free number) (800) 526-9909 All other students: (847) 446-8111 Hearing Impaired: 847.441.8111 (TTY)

Fax: (847) 446-0855

Email: student_services@hadley.edu

Hadley School Offers Course in Basic Economics

Does the study of economics sound remote and complex to you? Economics is actually a vital aspect of everyday life. And with Hadley's new tuition-free course "Economics," this topic does not have to be complex-or boring! Available in large print and braille (cassette coming soon), this course familiarizes you with the principles of economics at your own pace and in the comfort of your home.

The study guide for this course leads you through the textbook Pacemaker Economics, published by Globe Fearon. The course begins with a general discussion of economics and economic systems and the study focuses on the U.S. free market economy. The course examines the significance of the consumer, as well as the importance of money itself in the U.S. economy. Other important topics include the economy's health indicators and the economic role of the U.S. government. Finally, the course concludes with an assessment of the world's economic situation.

Instructor Vileen Shah says, "This course makes the principles of economics understandable. Learning basic economic concepts helps you make important decisions about money more confidently." This course is open to students in the High School and Adult Continuing Education Programs (available to students in the U.S. and Canada, only). Why not enroll in this course now so you can apply the principles of economics to your own life? To do so, just call Student Services at (800) 526-9909.

Founded in 1920, The Hadley School for the Blind is the single largest, worldwide educator of people who are visually impaired. Hadley offers over 90 tuition-free courses to eligible students. The school's 10,000 annual enrollments are from all corners of the United States and more than 100 countries. Courses are available to students who are visually impaired, family members, and professionals. Visit us on the Web at www.hadley.edu.

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Fax: (847) 446-0855

Email: student_services@hadley.edu

Science and Health

Legislation to Improve Vision Programs, Research and Rehabilitation Introduced

On May 26, U.S. Rep. Gene Green introduced the Vision Preservation Act, legislation to expand current federal vision and vision rehabilitation programs and to increase federal research into eye diseases. A co-chair of the Congressional Vision Caucus, Rep. Green was joined by his fellow Vision Caucus leaders Rep. Ilena Ros-Lehtinen, Rep. David Price and Rep. Pat Tiberi in introduction of the Vision Preservation Act.

An estimated 80 million Americans have a potentially-blinding eye disease. The number of Americans who are blind or visually impaired is expected to double by 2030.

Specifically, the Vision Preservation Act would expand federal research on eye diseases at the Centers for Disease Control and Prevention and the National Eye Institute (NEI), within the National Institutes of Health. The legislation also would expand current federal vision education and awareness programs and create an age-related macular degeneration (AMD) public education program at the NEI to increase awareness of AMD and stress the importance of early detection in preventing vision loss. Additionally, the legislation directs the Department of Health and Human Services to develop voluntary guidelines to ensure quality vision screenings. The Vision Preservation Act also provides for vision rehabilitation services under the Medicare program. The bill also authorizes a study on barriers faced by medically-underserved populations to vision services covered under Medicare, including vision rehabilitation

Gene Found to Increase Risk of Most Common Cause of Blindness

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BETHESDA, Md., March 22 - Scientists have identified a gene that is "strongly associated" with a person's risk for developing age-related macular degeneration (AMD). The finding was made by three independent teams, which include researchers with the National Eye Institute (NEI), part of the National Institutes of Health (NIH), and other leading research centers. Detecting an AMD-associated gene may lead to early detection and new strategies for prevention and treatment for the debilitating eye disease. Papers by all three teams appear in the March 10, online issue of the journal SCIENCE.

AMD is a disease that blurs or destroys sharp, central vision. There is no known cure for AMD. Most scientists think the cause lies in an interplay of hereditary and environmental factors. It is the leading cause of blindness in people over age 60. Family history of AMD is a risk factor for the disease. In recent years, eye researchers have been investigating certain portions of chromosomes to find AMD-associated genes. The new studies provide the strongest evidence yet of a specific gene association. "The three studies are a significant step in AMD research. They confirm a strong genetic component of AMD, which may allow scientists to develop tests for the disease before symptoms begin to appear and when therapies might help slow its progress," said Paul A. Sieving, M.D., Ph.D., director of the National Eye Institute.

