

# **Vision Access**

**A Magazine by, for and about  
People with Low Vision**

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**Vision Access welcomes submissions from people with low vision, from professionals such as ophthalmologists, optometrists, low vision specialists, and everyone with something substantive to contribute to the ongoing discussion of low vision and all of its ramifications. Submissions are best made as attachments to email or may also be made in clear typescript. Vision Access cannot assume responsibility for lost manuscripts. Deadlines for submissions are March 1, June 1, September 1, and December 1. Submissions may be mailed to Mike Keithley, Editor, 191 East El Camino Real #150, Mountain View, CA 94040; 650-386-6286, editor@cclvi.org.**

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## **Editor's Corner by Mike Keithley**

**Welcome to the Spring 2013 Vision Access. You will find format changes that should make the magazine easier to read. Margins are wider, headings are left-justified and we've switched to the block paragraph format. Please contact me with feedback.**

**By the time you read this, the ACB Legislative Seminar will have happened, but Jim Jirak tells us about one ACB legislative prerogative: removing video**

**equipment from the Eye Glasses Exclusion ruling. In the Science and Health section, we learn about the FDA-approved Argus II artificial retina and a new implanted telescope. In Quality of Life Elinor Waters tells us about her tour of the Holocaust Museum in Washington DC, and Jane Kardas tells us about a service to rent audio-described movies.**

**So enjoy Vision Access with a nice glass of wine!**

## Letters to the Editor

Lyn Gagne writes: Not that this is such a big thing, but I believe in giving credit where it is due. In the Winter 2013 issue, a letter was printed that referenced the movie Contact that starred Jodie Foster. I would like to point out

that Matthew McConaughey did not play the blind astronomer in the movie. He was played by William Fichtner, who, while not a blind person in real life, is an excellent actor. I feel he did a great job in the role.

## Organization News

### The President's Corner by Jim Jirak

Welcome to the spring edition of Vision Access. As I begin my remarks, the northeast part of the United States finds itself digging out of nearly 3 feet of snow thanks to winter storm Nemo. Luckily, as this issue of Vision Access is being circulated, spring is now here.

Turning my thoughts to legislative matters of importance to CCLVI, and with thanks to information provided by Eric Bridges, ACB's Director of Advocacy and Governmental Affairs, I want to address the status of the exclusion of video equipment with lenses from durable medical equipment.

in November of 2008, the Centers for Medicare and Medicaid Services (CMS) promulgated a regulation that has had a detrimental impact on the lives of countless individuals who are blind or visually impaired. To the

dismay of the blind community, the Durable Medical Equipment, Prosthetics, Orthotics, and Supplies (DMEPOS) Competitive Acquisition Rule contains a provision entitled "Low Vision Aid Exclusion" which states that all devices, "irrespective of their size, form, or technological features that use one or more lens to aid vision or provide magnification of images for impaired vision" are excluded from Medicare coverage based on the statutory "eyeglass" exclusion. CCLVI is well aware that this extremely restrictive reading of the "eyeglass" exclusion has resulted in the denial of vital assistive devices for seniors and other Medicare beneficiaries who may have disabilities, particularly those with vision loss, who need to use such devices to live healthy, safe and independent lives.

**This proposal has had a significant impact on beneficiaries with vision impairments who depend on assistive technology that incorporates "one or more lens" to aid in their vision. The expansion of the eyeglass exclusion has prevented access to devices such as hand-held magnifiers, video monitors, and other technologies that utilize lenses to enhance vision. These tools are often essential for individuals with low vision who, without the aid of assistive technology, cannot read prescriptions, medicine bottles, and other important materials containing content that is vital to their personal health and safety.**

**Without the aid of such assistive devices, many more individuals will be forced into care facilities and nursing homes as our population ages. Seniors on fixed incomes often find the cost of such devices burdensome and therefore are unlikely to be able to afford to purchase them on their own.**

**The initial impact of this unreasonably narrow interpretation of the eyeglass exclusion has meant a decrease in access to current devices, since prior to this rule change, it was not uncommon for Administrative Law Judges to require Medicare to provide them to beneficiaries who had visual impairments and could demonstrate the requisite necessity. We believe the proposal will have an even more detrimental impact in the long-term. The expansion of the statutory eyeglass exclusion to include any technology that uses**

**"one or more lens for the primary purpose of aiding vision," serves as a preemptive and unwarranted coverage denial for any new technology designed to assist individuals with vision loss.**

**CCLVI believes that this preemptive coverage denial is particularly harmful because it serves as a tremendous disincentive to innovators and researchers to develop new and progressive vision technology. Medicare coverage policies often drive the coverage policies of private health plans, which are influential when it comes to investments in research and development. If Medicare continues to maintain this preemptive coverage exclusion for low vision aids, we will undoubtedly see a decrease in innovation in this area.**

**At the recently concluded ACB legislative seminar, it was announced that ACB will urge Congress to introduce and promptly pass the Medicare Demonstration of Coverage for Low Vision Devices Act of 2013. This legislation would evaluate, through a five-year national demonstration project administered by the Department of Health and Human Services, the fiscal impact of a permanent change to the Social Security Act. This legislation would allow reimbursement for certain low vision devices that cost \$500 or more as durable medical equipment. Individuals will be eligible to participate in the demonstration project only after completing a low vision exam performed by a physician who**

would then deem a low vision device as medically necessary. The national demonstration project is designed to provide a rich, well-structured and defined data set that can yield Medicare-program-wide evidence-based conclusions using appropriate statistical methods.

