



VISION ACCESS

Council of Citizens with Low Vision International
6010 Lilywood Ln., Knoxville, TN 37921

Volume 28 | Number 3 |

<https://cclvi.org>

June 2021

Positives from the Pandemic

by Patti Cox, CCLVI President

As I sit down to write this, I am thinking about how we have communicated more through this pandemic than any other years.

The communication between members was relatively small before the Pandemic. We would either call each other on the phone, talk once a month on a board meeting call, or meet on a conference call if we happened to be on a committee.

Now we have chances to interact several times a week and other ways to keep everyone involved. Here are a few examples:

Last year we started our Constant Contact list. This has been a great way to keep everyone informed of upcoming events, distribute our Vision Access newsletter, and share other information to keep everyone up-to-date.

Last year at convention we had a great turn-out for game night. We have continued game night twice a month. We have played many different games, including Outburst, Blackjack or 21, Dice, Family Feud and many others.

We have three different chat calls each week. Anyone is welcome to come and just listen, socialize, or ask questions on how to make life a little easier with low vision.

The newest CCLVI event is our Sunday evening Tech Talk call with Aaron Linson, one of our newest and youngest members. Sometimes when you are transitioning from fully sighted to low vision, or from low vision to little or no vision, you need a little help with all your technology. Tech Talk gives you a chance to ask those little nagging questions and get handy tips that can help you every day.

What a difference a year makes! In March of 2020, some people said that we could do nothing but stay at home, isolated from those around us. CCLVI refused to be isolated. Instead, we reached out to our members and to others in new and different ways, added new events, and we now have 40 new members who were not part of our CCLVI family a year ago. I am so proud to say that CCLVI took a pandemic and turned it into a positive opportunity for our organization to grow and build for the future.

JOIN THE CCLVI FIRECRACKERS

You can make a donation to the team. One half of the money we raise from this walk comes back to CCLVI, and one half goes to ACB. To join our team or donate, go to <https://secure.qgiv.com/event/acbwalk2021/team/877308/>

ORGANIZATION

Publications Committee Report

by Tom Lealos

The feedback that we have received about the April edition of Vision Access has been favorable. Except for a couple of errors, it is apparently one of our best efforts to date.

At our monthly committee meetings we have sorted through the format preferences for each of our members. Hopefully everyone is receiving their chosen selection, i.e. large print or electronic.

We continue to work on editing and formatting, and it's evident that we still have to do a better job of proofreading prior to distribution.

If you have any constructive comments, please let us know via email at: vision.access@cclvi.org. If you would like to submit an article, please hold the word count to about 1,000 words or less and send it in a Word document as an email attachment to the above address.

Remember, this is your newsletter. It is published by us and for us, so please let us hear from you.

CCLVI CANDIDATES' FORUM

July 7, 2021 8:00PM Eastern
Watch your email for information

Scholarship Report

by Jim Jirak

Winners of our 2021 scholarships are as follows:

The freshman recipient is Carson Mc Keag from Geneseo, IL. He's always wanted to work in a field where ultimately he would be helping people and he's decided to major in mechanical engineering. His dream is to work for a company where he can help improve or develop products that will improve other people's lives.

The undergraduate recipient is Meghan Downing of Santa Barbara, CA. Meghan is attending the Berklee College of Music in Boston, MA. She is pursuing a Bachelor's degree in music therapy. Meghan was diagnosed with Stargardts Disease at the age of nine. Despite this, she learned to play several instruments, including violin, guitar, and ukulele. She was captain of her high school water polo and swim teams. She was also president of a club called the Youth Wellness Connection, which helped break down the stigma of mental illness. She is a member of the National Honor Society and has a GPA of 4.0. She is a member of ACB Students.

The graduate recipient is Matthew Turner of Cambridge, MA. He is passionate about optimization. He likes to take systems that work, dig into the underlying assumptions, and see if he can make them better. For example, at Black Rock last summer, Matthew created a model that would allow investors in the stock market to take sustainability and climate risk into account in their investment decisions. At the end of his internship, he presented this model to

the head of his department, who spoke highly of the innovative work. The ability to use these skills and interests in a corporate setting to make the world a better place is exciting for him. Congratulations to all.