The three studies described in SCIENCE used different methods to screen the genomes from different groups of AMD patients. Yet all three studies came up with a commonly inherited variant of the same gene, called complement factor H (CFH). The CFH gene is responsible for a protein that helps regulate inflammation in part of the immune system that attacks diseased and damaged cells. In certain patients with AMD, inflammation in the eyes may trigger a biological process leading to the disease. "This exciting work helps clarify how AMD develops and the relationship of the immune system with the disease. This could lead to entirely new approaches for therapeutics," said Emily Chew, M.D., deputy director, NEI Division of Epidemiology and Clinical Research, and collaborator on one of the studies.

Dr. Chew's team, headed by Josephine Hoh, Ph.D., Yale School of Public Health, New Haven, CT, found that people whose genetic make up includes a variant of the CFH gene are 7.4 times more likely to develop AMD. The study was based on whole genome analysis of participants from the NEI-sponsored Age-Related Eye Disease Study, a major clinical study that closely followed nearly 5,000 patients with varying stages of AMD. The team will next look at a larger number of patients and perhaps

look at genetic differences between patients with the wet and dry forms of AMD. Wet AMD occurs when abnormal blood vessels behind the retina start to grow under the macula, a part of the central retina, where light is converted to nerve signals to the brain. Loss of central vision can be rapid. Dry AMD occurs when the light-sensitive cells in the macula slowly break down. Central vision can be lost gradually.

The second team, headed by Jonathan L. Haines, Ph.D., Vanderbilt University Medical Center, Nashville, identified the CFH gene by using high resolution mapping of a portion of a chromosome that had previously been associated with AMD in family studies.

A third research team, also funded by NEI, was headed by Albert O. Edwards, M.D., the University of Texas Southwestern Medical Center, Dallas.

Editor's Note: The following three news items are summaries of articles originally reported in Vision Connection, a publication of Lighthouse International.

Depression and Self-Management Training for Patients with Macular Degeneration

Studies show a high degree of correlation between physical illness and depression in later life.

The Shiley Eye Center at the University of California, San Diego did a study to test the effectiveness of self-management training on mood and function for people with age-related macular degeneration.

People in this study took part in a 12-hour group program. The focus of this program was health education and problem-solving skills. After this program, participants reported "significantly less emotional distress, better function, and increased self-efficacy as compared with control subjects."

Six months later members of this study, as reported in the January 2005 issue of Archives of Ophthalmology, were able to sustain the gains they had made. In addition, they showed significantly less clinical depression than the control group. Therefore, a relatively simple program can improve the quality of life of people with age-related macular degeneration. result.

Genaera Reports Positive Preliminary Clinical Results for Squalamine

Six people with wet age-related macular degeneration in both eyes were treated with 40 mg. of squalamine. This study demonstrated that 100% of the eyes (n=12) maintained or improved vision at week three, week five, and two months after initiation of therapy. This study was a multicenter Phase 11 clinical trial with squalamine for the treatment of wet age-related macular degeneration. The Genaera Corporation announced this result.

FDA Approves Tonopach to Diagnosis Glaucoma

The U.S. Food and Drug Administration has cleared Tonopach, a new device to diagnose glaucoma. This device is manufactured by RetinaPharma.

Tonopach leads to more accurate diagnosis of ocular hypertension and glaucoma by providing for simultaneous determination of intraocular pressure (IOP) and corneal thickness. Therefore it is more accurate than current methods that rely only of measurements of IOP.

Glaucoma and ocular hypertension are leading causes of irreversible blindness and impaired vision in the industrialized world, with over 7.5 million individuals afflicted in the US alone. Elevated IOP is the key parameter used to diagnose the risk of glaucoma and ocular hypertension. But in 2002, the National Eye Institute published a large, randomized five-year study showing that when corneal thickness is combined with IOP, the combined measure predicts the likelihood of damage to the patient's vision in a highly significant way.