In order that we can communicate our concern surrounding this critical piece of legislation, I am including the names of influential law makers we should contact to urge the adoption of the Medicare Demonstration of Coverage for Low Vision Devices Act of 2013. They are:

United States Senate, Committee on Finance. Democrats: Max Baucus, Chairman (MT); John D. Rockefeller IV (WV); Ron Wyden (OR); Charles E. Schumer (NY); Debbie Stabenow (MI); Maria Cantwell (WA); Bill Nelson (FL); Robert Menendez (NJ); Thomas R. Carper (DE); Benjamin L. Cardin (MD); Sherrod Brown (OH); and Michael F. Bennet (CO).

Republicans: Orrin G. Hatch, Ranking Member (UT); Chuck Grassley (IA); Mike Crapo (ID); Pat Roberts (KS); Michael B. Enzi (WY); John Cornyn (TX); John Thune (SD);, Richard Burr (NC); Johnny Isakson (GA); and Rob Portman (O).

United States House of Representatives, Committee on Ways and Means. Republicans: Dave Camp, Chairman (MI); Sam Johnson (TX); Kevin Brady (TX); Paul Ryan (WI); Devin Nunes (CA); Pat Tiberi (OH); Dave G. Reichert (WA); Charles W.

Boustany Jr. (LA); Peter J. Roskam (IL); Jim Gerlach (PA); Tom Price (GA); Vern Buchanan (FL); Adrian Smith (NE); Aaron Schock (IL); Lynn Jenkins (KS); Erik Paulsen (MN); Kenny Marchant (TX); Diane Black (TN); Tom Reed (NY); Todd Young (IN); Mike Kelly (PA); and Tim Griffin (AR). Democrats: Sander Levin, Ranking Member (MI); Charles B. Rangel (NY); Jim McDermott (WA); John Lewis (GA); Richard E. Neal (MA); Xavier Becerra (CA); Lloyd Doggett (TX); Mike Thompson (CA); John B. Larson (CT); Earl Blumenauer (OR); Ron Kind (WI); Bill Pascrell Jr. (NJ); Joseph Crowley (NY); Allyson Schwartz (PA); Danny Davis (IL); and Linda Sanchez (CA).

Turning my thoughts to CCLVI's advocacy efforts, ACB's Board of Publications, (BOP) has asked us for feedback and input on large print matters in various ACB periodicals. I am pleased to report that our Secretary Lindsey Tilden and our Second Vice president Donna Pomerantz are CCLVI's liaisons with this entity. Having met via conference call in January and February, I am told that their input was well received, and significant design elements have been made to the print edition of ACB's Braille Forum. Beginning with the March edition, the page number point has been changed to size 18. Along with removing the italics from "The Braille Forum" and bumping up the point size there too, subheads are now black; paragraphs are now aligned left; and there are blank lines between subheads and the start of a paragraph.

Headlines and subheads are now mixed case. I am told that the copyright statement has been corrected and aligned left. On the inside back cover, font sizes of section headers are increased slightly and they're now black, too; and the underlining is gone from the ACB Officers list. Given these visually appealing enhancements Lindsey and Donna will continue to represent CCLVI on future calls when warranted.

Before concluding, I would be remiss if I didn't encourage all to attend the upcoming CCLVI convention and annual membership meeting this summer in Columbus, Ohio. Held in

conjunction with the annual ACB Conference and Convention, the overall dates are July 4-12 at the Hyatt Regency Columbus, with CCLVI's programming July 5-9. Our convention chair, Kathy Casey and her committee have been working diligently to ensure this convention is memorable for all of the right reasons. To be a part of the festivities, room reservations can be secured by mentioning the American Council of the Blind, or group code g-cane, by calling (888) 421-1442. Look for more information in the next issue of Vision Access.

Until next time, be good to one another.

## **CCLVI Toast Master Convention Program Submitted by Jim Jirak**

Need to conquer the fear of public speaking? Need to hone your public speaking skills? Need to improve your communication style? Then Toastmasters might be just what you have been looking for. The Council of Citizens with Low Vision (CCLVI), and Independent Visually Impaired Entrepreneurs (IVIE) will host a Toastmasters demonstration meeting at this year's CCLVI conference and convention on July 9 at 2:45 PM. Learn how to capture and keep

your audience's attention. Discover the effectiveness of humor and sincerity. Explore the challenge of extemporaneous speaking. Already a Toastmaster? Share your tips on handling notes, making eye contact and other possible obstacles. Want to be on the agenda for a speech or other role? Contact Mary Hiland at 614-471-1869 or email [mary.hiland@wowway.com](mailto:mary.hiland@wowway.com). Be sure to put the word toastmasters in the subject line. All are welcome.