Public Relations Committee Report

by Tom Frank

The PR committee continues to meet the third Monday of each month at 8:30 p.m. EST.

We are finalizing lists of organizations to whom we will be emailing our updated resource flyer.

We will be looking for a CCLVI member from each state willing to be a local contact and who can help distribute our flyer.

Announcing Dr. Sam Genensky Memorial Awards

by The Dr. Sam Genensky Memorial Award Committee

We are pleased to announce the 2021 recipients of the Dr. Sam Genensky Memorial Awards. They are: Jace Galyon, Knoxville, TN; Lily Hegazy, Atlanta, GA; Rose Hengehold, Hamilton, OH; Donna Williams, Clifton Heights, PA; and Tom Lealos, Powell, WY. They will each be receiving an iPad Air 9.7 with a carrying case and Bluetooth keyboard.

We appreciate the interest in this award and would like to thank all of the individuals who took the time to apply.

This award has been sponsored by CCLVI for the last 12 years in honor of Dr. Samuel Genensky, developer of the CCTV and founding President of our organization. Be advised that we have changed the title of this award, owing to the unavailability of late of donated video magnifiers. We intend to continue to offer other useful devices in coming years in honor of Dr. Genensky's outstanding contributions to CCLVI.

50/50 July Drawing

by Kathy Farina, Fundraising Committee Chair

The Council of Citizens with Low Vision International (CCLVI) is having a 50/50 drawing! The proceeds will go toward publishing Vision Access, our bi-monthly newsletter.

Tickets will be sold online starting July 1 until July 26. The winning ticket will be drawn on Monday, July 26 at CCLVI's game night.

Buy tickets at <https://cclvi.org> . If you need help, contact Robert Spangler at (319) 550-1748.

Good Luck!

ASSISTIVE TECHNOLOGY

OrCam

by Bryan Wolynski

OrCam Technologies utilizes the power of computer vision in the OrCam MyEye and the OrCam Read, personal artificial intelligence (AI) assistive technology devices designed for people who are blind or visually impaired.

OrCam MyEye is a small wearable device with a smart camera, about the size of a finger, that magnetically mounts onto almost any pair of eyeglasses. The device captures visual information and conveys the data to you auditorily through a discreet speaker positioned next to the ear, or via Bluetooth earphones. Since the device does not work with your vision, it can be utilized by anyone who is blind or visually impaired, regardless of their eye condition. The MyEye can read text from any surface - digital or print - and also recognizes faces, products, barcodes, colors, and denomination of paper currency. It has a telling-time feature activated by an intuitive hand gesture. OrCam MyEye is activated in one of three ways: (1) by a pointing gesture; (2) by following your gaze; or (3) by tapping the touch bar on the side of the device. MyEye is available in 25 languages in over 50 countries around the world.

The OrCam Read is a handheld device designed for people who are visually impaired and/or have reading challenges such as dyslexia. About the size of a large magic marker and held like a pen, OrCam Read instantly captures and reads text from any surface through wired headphones, out loud, or through

Bluetooth devices. It features intuitive point-and-click operation, which activates two precision laser guidance options. You can either select a laser bounding box to outline a section, paragraph or entire page, or target where to begin reading with a visual cursor laser. This easy-to-use reader is designed to improve reading efficiency, saving you time and also increasing independence for people with low vision.

A new revolutionary feature of both devices, Smart Reading, allows you to interact and speak to the device. Using simple voice commands, you can ask the device to identify the specific information you want from a text. For example, just say "read the headlines" of a newspaper. To read the second article on the page, simply say, "read the second article." To find certain words within the text, say "find" followed by the text you want. Within just a few seconds, the device will relay the requested information, making texts from newspapers and restaurant menus, bills and emails even more accessible to the reader.

Another new feature of the OrCam MyEye, Orientation, which is currently in beta, identifies objects in your surroundings. OrCam's vision is to empower people.



.Audio Format

Vision Access can be accessed in audio format by calling the CCLVI Information Line at (773) 572-6315. When prompted, select option #2 from the menu to get connected. While listening, press "7" to rewind, "8" to pause, and "9" to fast forward. To leave a voice mail, press "#", speak your message, and then just hang up.



