



VISION ACCESS

Council of Citizens with Low Vision International
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October 2020

Publications Committee Report

by tom Lealos, Chair

The members serving on this committee are: Patti Cox, Robert Spangler, Christine Chaikin, and Valerie Ries-Lehman. As chairman of this committee, I have the dubious task of trying to keep these talented, strong-willed, and very giving volunteers focused on publishing our house organ, Vision Access (VA). We have decided that we can accomplish this work without a named editor and are committed to doing so.

As I write this article, this cohesive team is busy collecting, reviewing, sorting, formatting, editing, printing, and mailing the October edition of VA to our members. If you have received this newsletter by the middle of this month, we will have accomplished our goal.

It should be noted that the Board has approved our committee's recommendation to publish VA six times a year (i.e. February, April, June, August, October, and December) as a "newsletter", not a magazine. This schedule will reduce our expenses, and at the same time keep our members better informed in a more timely manner.

Our committee has and will continue to reach out to eye care professionals, low vision specialists, CCLVI affiliates, and other

groupings of appropriate folks via email to solicit articles that may be relevant and helpful to the low vision community. Deadlines for these submissions are the 15th of the odd-numbered months. If you or anyone you know would like to provide such an article, please send it as an email attachment in a Word document to: vision.access@cclvi.org.

The Publications Committee, by all rights, should be responsible for all documents relating to our organization. Since we also have a standing Book Committee, that group will continue their efforts to produce a second CCLVI book. If a decision is made to not proceed with this project, our Publications Committee will incorporate any submissions for the book into the newsletter or other formats for our members.

Remember, Vision Access is produced by us and for us. We welcome any good ideas or suggestions you may have that will improve our publication. We can be contacted by email at: vision.access@cclvi.org or by phone at: (844) 460-0625.

WE LOOK FORWARD TO HEARING FROM YOU!

**DON'T MISS THE CCLVI
FRIDAY MORNING COFFEE BREAK
WITH KATHY FARINA
AND TOM LEALOS**

**Each Friday morning at 11:00am Eastern
Meeting ID: 838 9349 7160
Passcode: 432483**

Legislative and Advocacy Committee

by Sara Conrad

The CCLVI Legislative and Advocacy Committee held their first meeting on Thursday, September 10. The committee will continue to meet the second Thursday of each month at 8:00PM Eastern. The committee set goals for the year, including legislative imperatives, resolutions, and other topics of interest in the low vision community. Our overarching goals are to assist ACB with legislative imperatives, inform ACB national and CCLVI about low vision concerns, and educate the low vision community as well as the general public about advocacy needs. We welcome new committee members to join our project subgroups. If interested, please email the chair, Sara Conrad, at sjconrad88@gmail.com.

We've Here for You

by Zelda Gebhard, CCLVI Membership Committee Chairman

I'm pleased to report that the 2020-2021 CCLVI Membership Committee has representation from all across the country. Starting in the east and traveling to the west, our team includes: David Smith, Kentucky; Becky Dunkerson, Iowa; Zelda Gebhard, North Dakota; Steve Fiksdal, Washington; and Valerie Ries-Lehman, California.

We are excited to explore how we can grow the organization by adding new members and also do what we can to meet the needs of all of you. We will meet on the 3rd Thursday of each month.

Initially we are focusing our attention on setting goals and developing a timeline. After we have determined our goals, we will move on to putting things into action.

We invite you to contact us and share any ideas you may have for membership and also any membership issues or concerns. We are here to serve you. Together we will try to meet your needs and are committed to fulfilling the mission of our organization.

Please address your membership related communication to me, Zelda Gebhard, at 701-493-2399 or vice-president@cclvi.org.

CCLVI FUNDRAISING

The CCLVI Fundraising committee invites you to enter our holiday 50/50 drawing. Tickets can be purchased on our website starting November 15, 2020, until Friday, December 11, 2020. The winner will be announced on December 11 at the CCLVI coffee break call. Go to www.cclvi.org and scroll down to the link for the 50/50 fundraiser to purchase your tickets. If you need help or have any questions, email webmaster@cclvi.org or call Robert Spangler at (319) 550-1748. Good luck!!!

Do your holiday shopping and support CCLVI too! The Tee Spot online store has hats, visors and polo shirts in a variety of sizes and colors. There are also 11-ounce and 15-ounce ceramic mugs. Everything has the CCLVI logo. A portion of the proceeds goes to CCLVI. Go to <https://cclvi.webstoreorder.com> for more information. You can call the Tee Spot directly at (865)539-8220. Happy shopping!

Book Committee

by Christine Chaikin, Chair

The Book Committee is comprised of members Dr. Bill Takeshita, Robert Spangler, Linda Allison, Tom Lealos, Cathy Casey, Jim Jirak, and myself as chair. Our new President, Patti Cox, has been sitting in as well. We have been meeting since last winter through the pandemic up to last month to discuss whether or not to publish another book and what to include in it.

Our August meeting involved a discussion on putting out a survey to our members to find out how much interest or demand there might be for publishing another book. The theme of this book would possibly focus on accessible technology. We also floated the idea of using the information in the chapters we had received to date as articles in Vision Access or in a new linked section on our website.

The entire discussion at our September 23 Book Committee meeting focused on whether or not we thought there was sufficient need to publish another book. We decided against putting out a survey, but rather to save time, grapple with this within the committee. We posed the question of did we want to go through the same hassle that we experienced while producing the first book as a fundraiser, or did we simply want to provide useful information to the members. We brought the discussion to a head with two separate motions which were approved unanimously.