# **CCLVI Board Meeting Minutes**

## **Summarized by Mike Keithley**

**The Board of Directors meeting was held on February 11, 2013 at 8:30 ET. Roll call was taken.**

**Present were Jim Jirak, Donna Pomerantz, Lindsey Tilden, Mike Godino, Richard Rueda, Leslie Spooone, Brian Petraits, Grady Ebert, Bianca Knight, Dan Smith, Allen Casey, Michael Byington, Fred Scheigert, Annette Carter, and Mike Keithley; not present were Lucinda Talkington and Reba Landry.**

**Leslie Spooone is coordinating CCLVI's participation in the ACB Auction and Walk at the convention. The Walk will take place on Saturday, July 6` from 7 to 9 AM. Please let Leslie know if you would like to participate by June 15. The Auction will happen the evening of Tuesday, July 9th, and the deadline for submission is also June 15.**

**The minutes from the November 12 Board meeting were approved with minor corrections. They were distributed via email and not read. Donna Momerantz and Michael Byington abstained because they were not in attendance at that meeting.**

**The Treasurer's report was discussed. Assets are not reported here per request. Mike described payment of various bills, and it was agreed to roll the interest over on the 1 year CD. A question arouse about what the "Program Fund's focuses were intended to be, and this will be researched. The prescription drug group travel**

**reimbursement was paid. Annette would like the treasurer's report in a more accessible format as she found errors and inconsistencies. Donna suggested converting the Excel spreadsheet to a Word table to increase readability, and Jim will work on it.**

**Jim announced that Reba Landry and Lucinda Talkington have resigned from the Board effective immediately, and their resignation letters are attached to the Minutes in the permanent file. Jim suggests leaving the positions open until elections in July, and a motion carried (with one opposed) approving this.**

**Convention, Kathy Casey: The Convention Committee met once since the last Board meeting. The tentative schedule for the CCLVI program is Friday: 3 PM Board/organizational Meeting; 5 PM Nominating Committee. Saturday: 9 AM Introductions; 9:15 am Speaker; 10 AM Vendor Showcase; 4 PM CCLVI Mixer with pizza or veggie tray, sodas and beer. Sunday: 1:15 PM International Speakers Panel (Jane Kardas); 1:45 PM Leadership Panel; 7 PM Game Night (Ken Stewart). Monday: 1:15 pm Business Meeting. Tuesday: 1:15 pm Toastmasters Meeting (A member from Ohio and volunteers from her chapter will be leading the session. There will be an overview of a Toastmaster's meeting and some speeches.); 2:30 pm Break; 2:45 pm "Going**

**Blind" movie screening. Committee reports are typically presented on Saturday. With the exception of scholarship winners, resolutions, and constitutional amendments, reports will be presented at the business meeting on Monday.**

**Membership Jeff Harris: discussed his attached report.**

**Scholarship, Lindsey Tilden: The scholarship website went live on January 1. A number of applications are being worked on online. Annette reports that 15 people have logged in. Bernice and Ken will ask around for additional Scheigert Scholarship Committee members.**

**Website, Annette Carter: The committee discussed fundraising through the website. She is prepared to set this up and get running. ACB uses authorize.net, which costs less than PayPal. Annette will correct the links for our scholarship on a resource site for disability/blindness and scholarships. Vision Access will be posted once issues are properly formatted. It will be posted in html and MS Word formats.**

**Prescription Label Working Group: Annette attended the Access Board meeting in January. The group is working well, but taking more time than anticipated. They did not achieve all that they had wanted to in January, so they scheduled a phone conference, and still didn't finish all the work, and another follow up teleconference has been scheduled. The group is having difficulty finding a consensus on changing elements of labels. Some changes would require**

**legislation. Annette has also found that the industries want to use just one adaptation (large print, braille, or talking bottles), but the advocacy groups need to explain that all three options need to be available. The group's charge is to have best practices recommendations submitted by July, 2013. Annette wants our opinion on best practices for regular (not large print) pill bottles to make them more readable.**

**ACB Board of Publication Report: Donna and Lindsey have attended two BOP meetings regarding large print best practices for the ACB Braille Forum. [See President's Message in this issue.] They will continue to be on the BOP calls. Donna and Annette had a meeting to talk about the upcoming convention program. Donna will attend the ACB Mid Year meeting and Annette will be patched in via telephone.**

**The board was asked to vote on how they prefer AM/PM to be written: capitals with no periods, lower case with periods, etc. An email will be sent to the board list.**

**Good Search: Dan Smith looked at Good Search, a website sponsored by Yahoo, for potential CCLVI fundraising. Each time someone uses the search engine, their affiliated charity receives a penny. If we have lots of people registered and they use it repeatedly, it can generate money for our organization. They suggest having a group of 100 people use it twice a day. This would generate \$750 a year. People**

register with a charity of their choice. The site also has a shopping program; and if a user uses its vendors, the charity earns money. This would not generate a large amount, but doesn't entail much work and there is no sign-up cost to CCLVI. Video or repeated searches for the same thing do not earn money. It's not known if the site is accessible. However, members could ask families and friends to use it. A motion was made to submit an application as a charity, and it carried.

