Welcome to the winter, 2013 issue of Vision Access, the best affiliate magazine in all of ACB!

"O come on now, Master, isn't that a bit much?"

That's King my last guidedog who passed on six years ago and who hangs around with interesting remarks. Don't mind him! If I ever find that cynical hat he's wearing, I'll take it away. "That'll be the day!"

Anyway, I hope you enjoy the collection of articles you'll find here. Barbara Milleville contributed a Washington Post piece where NCCLV is highlighted in its campaign for better lighting in Washington Metro stations, and in the Assistive Technology column we have information on the new VisionEdge lighting system for
effective reading from Jasper Ridge Inc, a small company based in San Mateo California. Our "People" article is by Charles Nabarrette, who pursued a legal career despite his worsening vision. He leaves us with the inspiration that it's refreshing giving up an aspect of living that no longer works, thus its title, which might be discouraging to some, but shouldn't be.

And there's more!

Letters to the Editor

From Mike Vogl: Congratulations on your first issue (Fall 2012) as the new editor of VISION ACCESS. You presented a good selection of articles. I especially liked Come On People, Have Some Vision. It was informative, inspiring and "entertaining." It is good to hear how others have dealt with their low vision. Keep up the good work, Mike.

I would like to take this time to acknowledge and thank Joyce Kleiber for her many years of hard work and dedication and skill in producing excellent volumes of VISION ACCESS. I found every issue filled with a diversity of topics: informational, educational, technical, and motivational. I am sure I speak for all the readers as we send you a big THANK YOU, JOYCE!

From Ken Stewart: In the fall issue, I found “Come On People, Have Some Vision!,” submitted by Lucinda Talkington and authored by her daughter Marilee, quite interesting. There Marilee described her experiences auditioning for acting roles with her low vision.

In closing, let me tell you that it has been announced that the Let's Talk Low Vision conference has been canceled until further notice. Let's bring it back! Enjoy!

Correction

In the last issue (volume 19 No. 3) the byline for the article "Come On People, Have Some Vision!" is incorrect. It should be "by Marilee Talkington." My apologies for this error.
auditioners that throughout his audition, and probably mine to, the Warner Brothers staffer was on the phone behind his desk arranging his flight back to Hollywood!

As some Vision Access readers may remember, the part of the blind astronomer was played by Matthew McConaughey when Contact was released in 1997.

Editor’s note: In the spirit of Marilee’s article, let me add the following edited email.

2013 Script Writing Intensive and Competition for Students with Disabilities: The Kennedy Center is pleased to announce the new Script Writing Intensive for aspiring young writers with disabilities! The Intensive will bring a select group of high school writers with disabilities to Washington DC in September, 2013 for a weekend of pre-professional activities, including script workshops, roundtable discussions, staged readings, and more. The program is ideal for student-writers interested in writing for the stage or screen. The submission deadline is June 1, 2013. Please visit www.kennedycenter.org/PDP for more information. Cone on you low vision script writer, do it!

Organization News

The President’s Corner by Jim Jirak

Welcome to the holiday edition of Vision Access. As I begin my remarks, Christmas music has been playing on the radio for several days. Suffice it to say that I enjoy the sounds of the season. To all receiving this magazine in your media of choice, here’s hoping the holiday season is merry and bright and the New Year filled with nothing but peace, joy and happiness.

Continuing on, I am proud to announce that the Council of Citizens with Low Vision International (CCLVI) along with our parent organization, the American Council of the Blind (ACB), has been selected to sit on the US Access Board’s working group. This group will be tasked with identifying best practices for the delivery of prescription drug label information so that it can be made accessible to individuals who are blind or visually impaired. The work is intended to promote privacy and independence for individuals who take prescription medication. It appears to be a well-balanced representation of consumers and industry representatives.