For more information visit the RetinaPharma website.

CATARACTS

By Dr. Ikan C. Kleerly

One of my earliest memories was in the 1920's of my great-grandfather who was blind. This was my first experience with blind people. Since he was a hundred years old, I figured that he just wore out his eyes. Actually, he had cataracts which left him in the darkness for the last 40 years of his life. His spirit and determination is still active in my genes.

I was born legally blind in my left eye, but cheated by memorizing the "line above the green line" to get into the service at the beginning of WWII. My right eye had always been better than normal. However, a few years ago, I found myself having to stop my car, get out and squint at the street signs or house numbers to locate addresses. I wondered why all of my white shirts looked a dingy orange. I went for a routine eye exam. The doctor told me that I had cataracts in both eyes. Flash-backs of my blind elder appeared momentarily. However, I had known folks who had this procedure and it was successful. The appointment was made and six minutes after the doctor started he was finished.

During the procedure, I joked with the doctor encouraging him to have a drive-thru service so that the patient could make a bank deposit, order take-out food, get his car washed and have the surgery all at the same time. He laughed and said, "Remember, it is your eye I am cutting on." I saw that orange glob as he removed it and pure white light on my retina with no definition. Then, as he inserted the lens, I saw his face, distorted at first, then very distinct details. He covered the eye and instructed me to return the following day. When he removed the cover the following day, I was amazed at the brilliance of colors, particularly blue. Blues were bluer! The left eye was done the following week. This was more amazing because the eye which had 20/2000 vision was corrected to 20/40. I could read regular print with it. The doctor implanted a lens that corrected the severe deformity in the eyeball.

A cataract is the clouding or opacity of the normally clear lens. This happens with age in most individuals and is independent of race or color. It can also occur as the result of a blow to the eye area. This may develop immediately or in other cases appear years later. There are also cases where very young children developed cataracts. Because the clouding occurs within the lens, medication or peeling will not correct the vision. It is not like the cornea. Once the lens is removed, light can register on the retina, but it is necessary for a lens to focus the image on the retina. Several million of these procedures are performed each year in this country alone. When cataracts begin, both eyes are affected. Years ago, the physician would tell the patient to wait until it was "ripe" or ready. Now it is performed at the convenient time

for the patient. Other than avoiding swimming for a few days there are no restrictions following the removal of the patch the following day.

Something else that was not explained at the time of surgery is that over a period of years the plastic lens begins to develop a film on the surface like a dirty windshield. This is easily removed with the skilful use of laser treatment. A few quick zaps and the eyes are as good, or better, than new. The after effects of this procedure is that for a few weeks you find yourself grabbing at the bugs or cobwebs that begin to float down. This disappears shortly.

I am writing this article for anyone who might be facing the eventual prospect of cataracts. It is meant to set aside the fears of this procedure and to encourage following your ophthalmologist's recommendations. People with glaucoma are generally not good candidates for this procedure due to the potential increase in intraocular pressure.

I feel very fortunate to live in a time when my vision can be restored in five minutes while my great-grandfather spent his last 40 years in darkness. My prayers are that there will be a "quick fix" for other debilitating eye conditions in the near future.

NIH Senior Health Helps Seniors with Low Vision Learn about Maintaining Independence

The Internet is increasingly becoming a source that older Americans use to research everything from hobbies to health. In response, the National Institute on Aging (NIA) and the National Library of Medicine (NLM) have developed the NIH Senior Health Website <<http://nihseniorhealth.gov>>. This interactive site was designed specifically with the needs of older adults in mind, and includes large-print materials, relevant information, and features that are easy to use.

In an effort to increase awareness among older Americans about low vision and the benefits of vision rehabilitation, NIHSeniorHealth now includes user-friendly information, frequently asked questions, and other resources to help seniors with low vision learn more about maintaining an active and independent lifestyle. Content for this topic was contributed by the National Eye Institute (NEI).

