

# **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 , May 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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**Joyce Kleiber, Sarah Peterson, and Mike Keithley**

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**From the Editor's Desk**

by Mike Keithley

Welcome to the Winter 2016 issue of Vision Access. Today the wind is blowing a wind-chime concert and rain is on the way - again. But the house is warm, the best place to be!

This issue is a bit late because I accidentally deleted a directory holding an almost-finished Vision Access. It took a long time to rebuild, and it underscores the need to frequently back up data. Don't let this happen to you!

But I recaptured Sarah Peterson's nice profile of Kathy Farina, and we'll learn about the frustrations of high-level advocacy.

In closing, let me point you to a weekly program on ACB radio called "Eyes on Success." It's a program about people with blindness or low vision. Check it out at [www.eyesonsuccess.net](http://www.eyesonsuccess.net). Speaking Out for the Blind is another program worthy of your attention. It used to be on ACB Radio but is now a separate podcast. I listen to it on my Victor Stream.

Enjoy!

**Organization News****Meet the 2015 CCLVI Scholarship Winners**

by Lindsey Tilden

For many years CCLVI board member Fred Scheigert has generously provided a scholarship fund. Every year three scholarships are awarded to students with low vision to assist them in pursuing higher education. One is awarded to an entering freshman, one to a current undergraduate student, and one to a graduate student.

Scholarship recipients are usually presented at the annual ACB Conference and Convention. Due to complications with the online application, the 2015 application process was significantly delayed. However, I am hopeful that we will be able to present the 2015 scholarship winners along with the 2016 winners in Minneapolis.

The 2015 freshman recipient is Andrew Shaw from Rye Brook, New York. Andrew graduated from Blind Brook High School and is studying Economics and Business at the University of Michigan. He has overcome many challenges with his vision, including several eye surgeries, all while keeping up with his school work. He participated in a competitive problem solving program

called Imagination Destination, worked at a children's summer camp and was a high school class officer. He enjoys using the iPad to complete his school work and is particularly interested in how assistive technology can help him achieve his educational goals.

Those who attended convention in Las Vegas will recognize the undergraduate winner Staci Mannella, who received the freshman scholarship in 2014. Staci, from Randolph, New Jersey, is in her second year at Dartmouth College majoring in Biology with a minor in Ethics. Staci's long term academic goal is to attend veterinary school and receive her DVM. An avid skier who competed on the U.S. Paralympic team in 2014, Staci took the last year off from skiing to focus on her academic goals. She competed on the D1 Varsity Equestrian team at horse shows, took an internship at a small animal clinic, and held leadership roles with the Dartmouth Pre-Veterinary Society and STAR program mentoring high school students with disabilities.

The 2015 graduate recipient is Antonio Vega, also a repeat scholarship winner, from Miami, FL. Antonio is studying Japanese Linguistics at the University of Hawaii at Manoa with plans to teach at the university level. He is especially interested in sociolinguistics and pedagogy. In addition to experience teaching Japanese

in Miami, Antonio has taught English and Spanish in Japan. Some of Antonio's teaching experiences in Japan were at a school for the blind. Since beginning his graduate studies, Antonio has become involved with the PR committee for the Hawaii Association for the Blind. Antonio enjoys attending lectures outside of his coursework requirements. He presented a paper at a linguistics conference.

I would like to take this opportunity to thank my 2015-2016 committee: Allen Casey, Kathy Farina, Sarita Kimball, Fred Scheigert, and Leslie Spooone. Their flexibility, support, and hard work made it possible for us to award scholarships for this academic year. Thank you also to Robert Spangler for his work on the website, which has allowed us to return to our usual application procedure. Lastly, I must thank Mike Gravitt for his advisory support to my new role as committee chair. The scholarship program takes the work of many individuals; and I am thankful for everyone who gives of their time, energy, and resources to make it all happen.

**CCLVI 2016 Scholarship Announcement**

by Jim Jirak

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 have low vision, maintain a strong GPA and are involved in their school and local community.

Application materials must be received by March 1. Scholarship monies will be awarded for the 2016 - 2017 academic year.

To read the scholarship guidelines and complete an online application, please visit <http://www.cclvi.org> and click on the 'CCLVI Scholarship Programs' link.

Applications will be available to submit online until March 1 at 11:59 pm Eastern Standard Time.

Questions may be directed to CCLVI at (800) 733-2258 or [scholarship@cclvi.org](mailto:scholarship@cclvi.org).

We look forward to receiving your application materials!