With thanks to the Access Board for providing background information, the Board is undertaking an initiative to improve access to prescription drug labels. As part of this effort, the Board has organized a stakeholder working group to develop best practices for making information on prescription drug container labels accessible to people who are blind or visually impaired or who are elderly. This group includes representatives from advocacy and industrial organizations that include: American Council of the Blind, American Foundation for the Blind,
The working group will develop best practices for pharmacies on providing independent access to prescription drug container labels. Various alternatives will be explored, including braille, large print and auditory technologies such as "talking bottles" and radio frequency identification tags. The Board gained the responsibility to address this issue under the Food and Drug Administration Safety and Innovation Act that was signed into law in July, 2012. The law also calls upon the National Council on Disability to conduct an informational and educational campaign in cooperation with the stakeholder working group to inform the public, including people with disabilities and pharmacists, of the best practices.

With that said, I am pleased to announce that CCLVI's representative on this Board is Annette Carter. CCLVI is charged with emphasizing the low vision aspect of text on drug labels. Susan Crawford, chair of this committee, has been given CCLVI's low vision guidelines as part of our input. Look for periodic updates in future Vision Access publications.

Finally, CCLVI was recently approached by Lainey Feingold concerning its participation in providing low vision feedback on accessible mobile tools for a major entity's website. This project is being spearheaded by our very own Donna Pomerantz under the auspices of our web committee. If all goes well with this endeavor, it is hoped CCLVI can be the "go to" organization for low vision feedback for other entities seeking guidance in this area. Stay tuned!

Until next time, remember that a picture is worth a thousand words, but spending the holidays with family and friends is priceless.

CCLVI Scholarship Announcement

The Council of Citizens with Low Vision International (CCLVI) will award three scholarships in the amount of $3,000 each to full-time entering freshmen, undergraduate and graduate college students who are low vision, maintain a strong GPA and are involved in their school/local community.

Application materials must be received by March 1, 2013. Scholarship monies will be awarded for the 2013 - 2014 academic year.

To read the scholarship guidelines and complete an on-line application, please visit www.cclvi.org and click on the CCLVI Scholarship Programs' link.

Applications will be available to submit on-line until March 1 at 11:59 pm Eastern Standard Time. Questions may be directed to CCLVI at 800-733-2258.

We look forward to receiving your application materials!
CCLVI Fourth Quarter Board Meeting
by Mike Keithley

This is a summary of proceedings and is not official. The CCLVI Board held its fourth quarter meeting on Monday, November 12, 2012 at 8:30 PM ET. President Jirak called the meeting to order and read the agenda, which was accepted. Secretary Lindsey Tilden called the role. Absent were Lucinda Talkington, Donna Pomerantz and Michael Byington. All standing committee chairs were present.

Minutes from the August 2 meeting were read and, following several amendments, were unanimously approved. In addition to posting board minutes to the board list within 30 days following the proceedings, a motion was approved that Minutes be posted to the Board’s email list for review one week before scheduled meetings and that corrections be emailed to Lindsey for incorporation into formal Minutes that would be approved during the scheduled meeting.

The Treasurers report was read. It was agreed that this report be distributed on the CCLVI Board email list and handled like the Minutes.

It was agreed that the CCLVI pre-convention Board meeting will be at 3 PM on Friday, July 5. CCLVI's convention is part of the ACB convention that runs July 4 to 12.

President Jirak described his intention to have a monthly "Office hours" phone conference starting in January, 2013, date to be advised. Office Hours will help Jim keep in contact with us and appoint chairs for standing committees that currently don’t have them.

ACB now requires the phone numbers and email addresses of all members. This is a new wrinkle and you should contact Membership Committee chair Jeff Harris at jdh9257@yahoo.com or call 617-254-9861 to update your info.

Jim reported on CCLVI’s participation on the Access Board stakeholders group. See President’s Corner in this issue. You can check the Access Board’s website at www.access-board.gov to track the progress of the group. Discussion took place surrounding compensation for CCLVI's representative on the board. While there was no official motion, unanimous consent was that CCLVI needed to pay for being represented.

CCLVI will participate in December and January, 2013 meetings with ACB's Board of Publications to give feedback on the ACB large print convention program.