Low vision is a visual impairment that cannot be corrected with standard glasses, contact lenses, medicine, or surgery. The major causes of vision loss in older adults are age-related macular degeneration, glaucoma, diabetic retinopathy, and cataract. More than 16.5 million Americans have low vision. However, vision rehabilitation and devices can help people make the most of their remaining sight.

Additional eye health topics will be featured on the NIHSeniorHealth site in the coming months.

Get connected. Become informed. Go to the NIHSeniorHealth Website and find health information that older Americans need to know.

Travel

Armchair Travel through the Mexican Riviera

By Jane Kardas

If you've never been on a cruise, come along with me to the Mexican Riviera.

On September 22, 2004, Barbara Kron and I set sail on a ten day cruise to the Mexican Riviera. I did some research to determine the best cruise coupled with the best fares for the two of us. I checked the cruise recommended by both the American Council of the Blind and the California Council of the Blind. This cruise departed from

Long Beach, California. I discovered that we would save a considerable amount of money if we sailed directly out of San Francisco, California on another cruise line, thereby eliminating the cost of a round trip plane ticket to Long Beach, California. We both realized that the American Council of the Blind and the California Council of the Blind would have made a profit if we had chosen to leave from Long Beach, but the out-of-pocket expense was too significant.

Traveling from my home in Ukiah, California, and Barbara from her Windsor, California, home needed considerable planning. Barbara had checked into a special bus that she and I could take from the Santa Rosa airport. This bus would take us directly to our ship, the Sapphire Princess, on its maiden voyage from San Francisco to the Mexican Riviera.

The Sapphire Princess ship holds a crew of 3,770 and 2,670 passengers. You can imagine with its length of 954 feet, it was not difficult for Barbara and me to get lost. However, it became a standing joke with the rest of the passengers, when they ran into us, to say, "It looks like you are lost too!" It was a consistent dilemma for all aboard.

We had decided that rather than eat all of our meals with the same people, we would choose a dining program which was known as 'anytime dining'. Barbara and I allowed ourselves two meals per day, either breakfast and dinner or lunch and dinner. One has to keep one's waistline in mind! We met some very interesting people at mealtime. It was great to find out all of the different places people had traveled from and to discover what we had in common with other passengers.

On our second night aboard the ship, the couple sitting across from us at the dinner table noticed Barbara's cane and made mention of a special friend of theirs. The totally blind gentleman they were speaking of was Michael Hingson, who along with his guide dog Roselle, had come safely down from the devastation of the twin towers on September 11, 2001. The couple had been driven to the ship by Mr. Hingson's fully sighted, but paraplegic wife, Karen. Michael currently is a spokesperson for the Guide Dog School for the Blind in San Rafael, California. Can you imagine the odds that we would sit near them on such a huge ship? As a matter of fact, we never dined with the same person twice.

We stopped at several ports along the way. The first was Catalina Island off the coast of Southern California. Barbara and I put a great deal of thought into our shore excursion. We chose a walking tour called "Avalon by Foot." The 'Adventures Ashore' booklet noted that the tour involved moderate exercise and had frequent stops. Unfortunately, and to our astonishment, the tour guide (who was an independent contractor) refused to take Barbara and me along because of our visual disabilities. He obviously had never heard of the Americans with Disabilities Act. When we returned to the ship, we had a discussion with the person in charge of tours about our incident, and our money was promptly refunded. Despite this change in plans, we independently strolled through the streets of Catalina. I purchased a windbreaker jacket and we enjoyed a delicious ice cream.