**CCLVI and Vendors Partner to Award Video Magnifiers In Honor of Dr. Samuel Genensky**

by Catherine Schmidt Witaker

The Council of Citizens with Low Vision International (CCLVI), Enhanced Vision, Eye Tech Low Vision, HEMS, HumanWare and Los Angeles Low Vision are proud to announce recipients for the annual Dr. Samuel Genensky Video Magnifier Memorial Award. The partnership recognizes and celebrates Dr. Genensky's achievements and thirst for knowledge. CCLVI is grateful for vendor partner contributions and the meaningful difference these awards are making in the lives of individuals who have low vision.

In 2015, five video magnifiers were awarded to individuals with low vision with demonstrated need and potential to significantly improve their daily living with the use of a video magnifier. Recipients were chosen from a competitive pool of applicants.

Tenth-grader Brianneth Rocha has set a goal to be her class Valedictorian. An Optelec Video Magnifier (donated by EyeTech Low Vision) will empower Brianneth to pursue learning and her goals.

Linda Allison is the recipient of the Acrobat LCD 3 in 1 Electronic desktop magnifier (donated by Enhanced Vision). Linda sees the video magnifier as a tool to see orders and paperwork as she seeks to open a BEP food prep vending facility. Linda is also the CCLVI Treasurer.

Possessing a love for learning and the sciences, Aswarya Pa is an engaged high school student. By helping her see her course materials, the Enhanced Vision Amigo portable video magnifier (donated by Los Angeles Low Vision) will reduce barriers to learning for Aswarya.

The Synergy Desktop CCTV (donated by HumanWare) is awarded to Jack Duffy-Protentis. Jack has been accepted to Wentworth Institute of Technology as a mechanical engineering major. His goal is to create a robot that will assist people with disabilities.

The Candi HD5 (donated by HEMS) has been awarded to Ashutosh Pai, a high school student who aspires to major in business in college and become a CEO of a company.

A video magnifier is a machine that enlarges print material on a monitor to a font size two to 10 times

larger. The magnifier also allows the user to change the background and text color to maximize color contrast and eyesight usability. It is often referred to as a Closed Circuit Television (CCTV).

Dr. Samuel M. Genensky, inventor of the first CCTV reading device for individuals with low vision, founder of the Center for the Partially Sighted in Los Angeles, and the founding president of CCLVI, passed away June 26, 2009. Dr. Genensky inspired and mentored many within the low vision community. For more information about the video magnifier award, visit [www.cclvi.org](http://www.cclvi.org) and click on "scholarship and Awards." CCLVI and vendor partners award video magnifiers annually to individuals who have low vision. We welcome applications during our application time period.

## **New Initiative**

by Jim Jirak

CCLVI is launching an ambitious initiative: If you were a one-time member, re-connect with individuals who share a common theme: low vision.

As Membership Chair, I'm reaching out to encourage you to consider either renewing your membership or joining for the first time. By inviting you to join CCLVI,

we hope to strengthen our ranks, while providing education and greater opportunities for advocacy with a focus on Low Vision!

To be counted and certified for the upcoming convention (July 1-9 in Minneapolis, Minnesota), we must have the final count to our parent organization (American Council of the Blind) no later than 11:59 PM. on March 15, 2016. Because of this constitutionally mandated deadline, I need to hear from those wishing to renew or join no later than March 11. A membership application with the dues structure can be found in this magazine, on our website at [www.cclvi.org/node/38](http://www.cclvi.org/node/38) or by calling 800-733-2258. Please note that if you are applying or renewing as a CCLVI member at large, you can pay your dues on the CCLVI website.

In the words of Helen Keller, "Alone we can do so little. Together we can do so much."

## **Registration for 2016 Midyear Meetings**

by Eric Bridges

Registration for the 2016 Midyear Meetings is now available! Please visit [register.acb.org](http://register.acb.org). The meetings are Saturday, February 27, through Monday, February 29.

The Board meeting will be held on Saturday, February 27.

Affiliate presidents meeting will be Sunday, February 28.

Legislative seminar will be Monday, February 29.

Capitol Hill day is Tuesday, March 1.

We will be meeting at  
Crowne Plaza Old Town Alexandria  
901 N. Fairfax Street, Alexandria, VA 22314  
703-683-6000  
[www.cpoldtownalexandriahotel.com](http://www.cpoldtownalexandriahotel.com).

The program agendas for the Affiliate Presidents meeting and Legislative Seminar will be disseminated as we get closer to these events. We look forward to seeing many of you. If you have questions, please do not hesitate to ask.

I hope that you had a safe and wonderful holiday season!