ACB's Brenda Dillon Memorial Walk

by Kathy Farina, Fundraising chair

It's time for the CCLVI Firecrackers team to participate in the Brenda Dillon Memorial Walk.

You can participate in a couple of ways. You can join the Firecrackers team for \$25. You can make a donation. You can have friends, co-workers and family sponsor you and set a walking goal. One half of the money we raise comes back to CCLVI and the other half goes to ACB.

For more information go to

<https://secure.qgiv.com/event/acbwalk2021/team/877308/>

The Firecrackers team is counting on you!

CONFRONTING LOW VISION

Have You Been Told "Nothing Else Can Be Done"

by Mark H. Rinkov, O.D.

This is simply not true. There is life after a diagnosis of low vision. Low vision may be due to diseases such as macular degeneration, glaucoma, diabetic retinopathy, Stargardt's, strokes, and many others.

A low vision doctor has many tools to help one function better visually. These glasses and devices are normally not found at a typical eye doctor's office. These tools include bioptics, full diameter telescopes, HD digital reading devices, prismatic glasses, electronic devices, and others. Each has its specific place in the evaluation of a low vision patient. Following are a few case examples.

I saw a 10-year-old male with nystagmus. Nystagmus is rapid involuntary movements of the eyes. Vision is decreased due to the fact that light entering the eye does not focus consistently on the macula but rather goes across it like a windshield wiper on high speed. He had been having great difficulty seeing the board in school as well as reading. His best corrected acuity was OS 10/80 OS 10/100. For distance, he improved to 10/32.5 with a Bioptic Rx and 10/12.5 with Iris Vision. For near, he improved to J 1 20/20 with Iris Vision and also J1 with a variable focus magnifier with audible reading capability. This enabled him to be able to see the board work and read near or listen to tasks as well.

I saw a 90-year-old male with advanced macular degeneration. He was a very vibrant, active retired professor who was depressed and anxious because he could not read his literature, watch television clearly, or use his computer. His best corrected acuity was OD 4/700 OS 6/120 near, nothing measurable. For distance, a Bioptic Rx improved him to 10/50. He saw my face as well as television faces for the first time in years. For near, a portable HD digital reader with multiple magnifications and contrasts improved him to J120/20. For computer and television, Vision Buddy goggle allowed him to easily see his computer graphics. It also

streamed live television into the goggle which made it very easy for him to watch television.

These are just a few patients who had been told that "nothing else can be done." If you seek a low vision doctor, there can be a fulfilling life with low vision!

MEMBERS

"Kopings"

by Tom Lealos/Kathleen P. King

Dr. Kathleen P. King is a coach, workshop and keynote speaker, and retired professor. She is an accomplished author of a number of books. Being very new to low vision, she is now a member of CCLVI. Her story is a wonderful testimony to the strength of the human spirit. Thank you for sharing your uplifting story with us, Kathy, and welcome to our family.

This short article is about a few of my experiences coping with what I call "Disability 3.0." In CCLVI, usually we refer to this experience/condition as visual impairment. Read on, and you'll understand my nickname for it.

I thought I understood disability after fighting my way through 15 years of various physical impairments, including temporary paralysis, wheelchair confinement, multiple back surgeries, artificial knee implants, an internal pain pump, and permanent chronic pain. Notice the word "thought."

Now, I realize this phase of my life was only Disability version 1.0.

In 2019, Disability 2.0 began when I experienced a mini-stroke that left me with low vision. Suddenly entering a life of visual impairment, I experienced an entirely new world of disability. Thank goodness, due to the extensive research of friends and family, I stumbled upon the Florida Council of the Blind, ACB, and eventually CCLVI.

However, the story does not end there. “Disability 3.0” commenced in February 2021, when I was one of the rare 1% of individuals who have experienced NAION in both eyes a second time. I am now legally blind and only have “hand motion” vision in both eyes. Yes, I’m not even able to see anything on the eye chart.

NAION stands for non-arteric anterior ischemic optic neuropathy. Basically, an interruption of the blood supply in the optic nerve caused permanent damage to my sight. Technically, my eyes are just fine! However, the “cables“ (the optic nerves) that lead from my eyes to my brain scramble most of the information they are transmitting. I can now only read words in extremely large font and very short lengths (1-2 sentences).