Kathy Casey, Convention Committee chair, discussed programming for CCLVI's convention this July. It will be similar to last-year's program but she is thinking about Toast Master
activities that might include an article in the Toast Master magazine about Toast Masters at ACB. Kathy is actively looking for people to serve on the Convention Committee, which has its next meeting in January, 2013. Jeff Haris, Membership Committee chair, reported on the committee's October 17, 2012 meeting where procedures for updating the membership database were discussed including the new ACB requirement summarized above.

Mike Keithley, Publication Committee chair, reported that the committee will have regularly-scheduled conferences after each Vision Access is produced to monitor the quality of the magazine. Also back issues of Vision Access will be posted in their entirety on the website and rendered in HTML.

Mike Gravitt, Scholarship Committee chair, reported that advertising for the 2013-2014 CCLVI scholarship is proceeding and thanked Annette Carter for the performance of the website. See the scholarship announcement in this issue. Work commences on forming policy for American citizens studying abroad.

Annette Carter, website Committee chair, read a document written by second Vice President Donna Pomerantz describing the need for ten people to do testing of entity websites implementing better low vision accessibility. If you want to be connected with this group, contact Annette at annette.carter@pacbell.net. We also heard about a wish-list of improvements to CCLVI’s website, and one item concerned monetary compensation to the web master. Implementing this item requires a constitutional amendment as people providing services for CCLVI currently cannot be compensated.

There was no update on changing the 800 number.

A discussion followed regarding using a phone conference number that allowed recording. This number would be used for Board and committee meetings. A motion was passed empowering President Jirak to find one.

The next CCLVI Board meeting will be on February 11, 2013 starting at 8:30 PM ET with the number and ID code distributed via the Board list. The meeting adjourned at approximately 10:30 PM ET.

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Chapter news

MCLVI News
by Ken Steward


Last October, 2012 the Chapter met via conference call and friends of the Chapter were welcomed to join in the discussion of a variety of topics, mainly focused on local transportation.
Strategies for indicating to an approaching local bus that you are waiting for that bus and not just waiting to cross the street were identified, including facing toward the direction of its approach, and conspicuously holding out your fare card or fare.

Design features of new information displays that are coming to some New York City subway stations were considered. The Chapter is advocating to Transit Authority officials to incorporate audible and floor-tactile features to aid finding those information sites as well as technologies that could be used to allow a low vision user to control the level of brightness and font size of visual text being presented.

There was consensus during the conference call that the Vehicle Identification Number (VIN) of each local transit vehicle should be presented in accessible formats at an approachable place within the vehicle that a passenger could read, thus enabling a more effective complaint submission. It was observed that the bold availability of the VIN, such as just behind the bus driver’s seat, might also have the secondary benefit of motivating that driver to try harder to please his customers!

During the conference there also was discussion about what constitutes the most readable signage presenting information about a nearby point of interest, such as a landmark building. Those signs of course, are limited by size and curbside positioning restrictions.

Everyone was informed about the most recent policy changes relating to the use of paratransit, known as Access-A-Ride in New York City.

The call participants agreed on the importance of visual aspects of subway stairs and the proper positioning of handrails.

As this report goes to press, we are still learning more about how Chapter members fared during and after hurricane Sandy that arrived just before Halloween. Some of our members had to manage without heat and power for days. Fortunately Several were able to flee to unaffected neighborhoods. One person living without heat or power described being unable to find his way to an emergency shelter independently due to the absence of accessible building addresses on the streets of powerless lower Manhattan. (the New York City Code does not yet require building addresses to be presented immediately adjacent to entrances in large, high contrast raised letters.)
Metro riders tire of being in the dark, press for better station lighting

By Luz Lazo

Washington Post
December 1, 2012

Barbara Milleville, of the National Capital Citizens with Low Vision, at Farragut North Metro station on November 27, 2012 in Washington, DC. (Photo by Bill O'Leary/The Washington Post)

Everywhere you look, Metro seems to be busy rebuilding the subway system. That is, if you can see much of anything. As Metro spends billions to repair escalators and elevators and upgrade miles and miles of track, some riders and rider advocates say the transit system is continuing to neglect an even more basic need: light.