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**Advocacy Is Key: Meet Kathy Farina**

by Sarah Petersen

Whether referring people to community services at the mental health clinic, lobbying at state legislature meetings, or helping students further their education, Kathy Farina is dedicated to making a difference.

Hailing from a suburb a few miles north of Albany, New York, Kathy has a love for the northeast that was evident only moments into our November afternoon chat.

"The colors are pretty this time of year, and it's kind of chilly today," she described. "We get the changing of seasons here - I like that."

Kathy resides in Albany with John, her husband of 24 years. She reaches out to many community members through her social work position at the Albany County-Mental Health clinic. When not at work, she frequently takes advantage of the area's political happenings, advocating for various causes.

Born with retinopathy of prematurity and a member of the low vision community, Kathy finds empowerment through participating in various organizations and the camaraderie she's found with their members. She is involved with the American Council of the Blind, serving as the New York state affiliate president and Capital District chapter secretary. Each April, she and other members hold a legislative meeting to discuss current issues, as well as talk with state senators and representatives. Recent hot topics for the group include accessible traffic signals, large print restaurant menus, and accessibility for traffic signals, convention registration forms, and voting machines for local elections. She also represents CCLVI on the national Board of Directors. One of her favorite ways to serve is participating on CCLVI'S Fred Scheigert scholarship committee.

"I enjoy talking with the young people and reading about the things they're doing," she said. "There are

some awesome things they're doing out there! It's important to encourage people to get the education they need, because education is key to getting a good job."

Although affiliated with ACB for 30 years and CCLVI for 15, she vividly remembers feeling alone before her involvement, especially since she was the only person she knew with low vision.

"I read about all the interesting, inspiring things people were doing in the Braille Forum and Vision Access, and I felt like I was on the sidelines," she remembers.

"That's when I realized it was time to get involved."

Kathy has no vision in her left eye and 20/400 vision in her right eye. She learned Braille as a child, and she uses a white cane and various magnifying devices. While she admits it's not good vision, she appreciates that it's stable. Albany provides a good bus system and is a very "walkable" city. These tools help her overcome many obstacles, but her job remains the biggest challenge.

During her 27 years of social work at the clinic, she has been the only employee with a visual impairment. The facility has recently upgraded its own computer program which employees use to complete clients'

paperwork and records. Unfortunately, this new system does not work well with Kathy's JAWS and MAGic screen reading software. She continues to use the old system, despite several attempts to make the new one compatible with her assistive technology.

"It's not economical for them to find something different for one person," she explained. "But I'm retiring December 31, so I can stick it out. You have to pick your battles."

Kathy's retirement will mark a new chapter after many wonderful adventures. She obtained a Bachelor of Psychology from Pace University in 1977 and her social work master's degree in 1988 from the University of New York in Albany. After graduating from college, Kathy held a clerical position at the Watervliet Arsenal. After December, she looks forward to continuing hobbies such as Ham Radio, singing as a soprano in her church choir, reading, knitting and crocheting, visiting the gym, and doing volunteer work. She is even considering opening her own private mental health practice.

Most of all, Kathy is eager to spend more time with John, her husband she first met years ago at a program for youth with low vision. Completely blind, John has

the same eye condition and uses a Seeing Eye dog. He also holds a Master of Social Work. "He has been very helpful, and he's a positive influence with a good attitude," she described fondly.

Kathy cites her Teacher of the Visually Impaired as another positive influence. "She expected me to live up to my potential," she said. "She wouldn't let me get lazy, and she was insistent that I do the best I could. It helps when you have people who expect you to succeed."

She also remembers her father as one of her biggest supporters, assisting her when she quit her job at the arsenal so she could complete an internship. He helped her pursue her dream by reading for her and assisting her in library research. "He was concerned because I'd be without insurance and benefits at that time, but he knew I felt it was worth it," she remembered.

As time passes, Kathy is aware of the different challenges arising for the low vision community. For instance, technology changes so quickly that it's often difficult for people to keep up. According to Kathy, it's our job to stay on top of things by either learning new software or advocating for more accessible items as new tools become available. Because people with low

vision comprise such a small percentage of the population, we must be up for the challenge of reminding the public that we need to use the products too.

"We have to be diligent so that we can keep using technology," she said. "We've come a long way in developing the cutting-edge tools we need, but it's our responsibility to learn about new products and make sure we're not forgotten."

Being self-sufficient and one's own advocate are Kathy's top pieces of advice for individuals with low vision. She encourages people to learn all the skills and tools they can so they have a variety of ways to do things. Advocacy and educating the public, she reminds us, does not end at graduation; rather, it continues throughout our lives. Most of all, we must actively choose to be part of the solution, not the problem. For instance, employers will be more willing to help if we let them know what we need.