Travel guidelines were written in response to Annette's travel for

the prescription labeling group meetings in Washington DC. Jim's proposed guidelines are taken from those used by ACB Nebraska. Donna moved to table the discussion until the next Board meeting. Motion carried. Discussion of changes will be held on the board email list, and comments should be submitted by April 15. [Editors note: Emergency Board Meeting will be held April 2 to consider this.]

The next board meeting will be held on Monday, May 13. The meeting adjourned at 10:23 ET.

[Attached Reports: These are not dealt with here.]

## **On the Road to Full Access to Prescription Information by Annette Carter**

As most of you know, CCLVI is one of 18 represented on the US Access Board Working Group charged with developing best practices for making information on prescription drug container labels accessible to people who are blind or visually impaired or who are elderly. This is under Section 904 of the Food and Drug Administration Safety and Innovation Act that was signed into law July 2012. I'm sure you agree that it is about time that our prescription information be accessible to us wherever we obtain it. However, as all of you advocates know, whether you signed up to be one or not, the road is not as short as we would want it to be. Because of the tireless work of some of you and others, there has already been

great victory, and you may be enjoying safety in full access to the information needed regarding your medication. However that is not the case everywhere nor for everyone.

The Working Group's charge is just one step toward our goal. After July 2013, the mandated time that this working group must finalize the collective Best Practices, the National Council on Disability will lead the informational and educational campaign designed to inform individuals with disabilities, pharmacists, and the public about such best practices. Beginning January 2015 the U. S. Comptroller General will conduct a review of the extent to which pharmacies are utilizing the best practices, and the extent to which

**barriers to accessible information on prescription drug container labels continue. No later than September 30, 2016 the Comptroller General will submit to Congress a report on the review that includes recommendations about how best to reduce the barriers that still exist in accessing information on prescription drug container labels.**

**The work of the group is limited to the "prescription drug container label," although the best practices document submitted by CCLVI also includes guidelines on accompanying medication usage guides. You can access them via the CCLVI.org website and the U.S. Access Board's website via the following links to continue the advocacy where you obtain your medications and with your legislators. [www.cclvi.org/LPfor-RxLabels.html](http://www.cclvi.org/LPfor-RxLabels.html) or [www.access-board.gov/drug-labels/cclvi.htm](http://www.access-board.gov/drug-labels/cclvi.htm).**

**The battle has already been won as to the need for the various formats to access prescription information: braille, large print, audio, etc. It is now down to the criteria for each format and the best way to produce them. What we at CCLVI know is that we are a varied group with different vision conditions. The publication "Best Practices and Guidelines for Large Print Documents used by the Low Vision Community," the result of CCLVI's years of research and collaboration is the cornerstone of**

**CCLVI's large print format recommendations for prescription container labels. But large print according to our best practices is not the answer for everyone. There are some who would not think to ask for or could not use something as large as 18 point font, i.e. seniors or those beginning to lose their vision. That is where we need to think outside of the box of just a limited number of formats. The label should be clear enough for the "tweens" to read. I am happy that on the working group we also have the National Council on Aging and the Blinded Veterans Association who understand that need. We are the Council of Citizens with Low Vision International, not the Council of Citizens for Large Print International.**

**I value your voice on this road toward full access for all. Please feel free to listen in on the future meetings and participate via phone on the public comment portion. The meetings are being streamed via the US Access Board website at [www.access-board.gov/drug-labels/index.htm](http://www.access-board.gov/drug-labels/index.htm), phone: 888-603-7094, Passcode: 6317703. Contact Susan Crawford at [crawford@access-board.gov](mailto:crawford@access-board.gov) or call 202-272-0029. For questions or comments regarding CCLVI's involvement, contact Annette Carter at 559-355-4095 or [annette.carter@pacbell.net](mailto:annette.carter@pacbell.net).**

# Quality of Life

## The HKNC Confident Living Program from [www.hknc.org](http://www.hknc.org)

[I'm sure some of you have a hearing impairment along with your vision loss, and I hope the following is helpful. I participated in this program, and most of the people there had some vision.]

HKNC's Confident Living Programs (CLP) addresses two populations: seniors who are blind or visually impaired and hard of hearing and do not use sign language as their primary means of communication, and seniors who are deaf-blind or deaf and visually impaired and use sign language.

CLP at HKNC Headquarters: Held at our Sands Point, NY, campus, the one-week CLP provides information, resources and an introduction to skills necessary for senior citizens with vision and hearing loss to maintain as independent a life as possible.

CLP "On the Road": For those seniors who want to take advantage of the CLP but cannot, or do not want to, come to New York, we will come to you! HKNC partners with local agencies and organizations that host short-term trainings in the state or region near where the consumer lives. Since local service providers assist with the training, they also learn techniques to better work with older adults. Some of the training areas for the CLP are: understanding hearing and vision loss, mobility considerations, technology, home safety, elder law issues, communication skills and strategies, and having fun!