For years, many of Metrorail's stations have been plagued by dim - even dark pockets, yet better lighting has remained a low priority. Riders complain that stations are too dimly lit to read a newspaper or even make out an escalator step.

Wheelchair users and the visually impaired say navigating the system is even more difficult when the stations are too dark.

Farragut North - one of the busiest stations in the system - has gained a reputation as one of the darkest in town. "I call it the cave," Metro board member Tom Bulger said at a recent board meeting.

To focus attention on the problem, a group of rider advocates has inspected nearly 70 percent of Metro's stations and has confirmed what riders already knew.

"We have found that this is a very severe problem, and it impacts everyone in the low-vision community as well as the general public," said Barbara Milleville, president of the National Capital Citizens with Low Vision.

Milleville, who has limited vision, worked with members of Metro's Accessibility Advisory Committee to...
audit the stations. They plan to present their findings and recommendations to the Metro board this month and will urge the agency to incorporate the lighting needs into next year's budget. "In the past, lighting was not a priority, and we are trying to say it needs to become a priority," Millville said.

Over the past few years, Metro has had a lot on its plate. From catching up on long-delayed maintenance to making rail travel safer after the deadly Red Line crash in 2009, the transit system has been running a system and rebuilding it all at once.

Advocates acknowledge those needs but say they don't want lighting to, yet again, take a back seat to higher-profile needs.

It is a fundamental challenge facing Metro: how to carry out the work required to make the system safe and viable for the 21st century while ensuring reliable, comfortable service to the passengers of today.

A commuter heading home after a long day might want to read a book without having to canvass the platform for the rare spot with good light. A disabled rider with few options besides public transit might fret about navigating the inherent hazards of a subway station when the lighting is lacking.

Lighting problems in Metro are complicated by the distinctive architecture of the system, which opened in 1976. Designers wanted soft, indirect light that would highlight the cathedral-like arches of the underground stations. And, indeed, images of the system are known by subway aficionados around the world.

But that has made enhancing lighting a tricky endeavor. "In a sense, [the architects] wanted to create a kind of ambiance that gave you a feeling that you were underground and in a place that had a bit of mystery to it," said Roger K. Lewis, an architect and professor emeritus of architecture at the University of Maryland.

"It is quite difficult to remedy or fix the problem without destroying the original idea that goes back with the design. It takes a lot of careful analysis to do it right."

And then there is Metro's lax maintenance of the existing lighting, with dead bulbs common among the 300,000 fixtures at all of Metro's facilities. Improving lighting comes down to money, especially with budgets tight, said Lewis, who years ago was a consultant to Metro in a lighting design study.

Despite such studies and some improvements, many stations have uneven levels of lighting that make it difficult for riders inside the trains even to spot the station names on the walls along the tracks.

Some riders also worry that the poorly lighted platforms combined with ongoing construction at several stations create an unsafe environment. "It can be dangerous when people are running to catch the train," said John Federico, a Bethesda resident with partial sight who recently tripped into a construction cone inside Farragut North. "When the lighting is inconsistent, it is difficult to maneuver," he said. "Everybody can benefit from consistent lighting. You don't want people tripping."
Katrina Chavers, a daily Metro user who travels between the Shady Grove and Smithsonian Metro stations, agreed that lighting is often lacking. "It would be great to have some improvements," she said.

Any significant enhancements, however, would be costly to the system that is now in the middle of a $5 billion reconstruction that focuses on safety and performance. The Accessibility Advisory Committee says better lighting is needed on platforms, in the walls along tracks, and around the elevators, escalators and kiosks.

Improvements at about 40 stations noted in the group's report could cost nearly $25 million, according to estimates from Metro engineers. Improved lighting at Farragut North alone is estimated at $550,000. Metro officials say they welcome the committee's recommendations and say efforts to improve and maintain the lighting are ongoing. The agency has a pilot program at Judiciary Square where extra lights were installed at the F Street entrance mezzanine.