"Be your own best advocate, and remember that being belligerent, angry, and demanding things likely won't get you what you need," she encouraged. "Advocacy is about knowing ourselves, identifying our needs and being willing to explain them to others."

**Let's Talk Low Vision 2016 Schedule of Topics**

Submitted by Dr. Bill Takeshita

Each month, the Council of Citizens with Low Vision International (CCLVI) provides a forum addressing topics of concern to people with low vision. This forum is 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 participate in the conversation, please call 712-432-6100 and enter the participant passcode: 256613 #.

Note: All topics and speakers are subject to change. Please check [cclvi.org](http://cclvi.org) periodically for updates.

Tuesday, January 19, 2016: How to cope with low vision: Having low vision and the recent loss of vision are very difficult experiences to overcome. Dr. Bill shares how he has been able to overcome anger, frustration and depression after losing his perfect vision.

February 16: How to communicate with friends and family members to let them know how and how not to help you: Dr. Bill interviews a panel of people with low

vision who discuss how they were able to communicate with their friends and family members regarding their vision problems. These suggestions have been very helpful in eliminating difficult situations when friends and family members did not know how to help.

March 15: What's new in low vision technology: Dr. Bill discusses the latest developments in low vision aids, assistive technology, computers and more in 2016.

April 19: Social Security benefits for people who are legally blind: Dr. Bill discusses the requirements for one to receive financial benefits from the Social Security Administration, and he also discusses how people with low vision may be able to work and continue to receive financial assistance.

May 17; Update on self-driving cars: There are now multiple companies working on self-driving cars. Dr. Bill shares an update on the developments of the self-driving car, and he talks about the potential of people with low vision to use them.

June 21: Suggestions for traveling and vacationing with low vision:

July 19: What's new in sunglasses and lenses to protect your vision: Dr. Bill discusses the latest advances in the technology of filtering blue light and short wavelength radiation to keep the eyes healthy for people with macular degeneration, retinitis pigmentosa and other eye diseases.

August 16: Strategies to help you to succeed: There are many important skills that you can develop to increase your success in finding employment, getting promoted and achieving the things you want in life. This presentation will describe what you can do to gain success.

September 20: Tips and equipment to help you to succeed at school: Dr. Bill shares the latest in low vision aids and assistive technology to allow you to achieve your maximal potential at school.

October 18: Latest advances in lighting to improve your vision: There are now many new types of light bulbs to maximize the vision of people with vision problems. Dr. Bill discusses the importance of the correct type of light bulb, the ideal color of the bulb and its intensity.

November 15: Holiday gifts for children and adults with low vision:

December 20: Medical advances for eye diseases 2016: Dr. Bill reviews the most significant medical advances for macular degeneration, glaucoma, diabetic retinopathy, retinitis pigmentosa and other eye diseases.

## **Quality of Life**

### **Low Vision Survey**

as seen on the cclvi-announce email list

Subjects with Low Vision Needed for Research on Visual Reading Technology

Research is being conducted at the Minnesota Laboratory for Low-Vision Research at the University of Minnesota. The project is directed by Dr. Gordon E. Legge.

The goal of the research is to enhance our understanding of the use of reading technology by people with low vision. The results will be useful in designing reading aids for low-vision reading and for guidance in selection of appropriate reading aids for individuals with different forms of low vision.

The study involves filling out an online survey. It will take about one hour to complete. It involves questions about your vision status, the types of reading aids you use and the reading activities you do.

We invite you to participate in this survey if you are an adult with low vision, if your vision has not gone through any major changes in the past year and if you read visually for some purposes. Low vision is defined as acuity less than 20/60 with best prescribed glasses or contacts, or a visual field less than 20 degrees in extent. It does not refer to people who can achieve normal vision with the aid of glasses or contacts, nor to people who have normal vision in one eye and reduced vision in the other.

Subjects will be compensated with \$20 gift cards (such as Visa, Target, Amazon or Starbucks gift cards). We welcome people who live outside of the U.S. to take our survey. Unfortunately, however, we are only able to compensate U.S. residents with gift cards.

To access the survey, please email Christina Granquist at [lowvis@umn.edu](mailto:lowvis@umn.edu) and she will send you a personalized link to the reading survey.