The major lesson I gleaned from my first encounter with vision loss was the critical role that support communities played in my survival. I had kept in touch with Florida Council of the Blind, CCLVI, and ACB. But I was much less active, especially because it was during COVID. Now, I really needed my community. But to compound the situation I had moved to a different state.

Therefore, I went to the ACB website, found the affiliates list and contacted the state and regional (East Tennessee) associations. I was immediately encouraged and supported by people I had never met, and whose only connection with me was vision loss. They took me into their community as one of their own, no questions asked. My goodness, how my heart needed this welcoming reception.

Another important lifeline for me was the ACB Radio Community channel being hosted on Zoom and phone. I started reviewing the listings daily to find sessions that would encourage me, provide guidance, or offer insight into the new assistive technology that I so desperately needed.

One of my greatest frustrations was that I was no longer able to trudge along with my iPhone and iPad, switching between voiceover and minimal sight, the way I had been since my initial rehabilitation training in Florida during my first vision loss. Now, I would have to buckle down and commit to voiceover, a screen reader, and perhaps Braille. ACB Radio Community and CCLVI were critical for my survival because during the pandemic, my local Department of Blind Services was disrupted and delayed. It may be several months before I receive personal assistance. CCLVI and ACB Zoom calls filled in the gaps to provide direction, support, and encouragement in assistive technology. They also pointed me to the valuable free Hadley lessons, podcasts, and resources.

Meanwhile, as I live alone, I had to figure out how to navigate my apartment, cook meals, walk the dog etc. I began “rigging” the microwave, thermostat, stove, light switches, and TV remotes with more bump dots and large white stickers. After smashing several

glasses and jars by mistake, I banished all glass from the house, and now only use plastic. Finally, I also accepted that I needed to use my white cane to avoid more falls and alert others to my visual impairments. I am leaning heavily on the basic independent living skills I gained in 2019 from Central Florida Lighthouse and the precious encouragement of my virtual communities.

However, this progress has not been without tears. As you know, there is much more to coping with vision loss than I have described. Another big dimension is the internal struggle. And honestly, I'm still navigating this arena; CCLVI talkshows (Dr Bill's "Let's Talk Low Vision"), counseling, and family and friends are invaluable helping me walk the journey of grief, anger, loss, and eventually acceptance.

I'm still in the midst of that process. And I'm holding onto the knowledge that I survived my earlier rounds with disability and I will survive version 3.0. I remind myself of the resilience of people I've witnessed through my work in life coaching, community work, and as an educator of adults. By listening to my virtual friends (CCLVI and ACB), I also draw strength to conquer the battles of adjustment.

With the encouragement of the community, in April 2021, I began volunteering in small ways. Although quite modest, they are significant steps forward for me. On the ACB Radio Community Channel, I am co-facilitating a writing workshop with Cheryl McNeil Fisher. It appears that I will help lead a discussion session during our CCLVI conference this year. And with this column, Tom Lealos unwittingly provided the impetus for me to begin conquering my greatest challenge: resuming the writing which I enjoy so much.

Especially during this pandemic, CCLVI and ACB have been vital, welcoming communities for many of us in different ways. I thank all of you for your part in making it possible. I encourage us to continue to not only find the support we need in our life journey, but also to reach out to welcome and support others. We never know the needs of people when they attend via phone, Zoom, or in person (maybe soon?). As we reach out, I wonder who else we will encourage as they navigate their low vision journey.

Get to know Kathy on her website:

<https://transformationed.com/>

Living with Low Vision

by Zelda Gebhart, Membership Chair

Low vision is a term that encompasses many eye conditions and visual impairments. From reading to writing, and from recognizing faces to shopping, living with low vision can be challenging for you or someone you know. Here are some things everyone should know about low vision.

If you have low vision, you are not alone. 1.7 percent of the population, or nearly 7 million Americans, are expected to experience serious vision issues over the next decade, according to projections from the CDC.

Eye Diseases or Eye Conditions Causing Low Vision

Many eye conditions and eye diseases can cause low vision, such as macular degeneration, amblyopia, diabetic retinopathy,

cataracts, glaucoma, retinal detachment, retinitis pigmentosa, Stargardt's, retinopathy of prematurity, traumatic brain injury and more. It's important to know that the natural aging of the eyes does not cause low vision.