Six years ago, Metro's leadership said crews would replace burned-out bulbs within 10 days instead of three months and would do a total replacement and inspection of station lights every 10 months. Metro would not say whether that policy is being followed. But agency spokeswoman Caroline Lukas said Metro has a preventive maintenance schedule for light bulb replacement and that staff workers change out single bulbs when outages are reported. "If a customer reports a burned-out bulb, we make every effort to replace it as soon as possible," she said, adding that some lights are in difficult locations that can affect the replacement time.

Some lighting advocates, however, say the level of maintenance remains a top concern. "We are having a difficult time really finding out how often the light bulbs are supposed to be checked," said Marilyn Lutter, a member of the Accessibility Advisory Committee and head of the group that inspected the stations. The group counted numerous light bulbs out. Last month, for example, 69 dead bulbs were recorded at West Falls Church. "We wouldn't be finding burned-out light bulbs if indeed the light bulbs were monitored regularly," Lutter said. "There needs to be a clear policy that is very much enforced."

Metro officials say the agency has been moving toward more energy-efficient fixtures to reduce power costs and increase illumination. "With the size of our system, this isn't a quick change," Senior Planner Allison Davis wrote on the agency's online discussion board, where riders submit ideas for improvements.

Metro board members say they look forward to discussions about how to make the system brighter. "I think our standards were set on another era when there was not necessarily the same sensitivity about the environment or those with diminished vision capacity," Metro board member Tom Downs said at a recent board meeting.

The board, he said, welcomes the recommendations and is "anxious to pursue this in a way that it is constructive for all of the riders of the system."
Assistive Technology

New Hands-free, Portable Illumination: More Light, Less Glare
By Michele Klein

Millions of people have vision loss from causes such as macular degeneration, retinitis pigmentosa, Stargardt’s and aging, and need bright light without glare.

The new VisionEdge™ light is designed especially to help people with low vision to work, read small print, see menus in dark restaurants, and read in bed or on airplanes. It has many user features making it uniquely suited for those with low vision.

The VisionEdge VE-100 is made by Jasper Ridge, a Silicon Valley company that develops products to leverage the intersection of eye physiology and optical physics. It was recently exhibited at the Envision Conference 2012 (St. Louis MO), the Academy of American Optometrists (Phoenix AZ) and the California Optometric Association (Monterey CA).

The portable VisionEdge reading light has12 LEDs, delivering10-100X the illumination of conventional task lights or book lamps. At just 0.4 oz, its hands-free design enhances mobility. With rechargeable batteries, you never need to replace or buy new batteries. The VisionEdge uses special circuitry to maintain stable output for the full battery charge, unlike many battery-powered lights that dim as the battery ages. VisionEdge optics focus light only on the area being read (like a typoscope or reading guide), eliminating reflected light from the rest of the page. This reduces the eyestrain associated with glare. Patents pending.

Doctors’ studies with several hundred low vision patients, most with macular degeneration, show significant improvements in performance with VisionEdge lighting.

In one experiment on 152 patients in a low vision clinic, 88% of patients improved their reading performance an average of 2 lines on a logMAR reading card by using the VisionEdge at its high setting.

Studies by the Veterans Administration further indicate that use of colored LEDs, optionally available with Vision Edge, together with patented Jasper Ridge optics may provide improved comfort, especially with macular degeneration.

VE-100 allows many people to work and read more comfortably. Clips on glasses and visors Uses 12 high-brightness, long-lasting, safe LEDs Prevents excess glare and hot spots with special lens Uses rechargeable battery that never needs changing; runs 7-12 hours on a single charge, and can run while charging Maintains constant output through full battery charge Includes AC adaptor and travel case.
Every VisionEdge comes complete with an AC adaptor, controller, wire manager, manual and ballistic nylon travel case.

The VisionEdge™ was designed for people who want bright light without glare and the convenience of portability. The intense, uniform and directed light provides hands-free illumination without shadows or bulky lighting fixtures.

The VisionEdge™ illuminator mounts on most glasses, including many with thicker frames and lenses. The lightweight design (0.4 oz) allows it to be worn comfortably. The durable, soft, non-abrasive clips easily slide on glasses. For detailed work, it can be used with 2-5 diopter reading glasses. The illuminator clips easily attach to a visor, cap or headband. Just slide the clips onto the brim and adjust the tilt. This is a good alternative for those with bifocals, progressive lenses, and thick glass frames or lenses.