For questions or more information about the survey, please contact Christina Granquist at the Minnesota Laboratory for Low-Vision Research:

Christina Granquist

E-mail: [lowvis@umn.edu](mailto:lowvis@umn.edu)

Phone: 612-625-4516

## **Five Things I Wish People Understood About Being Legally Blind**

by Natasha Baebler

[Editor's note: This was posted Nov 5, 2015, on the [themighty.com](http://themighty.com) blog. The article can be accessed by going to [themighty.com/2015/11/5-things-i-wish-people-understood-about-being-legally-blind](http://themighty.com/2015/11/5-things-i-wish-people-understood-about-being-legally-blind).]

When you encounter me going about my daily life, you probably notice two things right away. I'm either traveling with the help of a canine or using a long white cane, and I can see. I don't fit most people's image of a blind person. I look at things.

There are numerous terms to describe those of us who live between the worlds of the fully sighted and totally blind: low vision, visually impaired, legally blind and partially sighted. Some who are partially sighted identify with the blind community. Others do not. Like our amount of residual sight, most of us are somewhere

in between. We live in a gray area. It's a confusing, ever-changing place where people can see some things, but not others. While what each of us can see can vary, we all have some things we'd like you to know:

1. Blindness doesn't always mean total darkness.

Only about 15 percent of people who have a blindness diagnosis have no light perception, according to VisionAware. Most of us see something even if it's just being able to tell the difference between light and dark.

There are two types of impaired vision: acuity (how clear things are) and field of vision (how much of an environment you see at once without moving your eyes or head). Individuals can be legally blind based on either or both of these factors.

For most of my years growing up, I was legally blind due to severely restricted fields. Technically, my field of vision is less than 2 degrees. That's roughly the size of a pinprick. If I could find it, I could see it. That meant I could read street signs, but I'd probably fall down a curb. Now my acuity has also fallen into the legally blind territory. Because of my severely restricted field of vision, it's difficult to even obtain an acuity reading. When I look at the big "E" on an eye

doctor's chart, I don't see the whole letter at the same time. On a good day, I can put the puzzle together and see that it's actually an "E." On a bad day, I can see there's something there, but I couldn't tell you if it was a letter or lamppost. Most of the time, we settle, say my acuity is worse than 20/200 and call it a day.

2. There is no easy answer to the question: "So what can you see?"

Some people who are legally blind have experienced full sight. Then others, like me, have no concept of what it's like to have "normal" vision. The answer to the question, "What can you see?" is a complicated one. Some people see colors or shadows. Others may see parts of things and spend their life figuratively putting together the pieces of a puzzle. Some people may be able to see a tiny speck of paper on the floor but will run into a chair that wasn't pushed in.

For many people with reduced acuity, their sight may be dependent on both internal and external factors. The lighting in a room, the weather outside and how tired they are can all affect how well someone can see. I often joke that whether I can see something depends on the alignment of the sun, moon and stars and whether Mercury is in retrograde. Never knowing if I

will be able to see something today that I could see yesterday is confusing for me and those around me. I'd rather you err on the side of me not seeing something. That way we can both be pleasantly surprised if I can.

3. We learn to use our residual sight.

I happen to be rather partial to the fact that I can see some things. I like to look at things. When I was learning to use a long white cane as a mobility aid, one of the things my instructor taught me was to let the cane do the work and let my sight compliment what I was feeling with my cane. She taught me to use my cane to locate objects and my vision to see them. Now that I primarily travel with a guide dog, I let my dog keep me moving in a straight line while I use my eyes to find the landmark I need to tell my dog where to go. The same thing applies indoors. I let my dog take me around people and displays to help me find the general location of items I purchase frequently. Then I use my residual sight to find the exact item I need. It's a win-win.

4. We benefit from accurate verbal directions and descriptions.

Yes, I can see something, but I don't see more than I can actually see. Phrases like "over there" mean nothing to me other than it's "not where I'm standing right now." I may need your help even, or perhaps especially, when I'm traveling with the help of my guide dog. I might even get lost in a familiar area.

If I ask for directions or help locating something, please use words to describe where things are in relation to where I am and how I am oriented. Phrases like "behind you and to your right" tell me much more than "back there." Likewise, telling me the store I'm looking for is still another block down, across the street and just past the train tracks provides me with excellent landmarks to help find my way. Just use clear adjectives and directional phrases, and I'll be on my way.

5. We're not faking.

Please don't accuse those who are partially sighted of faking their blindness. We aren't a social experiment. The last thing we want is extra special attention. We are men and women, mothers and fathers, daughters and sons who have a condition where we live in the gray area of the world. We work hard with what we have. We get frustrated. We rejoice. We compensate and compromise. A medical professional has run tests.