Low Vision Can Mean Many Things to Different People

Low vision presents itself in a variety of ways, including central vision loss, peripheral (side) vision loss, night blindness, blurred vision, hazy vision, or sensitivity to light. These symptoms can result in added difficulty in completing work or any activities of daily living.

Low Vision Cannot Be Fixed

Low vision may be treated with eyeglasses, medicine, or surgery. However, low vision often results in permanent vision loss. If you experience low vision, you will need to find new ways to do everyday tasks according to your remaining vision.

Low Vision Aids Can Help

Dozens of tools and aids can help people with low vision. Optical low vision aids include magnifying glasses, stand magnifiers, hand magnifiers, and telescopes. Non-optical aids include items that talk, large-print media or phones and watches that can all be helpful to people with low vision. Electronic devices such as audiobooks help people with low vision listen to electronic books. Smartphones, tablets, and computers all have functions that allow changes in text size and contrast. They may also respond to voice commands.

People with Low Vision May Be Eligible for Disability Benefits

You can get benefits if your vision can't be corrected to better than 20/200 in your better eye or if your visual field is 20 degrees or less in your better eye for a period that lasted or is expected to last at least 12 months. Benefits may also be available to you if you have vision problems and other health problems, and the combination of them prevents you from being able to work.

If you are receiving Social Security Disability benefits because of vision loss, you can earn up to \$2040 a month without fear of losing your benefits.

If you or someone you know has low vision, CCLVI can help. We provide opportunities to connect with others, so you won't have to deal with vision loss on your own. To become a member, go to <https://cclvi.org/join-cclvi> or call 701-493-2399. Also, our CCLVI website provides links to a great collection of low vision resources including information, equipment, organizations, and services. Find those at <http://resources.cclvi.org/>.

EVENTS

Events held on Zoom now require a passcode along with the meeting ID. To join our meetings, visit <https://zoom.us>, click on join meeting and enter the appropriate meeting ID and passcode. Or call (312) 626-6799 and enter the appropriate codes. Signup to get all the meetings and their information by subscribing to our Constant Contact list; visit <https://cclvi.org>. Meeting reminders are sent the week of each event. All are welcome to attend.

CCLVI Coffee Break:

Join Kathy Farina and Tom Lealos for a morning chat. Each Friday morning at 11:00 AM Eastern.

Meeting ID: 838 9349 7160

Passcode: 432483

Thursday Night Chat:

Want to meet others. Join us each Thursday evening at 7:00 PM Eastern. We have great conversations covering many topics.

Meeting ID: 883 1823 6600

Passcode: 360613

Tech Talk:

Have questions about today's technology? Want to learn how different programs can help you to better access your projects? Join us each Sunday evening at 8:00 PM Eastern.

Meeting ID: 879 5949 4614

Passcode: 123321

CCLVI Game Night:

Come join the fun the second and fourth Mondays of each month at 8:00 PM Eastern.

Meeting ID: 950 2360 8739

Passcode: 655392

CCLVI Chat:

First and third Mondays of each month (also on the fifth Monday should there be one) at 8:00 PM Eastern.

Meeting ID: 950 2360 8739

Passcode: 655392

CCLVI Board of Directors Meeting:

held the second Tuesday of each month at 8:30 PM Eastern.

Meeting ID: 896 397 845

Passcode: 225841

Let's Talk Low Vision with Dr. Bill Takeshita:

Join Dr. Bill and his guest for this monthly informative program.

The third Tuesday of each month at 8:30 PM Eastern.

Meeting ID: 793 242 226

Passcode: 270147

KCCLV Low Vision Support Calls:

First and third Wednesdays of each month, these meetings are informative for all low vision individuals across the United States.

Meeting ID: 86298896972

Passcode: 975864

Midwest CCLV

CCLVI's Newest affiliate. This affiliate meets the first and fourth Tuesday of each month. First Tuesday is the board meeting and the fourth Tuesday is the membership meeting.

Meeting ID: 871 2070 9853

Passcode: 100123



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VISION ACCESS is published six times a year in large print, audio and email.
Published in February, April, June, August, October and December.

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. Submission deadlines are January 15, March 15, May 15, July 15, September 15 and November 15. Send contributions to vision.aces@cclvi.org.