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The VisionEdge can supplement hand magnifiers. For best results, mount the illuminator on a visor or cap, and tilt it so that the beam shines under the magnifier.

The VisionEdge can be used with non-back-lit e-readers such as the Amazon Kindle.
Suggested activities
working or reading in dim light
reading in bed, or on planes or trains
writing checks and reading financial
statements assembling mechanical or
electrical parts woodworking, sewing
& other fine work, playing cards or
board games reading pill bottles

VisionEdge™ light, made in USA, is available from Jasper Ridge Inc.
www.jasperridge.net
info@jasperridge.net
650-804-5040

People

My Journey to Blindness by Charles D. Nabarrete

It began on February 5, 1965. I was nineteen years old, and attending Mt.
San Antonio College at the time. I had been accepted by UC Berkeley, but decided to attend junior college for financial reasons.

After not sleeping the weekend before because I attended the Winternationals drag races and was working a graveyard shift on weekends, I awoke on February 5 with extremely bloodshot eyes and blurred vision. During the next week I lost all sight due to detached retinas.

When I went to an Ophthalmologist, he could not diagnose the condition and consulted the Jules Stein Eye Institute. Thereafter I was treated with large
doses of Prednisone and anti-inflammatory eye drops. I was diagnosed with Vogt Koinagi Haradas Syndrome (VKH or Haradas disease, which is a rare eye disease, I have only met one person with this condition. In addition to the detached retinas, my entire eyes were chronically inflamed, I had white cells in my spinal fluid, some of my hair turned white, and had vertigo.

After about six months of treatment, my vision returned to what I would characterized as being high partial. I had a lot of scarring on the retina, vision acuity of about 20/80 to 100. However the maculas were not significantly damaged, and I was able to read with magnification.

I continued my education in September 1965 and completed a bachelors degree and graduated from The UCLA School of Law in 1971. In August 1971 I took the California bar examination. At that time it was an essay only exam which lasted two and a half days. I did not ask for any accommodations, but each session had questions printed on separate pages and after two days I was almost unable to read them because they were written on red and some other dark colored paper. Despite these problems I successfully completed the bar exam on my first try. After that I worked for public interest and legal aid offices. I litigated several civil rights cases including the Los Angeles County Sterilization case as well as numerous criminal jury trials.

My vision deteriorated slowly because cataracts were developing due to the chronic inflammation and the medications I was taking. In July and December of 1975, I had cataract removal surgery that improved my vision again.

In May 1979, I decided to enter private practice. My eyesight continued to deteriorate despite steroids, anti-inflammatory eye drops and eye drops to control the glaucoma condition that had developed due to the chronic inflammation and the medications I was taking. In 1983, I finally admitted to myself that I was visually impaired and might go blind. I joined the CCB Foothill chapter, which was led by Pat LaFrance-Wolfe at that time. In 1984, I purchased a CCTV machine using the Braille Institute partial funding program because I was no longer able to read with magnification devices. My practice was mainly Workers Compensation claims and car accident personal injury cases. I stopped doing Criminal trials because I was no longer able to select jury members effectively because of vision loss. In 1984, I underwent surgery on both eyes in an attempt to control the eye pressure. This surgery was somewhat successful, but my vision continued to get worse. Private practice became harder, not only because of vision loss, but also because when an adverse attorney became aware of my visual impairment, it would be harder to negotiate a satisfactory settlement for my client. By the late 1980's I felt that because of the stress of engaging in a private practice I would have to change careers.

Beginning in about 1986, I started to look into state or government employment. I was appointed an Administrative Law Judge for the California Unemployment Insurance Appeals Board (CUIAB) on August 31, 1990. In 1991, my vision had deteriorated to the point that I was no
longer able to use a CCTV effectively. An assistant was hired to read me files and assist me in hearings, and I began using a computer with a speech reading program, and and OCR program and scanner. By the late 1990's I had lost usable vision.