Maybe glasses or contacts help. Maybe they don't. Maybe we use a long white cane just in unfamiliar areas and travel without a mobility aide in areas we know well. I regularly travel to my mailbox without the aid of dog or cane. I know the route well.

So when someone asks me, "Are you really blind?" I take a deep breath before I reply. I spend my life figuratively putting together the pieces of a jigsaw puzzle to get some visual semblance of my world. Have you ever tried to put together a jigsaw puzzle without having a picture of what you were putting together? That's what every day is like for me, except I don't even know if I have all the pieces.

The next time you encounter someone who is partially sighted and curiosity is getting the better of you, remember that blindness is a spectrum and an individual experience. If you ask about a person's visual impairment, and I encourage you to, be open to an out-of-the-box answer because the person you asked is stepping outside of his or her box for your benefit.

**A Bipartisan Rant**

by Mark Richert via the ACB leadership email list

[Mark Richert is Director of Public Policy, American Foundation of the Blind.]

Hello, there, fellow ACB leader types (smile),<sup>4</sup>

So I'm just sharing a few thoughts with my ACB friends, because hey, that's what a group like this should be for, right? Anyhow, I'm just so frustrated right now I could scream, frustrated frankly with both the Obama administration and with the Republican-controlled Congress.

It's come to my attention that a number of the federal regulations we've been waiting for and that we've been essentially begging for from the administration have basically been put on ice. Remember that little thing call section 508 and the process to refresh it that has been going on since the summer of 2006? Well, now we're being told that it's going to be July of 2016 until we have a final rule! And mind you, this is only a projected date; we've been promised hard deadlines in the past that they've routinely put off.

The even greater outrage in my book, though, pertains to the ADA regulations we've been advocating for the past decade, but certainly since 2008. These involve online-only public accommodations, as well as medical and other technologies such as hotel check-in kiosks. These regulations won't even be formally proposed until, wait for it - 2018! That's right, 2018. Well, into the next administration, whomever that may be.

Particularly regarding the ADA web regulations, I think this announcement by the administration, through its semi-annual regulatory agenda announcement that has just come out recently, is absolutely a slap in the face of the blindness community. There have been multiple letters going to the President and to the Attorney General from blindness groups asking for immediate action on these rules; there have been letters from the Congress asking for movement ... and yet no response from the administration until now, and the response is really the legal equivalent of an obscene gesture.

I cannot tell you how heartbreaking and frustrating it is to see this kind of thing after years and years of trying to bring some of these things to fruition. And when these kinds of things happen in an environment where we aren't seeing a lot of champions in the Congress either, well, that's pretty discouraging.

I am so sick of people telling me how grateful we need to be to this administration for all its tremendous commitment to people with disabilities, at least with respect to blindness issues and technology accessibility. In my opinion, they get a D minus. And the only reason why they don't get an F is because some of us essentially forced the hand of the FCC to punch out a gazillion regulations to implement the communications, description, user interface, and on and on provisions of the Communications and Video Accessibility Act, which the administration didn't lift a finger to help us enact and which was essentially out of the administration's hands because the FCC is an independent agency.

Especially with regard to the ADA regs, I think it's absolutely disgraceful how some of the zealots in the disability community who have gone to work over there are bragging about all the work they're doing to cut the rug out from under so-called segregated settings and special schools and workshops and nursing homes and on and on ... as if it takes any real courage or commitment to attack those entities. I mean, come on, how much real flack does the administration take for challenging places like nursing homes and sheltered workshops, entities that really don't have any meaningful allies and any meaningful political power? So our colleagues get to sound all self righteous about

the tremendous work they're doing for people with disabilities while going after the lowest hanging fruit there is. Why don't we see them holding the hotel, banking, retail, medical and other consumer technology, etc., industries more accountable for our access? Simple: they do not have the courage and political will.

And while I'm on this rant, let me also say that I'm so sick of hearing from some folks about how Republicans in Congress will come around on our issues if we just talk to them the right way. If I have to listen to yet one more Republican staffer spew nonsense out-of-touch ideology to justify their deliberate indifference to the education of blind kids as they fail to act on the Macy Act, I think I'm going to explode. Okay, we finally got a Republican member of the House to join with a Democrat to get the bill introduced in the House again, but this happened because the member himself has hearing loss and we've partnered with deafness on the bill. Even with a couple more Republicans coming on as cosponsors in the House, the truth is that we've done literally dozens and dozens of meetings with Republicans in both the House and the Senate, and you would be amazed, or maybe you wouldn't be, at the imperviousness of those folks.