For more information, contact Paige Berry, Coordinator; Phone: 804-827-0920 (Voice/TTY); E-mail: [paige.berry@hknc.org](mailto:paige.berry@hknc.org).

## Visiting the Holocaust Museum: An Informative and Emotionally Exhausting Experience by Elinor Waters

[Elinor Waters is a member of NCCLV.]

Somber, brilliant, tragic, impressive, horrific, unbelievable- these are but a few of the

adjectives that ran through my head as a small group of blind and visually impaired people visited the United States Holocaust Memorial Museum in Washington,

**D.C. The tour was organized by Mikey Weisman for attendees at the ACB Leadership meeting but was open to others.**

**Six of us received very personal attention from two volunteer guides and a new staff member. They did an excellent job of explaining the architecture and ambiance of the building as well as describing many of the exhibits. This is not your typical museum designed to maximize light on paintings. Rather, it is drab with daylight obscured by steel girders and beams to simulate the feel of detention centers, concentration camps and cattle cars that transported victims to gas chambers. The floors are made of different textures to suggest surfaces on which Holocaust victims may have walked. These features contribute to the somber feel of the museum. I heard no loud voices or teen-aged giggles, although our guides told us many student groups were present.**

**The award-winning architect of the Museum, James Ingo Freed, was born in Germany in 1933 and escaped to the United States in 1939; so he was part of the early history depicted in the Museum. Our guides told us that he visited ghettos, concentration camps, detention centers and other places where Holocaust victims lived to help him design a building that reflected their experiences. He also benefited from discussions with many Holocaust survivors.**

**Our tour lasted only two hours. It included just a smattering of the history of the Holocaust**

**interspersed with human interest stories. We assembled in a large bleak room at street level of the Museum, lit only with daylight coming in from the top of the building. Each of us, like all visitors, was given a personal identification card, actually a few pages in print or braille, that tells what happened to a particular person who lived during the Holocaust. As we progressed through various stages of the Holocaust, we were told to turn the page to see what had happened to "our person."**

**Permanent exhibitions are displayed on three floors. The 4th floor, called The Nazi Assault, 1933-1939, covers the period from Adolph Hitler's rise to power to the outbreak of World War II. The 3rd floor, entitled The Final Solution 1940-1945, documents the evolution of Nazi policy during the war, from persecution to separation in ghettos, to annihilation. The 2nd floor, The Last Chapter, records various ways people responded to the Holocaust. It pays special tribute to non-Jews who hid or in other ways aided Jews in their struggle to survive.**

**On each of the floors, guides described some of the photographs and artifacts that document the rise of Nazism, the desperation of people wanting to flee and the response of the rest of the world. Hitler was determined to purify Germany by eliminating not only Jews, but also Romas (gypsies), homosexuals, Jehovah's witnesses, and people with disabilities.**

Thanks to the perceptiveness of our guides and their clear descriptions, a few of the exhibits had a profound impact on me. As we stopped in front of some of them, I felt I was witnessing the barbarities of Nazis. For example, Kristalnacht, or the night of broken glass, tells the story of the nights when Nazis destroyed homes, businesses and synagogues of Jews throughout Germany. Sounds of breaking glass augment the impact of the photographs described by the guides.

Another heartbreaking exhibit was a four-story high display of family photographs of residents of one Polish city, all of whom perished. There are descriptions of life in the ghettos along with samples of armbands that Jews and other victimized groups were forced to wear. An exhibit of hundreds of shoes of all sizes that had remained after bodies were gassed, seemed a metaphor for the wanton destruction of lives of men, women and children. Walking through a simulated box car like those that transported victims to the concentration camps was a chilling experience.

Various scenes and voices from World War II are depicted with statements from world leaders interspersed with samples of children's diaries. The end of the War and the freeing of people still living in the camps is vividly described.

Our guides told us of many displays documenting heroic resistance efforts by Jews such as the Warsaw ghetto uprising. They also described courageous efforts

of non-Jews to aid Jews in peril. One exhibit contained a model fishing boat like those used by Danes to ferry Jews out of the country when word came of their impending round up.

The tour ended in a large, brightly lit room called the Hall of Remembrance. The hall is six-sided, with each side representing one million of the estimated six million Jews killed during the Holocaust. Many Holocaust survivors come here to tell their stories. Visitors are encouraged to light a candle or observe a moment of silence in memory of victims. As we stood in this hall, our guides explained that the mission of the Museum is to make sure we remember the Holocaust. Our guides helped us understand this mission as they kept us safe and together despite our being in a somewhat difficult environment.

The Holocaust Museum is not alone in providing special accessibility services. When I typed the words "museum tours for the blind" into my Google search, up came descriptions of accessibility services at many different locations, video tapes of accessible tours and suggestions for guides leading such tours. Many of the sites recommend that visitors who have special needs call ahead to arrange for appropriate services. On our tour for example, our guides had arranged early admission so that we could become oriented to the building before the public was admitted.