Our next stop was Puerto Vallarta, Mexico, where we were transferred by bus to the "Dolphin Encounter." In contrast to our previous tour experience, the treatment we received here was excellent. The dolphin trainer advised the group not to touch the dolphin's sensitive eyes or blowhole. Barbara and I were concerned that maybe we should not continue. We felt that, with our visual impairments, the possibility of accidentally touching these sensitive areas could occur. We both suggested that perhaps we should not participate after all, but the dolphin trainer insisted that he could guide us through the process without injury to these magnificent mammals. Barbara and I got into in a separate salt water pool from the rest of the group to receive individual attention. During the incredible half hour we were in the pool, the dolphin obtained many fish rewards. You could definitely sense the trust and

attachment between dolphin and trainer. We had a wonderful and successful encounter and we each left with a photo of ourselves being kissed by the dolphin. Incidentally, the tour symbol (which indicates the skill level needed for involvement of the activity) was the same as the walking tour from which we had been excluded!

Our third destination was Mazatlan, Mexico, where a family that I have known for many years resides. This family and I have become quite close, as they visited me when I had my large home on the coast in West Marin, California. When we arrived in Mazatlan, Barbara and I quickly discovered that it is not what you know in Mexico, but who you know. As we were searching for a cup of coffee and planning for a 10 a.m. departure to meet our friends, I was approached in the dining room by a gentleman who said, "I know who you are, you're Jane!" I was astounded and puzzled. He took Barbara and me to the boatyard where we were greeted by not only our friends, Ana Belen and her mother-in-law Toy Prunada, but also by a uniformed gentleman who was the Port Authority for all of Mazatlan. We all transferred into his van and were taken to our friends' private vehicles. Next, we were driven to their home in the hills of Mazatlan which had a spectacular view of the ocean and rocks below. Here, Barbara and I were, at last, served coffee and cake. For lunch we dined at the family-owned hotel and then off to do some serious shopping at the local boutiques with our friends to interpret. We got back to the ship just in time for fine dining and meeting new acquaintances.

The next port was Cabo San Lucas, Mexico. We took a tour of a glass blowing factory that was hotter than Hades inside! An obnoxious tour guide lead us through the factory where we watched workers hand blow margarita glasses for export. Afterwards, Barbara and I stopped in several upscale shops. Then back to the ship once again for marvelous onboard entertainment.

Our last stop was San Diego, California, where Barbara and I decided to stay onboard the ship and treat ourselves to a massage, shampoo, and blow dry. In other words, pamper ourselves that very last day. While the ship is at port, these services are substantially reduced in price.

The next day, we awoke to find ourselves back in San Francisco having wonderful memories of our incredible adventure on the high seas. If you are planning a cruise, I would highly recommend traveling to the Mexican Riviera aboard the Sapphire Princess.

However, one note of advice: do some serious investigation before paying for onboard health services. For a minor health accident aboard the ship, I not only paid the \$100 for onboard insurance and had to deal with a rude doctor, but was also charged nearly \$200 for the health services I received. These expenses were automatically drawn from my credit card and despite all my efforts I have been unable to have the charges credited back to me. Beware of the fine print!

People

Meet Mary P. Blanton

A mother and her daughter walked into my store this afternoon. The daughter was using a white, red-tipped cane. As we were talking, I mentioned the Low Vision Workshop I plan to offer. In our conversation, something came up that led me to talk about Jaws and Dragon Naturally Speaking. This teenage girl told me, an old woman of 43, "You are the coolest person on the face of the planet." That is because I could talk her language, I can hear the high pitched noise florescent lights and cathode ray

tubes (CRTs: computer monitors and tube TVs) make, I can SEE the flicker the florescent lights make and I could do things like needlework.

I showed her my Big Eyez lamp with the double magnifier and fabric stretched with a Q-Snap frame. She has only one eye and she lost the majority of the vision in that eye due to a retinal detachment. She can still see enough and I think that if we get the right devices, magnification, stretching and lighting, she will more than likely be able to do what her mother has so enjoyed for so long, the stress relieving and relaxing obsession of Counted Cross Stitch.