Anyway, I just needed to get this off my chest. I'm tired of hearing about how supportive the Obama administration is and how grateful we should be, and I'm sick to my stomach over how we need to beg and plead for the most basic things from Republicans in Congress who are incapable of giving a damn. I have to say, if you're a Democrat, I hope you give the administration hell and that you don't perpetuate this myth that the administration is the best friend people with disabilities have. Maybe for some people with disabilities, but not us. And if you are a Republican, then you get on the phone right now with your members of Congress, especially Republicans in the Senate, and you tell them that you're a Republican and that it's time for Republicans up there to do the right thing and show some leadership for blind kids. As you can tell, I need a vacation (smile)! And so this Thanksgiving's coming at the right time. I'm thankful to have a community like this to share things with. I'm thankful for the incredible results we've been able to achieve over the course of time with not a whole lot of friends helping us. I'm thankful for the rare folks in both political parties who get the blindness issues. But friends, we really, really, really need to cultivate a lot more champions for our stuff. I don't have any bright ideas on a Monday afternoon on how to do that other than building relationships one at a time the old

fashioned way. But maybe as a community we need to start thinking about committing to a New Year's resolution on cultivating a few more champions in both parties who can help us hold the parties much more accountable.

Thanks for listening,  
Mark

## **Science and Health**

### **NEI News Briefs**

#### **Space Lab Technology May Help Researchers Detect Early Signs of Cataract**

By Kathryn DeMott

{You can access this article at [nei.nih.gov/news/briefs/space-lab-technology-may-help-researchers-detect-early-signs-cataract.](http://nei.nih.gov/news/briefs/space-lab-technology-may-help-researchers-detect-early-signs-cataract.)}

As we age, proteins in the lenses of our eyes start misbehaving: they unfold and congregate in clusters that block, scatter and distort light as it passes through the lens. A cloudy area, or cataract, forms. In a new

study, scientists found that throughout our lifetime, levels of a key protein decline and may be an early warning sign of a developing cataract. The study, conducted by scientists at the National Eye Institute and the Wilmer Eye Institute of Johns Hopkins Hospital published online in *Ophthalmology*, suggests that there is a window before cataracts develop when there may be time to intervene and prevent them.

While cataract surgery is an effective treatment, its cost and the lack of well-trained surgeons limit its availability in many parts of the world, making cataracts the leading cause of blindness.

The protein at the center of the study, alpha-crystallin, is a major structural protein that, under healthy conditions, forms a transparent lattice in the lens. It also acts as a chaperone, binding with other lens proteins that are starting to misfold, which stabilizes them and deters them from clumping together. We're born with a finite amount of alpha-crystallin, which doesn't pose a problem in our early years. However, over time, this supply of alpha-crystallin diminishes, and it may not be enough to keep pace with the unfolded proteins that accumulate in the lens as we age, said the study's lead investigator, Dr. Manuel B.

Datiles, III, medical officer and senior clinical investigator at NEI.

Dr. Datiles and Dr. Walter J. Stark, professor and chief of the cataract and corneal diseases program of the Wilmer Eye Institute, studied this loss of alpha-crystallin over time by measuring levels of the protein every six months among 45 people, aged 34 to 79, (66 eyes). All participants had sought eye exams or treatment for suspected cataract.

After a mean of 19 months, the researchers found that cataract progression was far more rapid in lenses with the lowest baseline levels of alpha-crystallin, or the higher rates of alpha-crystallin protein loss, compared to those lenses with the highest baseline levels of alpha-crystallin or slowest rates of loss. By the researchers' forecast, those with the lowest baseline levels of the protein would be at the highest risk for needing cataract surgery within four years.

The researchers measured and monitored alpha-crystallin levels using a fiber optic-based technology called dynamic light scattering, initially developed to conduct fluid physics experiments in space. Dr. Datiles collaborated with Dr. Rafat Ansari, a physicist, and his team at the National Aeronautics and Space Administration's (NASA) John H. Glenn Research Center

in Cleveland, Ohio, to adapt the device so they could detect alpha-crystallin noninvasively in a living person. Prior to this development, the only way to study these lens proteins was by grinding up the excised lens in the laboratory. Conventional eye exam equipment, such as a slit lamp, is unable to measure proteins in the lens; it merely shows whether the lens is clear or cloudy.