I found the Museum to be truly awesome. Its essence is captured in a quote from Elie Wiesel,

**Holocaust survivor, author and consultant to the Museum. "I**

**don't want my past to become anyone else's future."**

## **Audio Described Movies by Jane Kardas**

**On several occasions, I had the opportunity to attend audio described Broadway musicals in San Francisco. It was fantastic to have a small ear piece with someone off-stage describing action on-stage. I especially enjoyed "Phantom of the Opera," "Mama Mia," and I hope to see "Jersey Boys" before too long as the music is fantastic. As you may know having a friend accompany you to a movie in your local theater can often present a problem as other people in the audience do not enjoy your friend's verbal description when they're deeply engrossed in a show. I recall at a national ACB convention the movie "Ray," which was about Ray Charles. We had the audio described movie played for us and if that wasn't enough the director of the movie was there to answer questions about the making of this film. I once saw this movie in my local theater but realized how much I missed before it was audio described. Some time ago in the Braille Forum there was an announcement concerning an audio described movie service, and I quickly jumped on it and began receiving movies.**

**Now I hope I have wetted your appetites! There is a service**

**through the Texas Center for the Visually Challenged that offers 250 major movies. There are movies for toddlers, teens and adults. Some of my favorites are "A Beautiful Mind," "Pretty Woman," and one of my all time favorites: "Scent of a Woman" that stars Al Pacino. It's simply amazing how a sighted actor could portray a blinded war veteran who goes on his last hurrah wining, dining, and sex before he planned to commit suicide. I can personally think of several blind men who would enjoy this one, and to think it's audio described!**

**For a life time subscription of 25 dollars, movies will be sent and returned via free matter for the blind. I am assuming you have a TV so you will only need a DVD player. I have checked at Walmart--they can be purchased for as low as 25 dollars! You can contact Ken Mann at 972-530-2949. You will obtain your own list of movies and new ones are added all the time. So, all you'll need is a bag of popcorn, and your favorite beverage, and might also consider inviting friends for your very own movie night in your very own home.**

# Conferences and Tours

compiled by Mike Keithley

## Let's Talk Low Vision

Each month the Council of Citizens with Low Vision International (CCLVI) provides a forum addressing topics of concerns to people with low vision titled "Let's Talk Low Vision". We are fortunate to have Dr. Bill Takeshita as the moderator and master of ceremonies for these presentations. The presentations occur the third Tuesday of each month and start at 5:30 PM (Pacific), 8:30 PM (Eastern). To be part of the conversation, please call 218-339-2699 and enter the ID 764516.

Below is the schedule from April to December, 2013. However details can change without notice, so you should check [www.cclvi.org](http://www.cclvi.org) frequently.

In addition, podcasts of previous conferences are available there and on the Audio Internet Reading Service website [www.airsla.org](http://www.airsla.org).

**April 16: How to Deal with Uncomfortable Situations as a Person with Low Vision:** Donna Pomerantz, CCLVI 2nd Vice President, along with several fellow Board members, discuss strategies to help people with low vision deal with uncomfortable situations. They share ways to promote a robust and inclusive environment, whether in conversations, social situations or sharing how people can be of assistance to us.

**May 21: What's New in Low Vision Technology?** Dr. Bill describes the latest in low vision technologies that were introduced at the 2013 CSUN Disability Conference. It will be a way for callers who could not attend the conference to learn about the latest in technology.

**June 18: Research Update 2013:** Dr. Bill interviews a panel of ophthalmologists who discuss the latest treatments and clinical trials to help people with macular degeneration, diabetic retinopathy, glaucoma, and other diseases.

**July 16: The Importance of Filters and Sunglasses:** Dr. Bill interviews Dr. Bruce Rosenthal, OD, FAAO, Chief of Low Vision Programs at Lighthouse International. He will talk about the latest advances in sunglasses and filters. Dr. Rosenthal shares his experience regarding the colors of filters that enhance vision of those with low vision.

**August 20: My Favorite Cell Phone Applications:** Dr. Bill interviews a panel of speakers who describe their favorite applications for use on their cell phones. They discuss their favorite GPS application, bar code reader, color identifier and more.

**September 17: Should You Reveal You Have a Vision Impairment?:** Dr. Bill interviews a panel of guests who describe their experiences after they revealed

they had a vision impairment. They share their recommendations for revealing their vision problem when going on job interviews, dating and other situations.

**October 15: Nutrition and Your Vision:** Dr. Bill interviews Natalie Nankin, a certified nutritionist who has lectured extensively on the topic of vision and nutrition. Ms. Nankin discusses the importance of taking the appropriate vitamins and eating specific foods to maximize the health of your eyes.

**November 19: Strategies to Keep a Positive Attitude:** Dr. Bill interviews Dr. Phyllis Amaral, who discusses ways to keep a positive attitude. Often having low vision can be a challenging experience, and she shares very helpful tips.

**December 17: Gene Therapy Update:** Gene therapy is one of the fast-growing areas of research to treat and reverse vision loss. Dr. Bill discusses the latest in research and inform listeners of eye conditions that may benefit from gene therapy.