Oh, and I talked about my "vision" for this Low Vision Workshop at The Nashville Needlework Market. After I picked the people up off the ground when I revealed I am legally blind, I started to gather some real traction for the idea that people who are legally blind can do needlework. TWO floor/lap stand manufacturers are going to alter one of each of their products so I can "kick the tires" and one of them (the owner of Handi Clamp) GAVE me a scroll frame to have and to use in my workshop. The person representing Needlework Retailer, a free trade magazine, started talking to some of the shop owners, and they began to realize that if they could offer assistive devices to their customers, they might not lose as many elderly customers who are experiencing vision loss. Needlework Retailer wants me to write an article to help the other shop owners start down the right path.

Now, I am developing some "guidelines" to help shop keepers get started. It all sort of comes naturally to me because I am visually impaired. But it will be MUCH harder for the other shop owners to figure it all out. I may have to take this one "on the road" to get other shop owners a small part of that "knowledge base" I have spent the last 43 years accumulating.

I inherited an eye condition called Coloboma of the Iris and Lens. This is like spinabifida or cleft palate of the optic system. This means that there is an opening at the bottom of my iris that limits my vision to 20/400. Recently I have been part of the artificial iris reconstruction implant research headed by Dr. Kenneth Rosenthal of Great Neck, NY, www.eyesurgery.org. Following surgery in December, 2004, my vision has been measured at 20/200.

I was the oldest in a family of 4 children. My parents never focused on how significant my vision loss was, and they said "No" as little as possible when I asked to do something. I can imagine my mother thought I might scratch my eye with a needle when I asked her to teach me needlework.

In 1969 when I was beginning my education, my family moved from Appleton, Wisconsin to New Jersey where my father took a new job. My mother had done research about the public schools and special education in New Jersey. She learned that New Jersey was a leader in providing opportunities for children with special educational needs. At that time other states might not have allowed me and two of my siblings to be mainstreamed. My parents did not let me use my vision as an excuse to avoid facing challenges. My mother was like a piranha, a barracuda, a grizzly bear or a lioness protecting her cubs if teachers suggested that anyone of her special needs children should not be promoted due to their disabilities. My mother was blazing the trail not only for her own children but for special needs children throughout our country.

The state of New Jersey funded my education at the University of Toledo-believing that it would be better for me to be a tax paying citizen than one who requires public assistance. At the University of Toledo I prepared to teach special education and high school math. For my math minor I took courses in computer science and discovered that I enjoyed and was good at computer work. I took two more computer courses and then went to work as a software engineering programmer. My first job was to develop computer based training--writing programs for the "help" function on various operating systems. After that I went to work for Equifax, a company that deals with credit reports,

claims reviews, and life insurance eligibility. Often my coworkers could not believe that I was legally blind.

Last year due to a number of health problems, I left my job as a programmer. Following surgery, just to get back to work gradually, I went to work for Michael's Art and Crafts as a cashier. My employer learned that I could actually help customers because of my skills in sewing, crocheting, knitting, counted cross stitch, needle point, macramé, and quilting. I was directed to close down my cash register in order to help customers with their questions.

I now operate my own business in Atlanta, Georgia--NeedleworkHouse. I am developing point of sales software for needlework shop owners. My passions for computer programming, for needlework, and for encouraging others with vision impairments are coming together. I am very happy this new opportunity.

Mary P. Blanton - The Coolest Person on the Face of the Planet, Owner, The Needlework House, 3360 Satellite Blvd, Suite 5, Duluth, GA 30096, (770) 622-4249, Mary.Blanton@Mindspring.com NeedleworkHouse@BellSouth.net <http://www.needleworkhouse.com>

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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.

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800-733-2258

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

Metropolitan Council of Low Vision Individuals
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National Capitol Citizens with Low Vision
703-645-8716
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Hadley School for the Blind
www.hadley.edu.
Student Services:
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All other students: (847) 446-8111
Hearing Impaired: 847.441.8111 (TTY)
Fax: (847) 446-0855
Email: student_services@hadley.edu

Lighthouse International
800-829-0500

NIH Senior Health Website <<http://nihseniorhealth.gov>>.

Medicare Rights Center
www.medicarerights.org/hiddenlives.html
mrcadvocacyupdate@medicarerights.org.

National Vision Rehabilitation Association
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