With the improvement of the Internet, the legal resources I needed for my current job are on line. I am able to judge credibility of witnesses well because research has established that patterns of speech and voice changes are better guides in determining credibility than facial expressions. In addition, I ask the witnesses questions; and if I have a doubt about the truthfulness of the testimony, I ask additional questions to clear up that issue. Effective examination is a good way to establish the credibility of a witness' testimony. The ALJ who trained me believed that I would develop into one of the best ALJ's in CUIAB, and I am generally considered to be a very good ALJ.

During the time I was losing sight I experienced a high level of stress. Since I have become blind, that stress has mostly gone away, and I feel that I can live a contented and happy life albeit a different one.

Science

NIH Study Suggests Immune System Could Play A Central Role in AMD
November 27, 2012: Changes in how genes in the immune system function may result in age-related macular degeneration (AMD), the leading cause of visual impairment in older adults, based on preliminary research conducted by National Institutes of Health (NIH) investigators.

"Our findings are epigenetic in nature, meaning that the underlying DNA is normal but gene expression has been modified, likely by environmental factors, in an adverse way," said Dr. Robert Nussenblatt, chief of the National Eye Institute (NEI) Laboratory of Immunology. Environmental factors associated with AMD include smoking, diet, and aging. "This is the first epigenetic study revealing the molecular mechanisms for any eye disease."

The study identified decreased levels of DNA methylation, a chemical reaction that switches off genes, on the interleukin-17 receptor C gene (IL17RC). The lack of DNA methylation led to increased gene activity and, in turn, increased levels of IL17RC proteins in patients with AMD. IL17RC is a protein that promotes immune responses to infections, such as fungal attacks.

The study, conducted by research teams from the NEI and other NIH institutes, including the National Heart, Lung, and Blood Institute and the National Center for Complementary and Alternative Medicine; the University of Melbourne, Australia; and Oregon Health and Science University, appears in the Nov. 29 issue of Cell Reports.

"Our study also suggests IL17- and IL17RC-mediated immune responses can be crucial in causing AMD," added
Dr. Lai Wei, also of NEI's Laboratory of Immunology and first author on the paper. "By measuring IL17RC gene activity in at-risk patients, we have also potentially identified an early method to detect AMD."

AMD damages the light-sensitive cells of the macula, the central part of the retina that allows us to see fine visual detail. As the disease progresses, patients encounter great difficulty reading, driving, or performing hobbies and tasks that require hand-eye coordination. Treatments exist to prevent severe vision loss in certain types of advanced AMD but none prevent or cure the disease. Currently, 2 million Americans have advanced AMD and another 7 million have intermediate stages.

Recent studies have identified several genes with alterations that increase the risk of developing the disease. In addition, environmental risk factors have also been suggested as possible causes of the disease. One explanation may be that environmental exposures influence DNA methylation, which regulates gene expression. Changes in this process may result in the production of too much or too little of a gene's protein, leading to cellular dysfunction and disease. Changes in DNA methylation have been implicated in cancer, lupus, multiple sclerosis, and many other diseases.

To test whether changes in DNA methylation might play a role in AMD, the investigators evaluated three pairs of twins—one pair identical and two pairs fraternal—where only one of the siblings had AMD. Identical twins have the same genetic makeup while fraternal twins share about half of their DNA. Because of their similar genetic backgrounds, identical and fraternal twins can be helpful in studying the differences between the effects of genetics and the environment. When compared with the unaffected twins, methylation patterns were altered in 231 genes of affected twins. This finding is consistent with the hypothesis that environmental exposures may epigenetically regulate expression of many genes and lead to AMD.

Among the 231 genes, the investigators found that DNA methylation was absent in a region of the IL17RC gene in twins with AMD. The lack of methylation in the IL17RC gene led to increased gene activity and, in turn, increased levels of its protein in circulating blood. The investigators further validated these findings by comparing seven siblings with and without AMD as well as 202 AMD patients and 96 control subjects without the disease. These studies also found increased IL17RC levels in circulating blood and, most importantly, in the retina of patients with AMD but not controls.