The findings help scientists better understand how cataracts form and suggest potential targets for new therapies. Alpha-crystallin appears to be depleted in the process of acting as a chaperone, so supplementing it before levels get too low may be a viable prevention strategy. But since alpha-crystallin protein is itself too large to be delivered via eye drops, NIH-funded researchers are trying to identify pieces of alpha-crystallin that may act as a kind of mini-chaperone with a similar anti-cataract effect. Dynamic light scattering may also be used to study the effect of some new potential anti-cataract medications recently reported to reverse cataracts in animals and lenses in tissue culture when these medications are ready for human testing in the eye clinic.

Dynamic light scattering might also be helpful in clinical trials of new medications that were shown to cause cataracts during pre-clinical animal safety testing,

Datiles said. It may also help with earlier detection of other eye disorders such as presbyopia, the forty-something phenomenon when tasks requiring close-up vision become difficult as the lens becomes stiff and unable to focus light as effectively as it once did. Preliminary evidence from human lens studies in the laboratory suggests that alpha-crystallins are involved in presbyopia.

Although the dynamic light scattering technique is currently used only for research, Datiles said that he can envision it being used in future clinical practice as a way of evaluating people for their risk of developing cataracts and presbyopia. The cost of the device would need to drop significantly. However, much like the way creatinine levels [as seen in a blood test for kidney function] are used to monitor kidney function in people at risk for kidney disease complications, if measuring alpha-crystallin became economically feasible, it would provide a biomarker to monitor the health status of the lens, a kind of early warning system that lifestyle changes or other interventions are warranted.

**Glaucoma Awareness Can Help Save Vision for Millions**

[nei.nih.gov/news/briefs/awareness\\_help\\_save\\_millions](http://nei.nih.gov/news/briefs/awareness_help_save_millions)

With Glaucoma Awareness Month in January, it's a good time to think about scheduling a comprehensive dilated eye exam, especially if you're at risk for glaucoma.

"It's one of those things in life, like changing oil in your car - you just need to do it," said John Schmelzer, a retired engineer in Durham, North Carolina. Schmelzer was diagnosed with glaucoma in the summer of 2013 during a routine eye exam.

Glaucoma is a major cause of vision loss in the U.S. While it currently affects about 3 million Americans, estimates show 6.3 million could have glaucoma by 2050.

The National Eye Institute (NEI) leads research toward better prevention, detection, and treatment of this potentially devastating disease. In its early stages, glaucoma typically has no symptoms. Late in the disease, once vision has been lost, it can't be restored.

"Early detection by having a comprehensive dilated eye exam is key to protecting vision," said Paul A. Sieving, M.D, PhD, director of the NEI. Anyone can get glaucoma, but African Americans over age 40, everyone over age 60, especially Mexican Americans, and people with a family history of glaucoma are at higher risk. People at higher risk should have a comprehensive dilated eye exam every one to two years.

Glaucoma is a group of diseases that damages the optic nerve, the bundle of nerve cells that relays visual information from the eye to the brain. In the most common form of glaucoma, called primary open angle glaucoma, nerve damage results from increased pressure inside the eye. Increased eye pressure occurs when the fluid that circulates in the eye drains too slowly.

"If glaucoma is detected in its early stages, pressure often can be controlled through medication or surgery, and the progression of the disease can be delayed," explained Dr. Sieving.

Glaucoma is usually painless, initially affects peripheral vision, and progresses slowly, which helps explain why half of all people with glaucoma don't know they have it. Schmelzer said he had no noticeable symptoms of

glaucoma. But during his eye exam, "the pressure in my eyes was remarkable how far out of line it was," he said. So much so that his eye care professional at the Duke Eye Center in Durham checked it a couple of times and then quickly prescribed treatment, which for Schmelzer is pressure-lowering eye drops.

Without adequate treatment, glaucoma eventually affects central vision and progresses to complete blindness.

Schmelzer added that maintaining his eye health is especially important to him now that he's retired.

"There are so many things I want to do, and we are doing, my wife and I," he said. "I'm reading, traveling and experiencing life."

For more information about glaucoma, comprehensive dilated eye exams, and financial assistance available for eye care, visit [www.nei.nih.gov/glaucoma](http://www.nei.nih.gov/glaucoma).

The NEI National Eye Health Education Program (NEHEP) provides a variety of educational resources, in English and Spanish, as part of its broad eye health outreach effort. To find educational resources available from NEHEP, visit [www.nei.nih.gov/nehep/GAM](http://www.nei.nih.gov/nehep/GAM).

NEI leads the federal government's research on the visual system and eye diseases. NEI supports basic and clinical science programs to develop sight-saving treatments and address special needs of people with vision loss. For more information, visit [www.nei.nih.gov](http://www.nei.nih.gov).

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