## **Museum Tours**

**Science Sense Tours, New York City: American Museum of Natural History:** Visitors who are blind or partially sighted are invited to attend this program, held monthly in the Museum galleries. Specially trained Museum tour guides highlight specific themes and exhibition halls, engaging participants through extensive verbal descriptions and touchable

objects. Science Sense is free with Museum admission, and are available to individuals or groups. Space is limited and advance registration is required. Programs may be subject to change.

For additional information or to register for a Science Sense tour, please call 212-313-7565 or email [accessibility@amnh.org](mailto:accessibility@amnh.org).

## **Focus on Eye Health National Summit**

Prevent Blindness America will host the second annual Focus on Eye Health National Summit on June 18, 2013 at the Washington Marriott at the Metro Center from 8 AM to 3 PM. Some presentations include Economic Impact of Vision Problems, Health Care Reform and Vision Benefits for Children, Women's Eye Health, and A Systems Approach for Vision Health.

Attendees include patient advocates, community-based organizations, national vision and eye health organizations, government agencies, and policymakers.

Registration is free but seating is limited. Register at [www.preventblindness.org/eyesummit](http://www.preventblindness.org/eyesummit).

# Science and Health

## Device Offers Partial Vision for the Blind

by Pam Belluck

[This article comes from the New York Times for February 14, 2013. Several complex web addresses were removed.]

The Food and Drug Administration has approved the first treatment to give limited vision to people who are blind, involving technology called the artificial retina. The device allows people with a certain type of blindness to detect crosswalks on the street, the presence of people or cars and sometimes even large numbers or letters. The approval of the system marks a milestone in a new frontier in vision research, a field in which scientists are making strides with gene therapy, optogenetics, stem cells and other strategies.

"This is just the beginning," said Grace Shen, a director of the retinal diseases program at the National Eye Institute, which helped finance the artificial retina research and is supporting many other blindness therapy projects. "We have a lot of exciting things sitting in the wings."

The artificial retina is a sheet of electrodes implanted in the eye. The patient is also given glasses with an attached camera and a portable video processor. This system, called Argus II, allows visual signals to bypass the

damaged portion of the retina and be transmitted to the brain.

With the artificial retina or retinal prosthesis, a blind person cannot see in the conventional sense, but can identify outlines and boundaries of objects, especially when there is contrast between light and dark--fireworks against a night sky or black socks mixed with white ones.

"Without the system, I wouldn't be able to see anything at all, and if you were in front of me and you moved left and right, I'm not going to realize any of this," said Elias Konstantopolous, 74, a retired electrician in Baltimore, one of about 50 Americans and Europeans who have been using the device in clinical trials. He said it helps him differentiate curbs from roads, and detect contours of objects and people. "When you have nothing, this is something. It's a lot."

The F.D.A. approved Argus II, made by Second Sight Medical Products, to treat people with severe retinitis pigmentosa, in which photoreceptor cells, which take in light, deteriorate.

The eyeglass camera captures images, which the video processor translates into pixelized patterns of light and dark, and transmits them to the electrodes. The

electrodes then send them to the brain.

"The questions that this particular device raised for F.D.A. were very new," said Dr. Malvina Eydelman, the F.D.A.'s director for the Division of Ophthalmic and Ear, Nose, and Throat Devices. "It's a big step forward for the whole ophthalmology field."

About 100,000 Americans have retinitis pigmentosa, but initially between 10,000 and 15,000 will likely qualify for the Argus II, according to the company. To be eligible, people must be over 25, have previously had useful vision, and be so visually impaired that the device would be an improvement.

But experts said the technology holds promise for others who are blind, especially those with advanced age-related macular degeneration, the major cause of vision loss in older people, affecting about two million Americans. About 50,000 would be impaired enough for the device to help, said Dr. Robert Greenberg, Second Sight's chief executive.

In Europe, Argus II received approval in 2011 to treat severe blindness from any type of outer retinal degeneration, although so far it is marketed there for retinitis pigmentosa. In the United States, additional trials are necessary for such approval.

Eventually, the company plans to implant electrodes directly into the brain's cortex to "allow us to address blindness from all causes," Dr. Greenberg said.

Initially, Argus II will be available at seven hospitals in

New York, California, Texas, Maryland and Pennsylvania. It will cost about \$150,000, excluding surgery and training. Second Sight said it was optimistic that insurance would cover it.

Argus II was developed over 20 years by Dr. Mark S. Humayun, an ophthalmologist and biomedical engineer at the University of Southern California. Some financing came from private sources and the National Eye Institute, the National Science Foundation and the Department of Energy, all federal agencies.

Dr. Humayun said he envisioned applying the technology to other conditions than blindness, implanting electrodes in other parts of the body to address bladder control problems, perhaps, or spinal paralysis. "We don't think of the human body as an electrical grid, but it runs off electrical impulses," he said.