Based on these results, the authors propose that chronic increased levels of the IL17RC protein in the retina likely promote inflammation and recruitment of immune cells that damage the retina and lead to AMD.

"This study strongly implicates epigenetic DNA methylation as another crucial biological pathway for understanding the molecular basis of AMD," according to Nussenblatt.

The investigators next plan to evaluate what environmental factors may be responsible for the regulation of IL17RC and how the epigenetic regulation leading to the chronic
inflammation in AMD patients can be reversed by novel therapies. They will also evaluate the role of epigenetics in other eye diseases.

The National Eye Institute (NEI), a component of the National Institutes of Health, is the federal government's lead agency for vision research that leads to sight-saving treatments and plays a key role in reducing visual impairment and blindness. For more information, visit the NEI Web site at www.nei.nih.gov.

Tidbits

compiled by Mike Keithley

Social Security Payments and Federal Benefits
The US Treasury will no longer send paper checks as of March 2013, therefore anyone receiving federal funds will be required to either have their checks direct deposited into a specified bank account or they will be receiving the Direct Express MasterCard for future payments.

If you are currently using direct deposit you will continue to receive your monthly payment in the same manner unless you request a change.

Contact the Social Security Administration by dialing (800) 772-1213.

Filing A Video Description Complaint at the FCC
Since the video description requirements became effective in July, 2012, ACB has heard from many individuals who have experienced extreme difficulty in receiving described programming. We are aware that many cable/satellite companies have not adequately trained their customer service representatives to work with people who are blind or visually impaired to trouble-shoot these challenges.

We have created a video description complaint guide that is designed to more formally allow consumers to lodge their challenges with the Federal Communications Commission (FCC). The link to the guide is at acb.org/node/1014.

Book
Out of Sight Science Experiments is a new book from the National Braille Press that encourages vision impaired kids to get into science. Order the book at www.nbp.org/ic/nbp/SCIENCEEXP.html.

Scholarships
The following AFB page lists non-AFB scholarships and grants for students who are visually impaired: www.afb.org/section.aspx?DocumentID=1845

Tech Note 101 for Latest Tech News and Comment
The Tech Note 101 blog is a new Internet resource to read and discuss announcements of new technology. A project of Accessibility Dot Net, Tech Note 101 is at www.technote101.com.

Guide Dog Etiquette Tip sheet for Restaurants
The California State Board of Guide Dogs for the Blind has completed its second phase of developing a tip sheet of guide dog Etiquette in restaurants. It is available at www.guidedogboard.ca.gov/resources/restaurant_tips.shtml.

New AFB Low Vision Technology Webinar Series

The American Foundation for the Blind (AFB# Low Vision Technology Webinar Series is now available in the AFB eLearning Center. These four webinars are presented by Ike Presley and titles include: Overview of Technology for People with Low Vision; Using Video/Electronic Magnification Tools for Accessing Printed Information; Computer/Screen Magnification Technologies: Hardware & Software; and Other Useful Technologies for People with Low Vision.

Individual webinars can be purchased for $25 each from the AFB bookstore, or the entire series of four webinars is available for $65. The AFB bookstore can be reached at www2.afb.org/store.

In addition, the first webinar of the series, called Learning to Listen: Exploring the Link between Listening and Literacy Skill Development is also available for purchase through the AFB bookstore.

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.

2012 Membership Application

Name____________________________________________________
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City_________________________ State _____ Zip Code ___
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Membership Status: I am:
___ New member. ___ Life member of CCLVI.
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I wish to receive the CCLVI publication, Vision Access in:
___ Large print ___ Cassette ___ E-mail ___ Audio CD
_____Data CD _____Do not send
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Make check or money order payable to "CCLVI" and send to
CCLVI Treasurer:
Mike Godino
104 Tilrose Avenue
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Date Paid:_______, Date of Dep_________
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Council of Citizens with Low Vision International
2200 Wilson Blvd., Suite 650
Arlington, VA 22201
800-733-2258
www.cclvi.org

**CCLVI Officers, Directors and Committee Chairs**

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