The Argus II was approved under a special F.D.A. program designating it a "humanitarian use device," which Dr. Eydelman said applied to therapies that would be used for fewer than 4,000 people a year. Argus II is only the 57th humanitarian device exemption granted by the agency. Companies applying for humanitarian device approval can conduct much smaller clinical trials--Second Sight submitted data on only 30 patients--and must only demonstrate safety and "probable benefit," not proof of effectiveness, Dr. Eydelman said.

The F.D.A. worked with Second Sight to develop ways to measure that benefit, including tasks like

walking on a sidewalk without stepping off, and matching black, gray and white socks.

Of the 30 Argus II clinical trial patients, 11 experienced a total of 23 negative effects, the F.D.A. said, including retinal detachment and erosion of the clear covering of the eyeball.

Dr. Eydelman said the company had "taken substantial steps" to address safety concerns, making "many device modifications." Dr. Greenberg said only two people needed to have the implant removed. An F.D.A. advisory panel voted unanimously last September to recommend approval, finding that benefits outweighed the risks.

Some patients see more improvement than others, for reasons the company has not been able to determine. Kathy Blake of Fountain Valley, Calif., said she has had success with a Second Sight exercise to see if patients can identify large numbers or letters on a computer screen.

Dean Lloyd, a lawyer in Palo Alto, Calif., said he initially wondered, "Is it really worth all the time and expense? I, at first, did not think so." Early on, only nine electrodes were working, but over time his implant was adjusted so more electrodes responded, and now 52 of them work. He can see flashes of color, something not every patient can, and he wears the glasses and video processor constantly.

"If I don't wear it, it's like I don't have my pants on," he said. "I've even fallen asleep with the blooming thing."

Stephen Rose, the chief research officer for the Foundation Fighting Blindness, which supported Dr. Humayun's very early work but has not financed it since, said the artificial retina would eventually be only one of the options to help blind people.

"I think there are tremendous possibilities," he said. "I'm not downplaying the retinal prosthesis, don't get me wrong. It's huge for some individuals, and it's here now."

Barbara Campbell, 59, relishes how the device helps her navigate Manhattan streets, locate her bus stop, and spot her apartment building's foyer light while riding in a taxi. Most exciting, though, is how it enhances her experience of museums, theater and concerts.

At a performance by Rod Stewart, "I could definitely see his hair," which was white-blond under the lights, she said. At a concert by Diana Ross, even though Ms. Campbell sat far away from the stage, she said Ms. Ross "was wearing a sparkly outfit, and I could see her." No such luck at a performance by James Taylor, though. His low-key clothing created no contrast for the artificial retina to register. Alas, Ms. Campbell said, "He wasn't so sparkly."

# **Better Vision In Sight for Suffers of Age-related Eye Disease**

**submitted by Joyce Kleiber**

[This is a summary of an article from John Hopkins Medicine for winter, 2013, issue 19.]

The Johns Hopkins Wilmer Eye Institute is one of the first in the country to offer an implanted miniature telescope. This device replaces the eye's natural lens and can help certain people with age-related macular degeneration (AMD). With this implant, many patients will recognize facial expressions, pick up cues to social interactions, view television, and track moving objects more easily. An implanted miniature telescope is an alternative to external telescopes that can be

cumbersome and provide a narrow field of vision.

Ideal candidates for the implant are people ages 75 and older who have stable AMD, aren't undergoing active injection or laser treatment, haven't had cataract surgery in at least one eye, and experience a measured benefit using an external telescope. According to a long-term safety study, the implant, which Medicare covers, improves vision an average of three lines on the eye chart.

For more information, appointments or consultations, call the Wilmer Eye Institute at 877-546-1872.

## **Tidbits**

**compiled by Mike Keithley**

The Virginia M Wolf Foundation produces black & white large print material and distributes it in PDF format through CD or downloads. They have fiction and nonfiction offerings plus diabetes and veterans documents. You can reach the Foundation by emailing [woolf-foundation@ca.rr.com](mailto:woolf-foundation@ca.rr.com).]

If you like to collect recipes, you might want to join the Mamas-Corner email list. You receive a daily recipe, and they are accumulated in collections that you are able to download. Existing collections apparently include "Best Recipes: From the Backs of Boxes, Bottles, Cans and Jars" and "Great American Recipe

**Card Collection." To join, send a blank message to [mamas-corner-subscribe@yahoogroups.com](mailto:mamas-corner-subscribe@yahoogroups.com).**

**The National Library Service is conducting an online or phone survey to understand how to better serve the needs of readers of talking books and braille plus services non-NLS people are looking for. Access it at [www.icfi.com](http://www.icfi.com) or call 866-545-1618.**

**Beginning August, 2013 the US Postal Service will adopt a new delivery schedule of six days of package delivery and five for mail.**

**The American Foundation for the Blind has developed a search tool to list video described TV shows in your area. Access [www.afb.org/tv.aspx](http://www.afb.org/tv.aspx). Also five channels of video-described TVShows can be heard on your computer by accessing [www.blindy.tv](http://www.blindy.tv).**

## **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 1317540.**

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**Please send the American Council of the Blind Braille Forum in:**

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