Motion #1 called for the submitted chapters that were already received and those to come to be used as articles in Vision Access instead of in a second book.

Motion #2 called for suspension of the ad hoc Book Committee at this time, with the proviso that it could be reinstated at a later date if the need to publish another book arose.

It was agreed that the members of the Book Committee would be absorbed into the Publications Committee. Since the majority of the Publications Committee were in attendance at this meeting, we agreed that we would schedule regular meetings for this enlarged committee for the 4th Wednesday of each month. This will allow us to improve CCLVI's efforts to keep our membership better informed through the publication of Vision Access, our now bimonthly newsletter.

New CCLVI Director, Valerie Ries-Lerman

At 1lb and 15 oz, I was born legally blind due to retinopathy of prematurity. As I was growing up, I can remember being asked often by my parents if I could see this thing or that, and I knew just exactly which answer was required. Mine was a successful family, but a dysfunctional one, as you might have guessed. This added to my issues making my place in the world.

At my “sight saving class”, carrying a blind cane was never even discussed or considered. I was uninformed and in denial, as my parents nor school ever spoke with me about issues surrounding low vision.

Entering adulthood, I was determined to be a success. I desperately wanted to prove myself. With the help of the Department of Rehabilitation, I earned a BA degree in psychology from U.C. Santa Cruz. As my first foray into employment, I ran a vending stand with the California Business Enterprise Program. I received an award from the legislature for my work there.

My calling, though, was to do something more. After a rocky start at the California Franchise Tax Board (in files), I found my true career. My avocation being to help others, I became a reader advisor with the California Braille and Talking Book Library. Using Zoom-text on the computer along with a reading stand assisted me. I was privileged to work with the BTBL library for over 35 years, 10 of which being honored to be employed as a retired annuitant.

Making my home with my loving husband in Sacramento, I am a published poet, and do impressionistic paintings that sometimes work.

I now carry a blind cane, not only to assist at times in my travels, but as an educational tool. Yes, I get all of those crazy questions, but enjoy informing others about low vision.

Coming this far from such humble beginnings has by no means been easy. But I'm sure it's possible for anyone, with hard work, dreams, and determination.

It is my hope, in being a part of CCLVI, that I might in some way help empower and inspire those of you with low vision.

All the Best

Meet 2nd Vice-President, Steve Fiksdal

It's kind of ironic that the one subject we are most familiar with is the hardest to write about...ourselves. Am I saying too much? Too little? Am I coming across as braggadocios? So many questions. Well I'll give it a stab.

Up until about ten years ago, I had perfect vision, actually better than perfect. Then, thinking I was getting old, I needed to get reading glasses. But my vision continued to decline. A visit to the ophthalmologist confirmed the worst. I could go blind without immediate action. In fact for five years I was legally blind. Now, after laser treatments and injections, my vision has improved. Many, if not most, of you have been down this road.

In my earlier life I was a real estate executive who managed real estate offices that specialized in new home sales. Then, when I could no longer read real estate contacts or drive, I was forced to retire from that career. Actually, it wasn't so hard, as I was getting tired of the many years of the so-called same old thing. I needed change, but not because of blindness.

In 2013, I had an opportunity to attend the annual state convention of the Washington Council of the Blind. I was hooked. Two years later I was elected Secretary of the state affiliate, then one year later as President. I was unable to seek a second term because my vision had slightly improved and I was no longer considered to be legally blind, a condition mandated by the state organization constitution. I'll leave it at that.

Having not completed my college degree, I went back to school. In 2017, I earned my B.S. in organizational leadership and Certificate in Leadership Studies from Fort Hays State University. Check that one off the bucket list.

Currently, I am the founder and owner of the Strengths Institute, an organization committed to helping others identify their Dependable Strengths. These are strengths that we have exhibited throughout our lives and bring us the greatest happiness.

I am married - 39 years to the same person. We have three adult daughters and two granddaughters. Yes, I am surrounded by women. My wife and I live in Auburn, Washington.

It's an honor to be in your midst. I look forward to serving you and sharing the CCLVI mission.

CCLVI GAME NIGHT

Come join the fun each second and fourth Monday evenings with the CCLVI Game Night.

Starts at 8:00pm Eastern

Meeting ID: 857 3352 6427

Passcode: 257307

**Your hosts are Patti Cox and Robert Spangler
assistant Samantha Hubbard**

“Kopings”

by Linda Allison/tom Lealos

This submittal to “Kopings” comes from our Treasurer, Linda Allison. She writes her story in her own words and describes the many obstacles she encountered throughout her life as a low vision person. She is most accomplished and I think you will find her story very inspiring and, at the same time, glean some helpful ways to improve your own low vision journey.

I was born in Knoxville, Tennessee, in January, 1963, to an American father and an English mother. They had met on Skullthorpe Air Force Base, where my father was stationed, and were married in 1961. Ironically, I was the first successful and only normal birth. My rationale for mentioning this information is that, when I learned of the recessive genetic cause of my Stargard's macular dystrophy and its one in ten-thousand occurrence, I joked with my father that he had to travel four thousand miles to find the perfect genetic match to produce me. There are no other occurrences of the condition in my family on either side. I should also add that I only found out this diagnosis after genetic testing was completed through the Foundation Fighting Blindness last year. Before this test, I had had three differing diagnoses, ranging from juvenile macular degeneration to retinitis pigmentosa.

My condition came on rapidly and unexpectedly. At the age of eight, I started my school year, at the back of the classroom. Before the year was over, I was sitting at the front. My parents took me to an ophthalmologist in hopes of finding out what was going on. His diagnosis was that I was perfectly fine and this was simply an attempt to get attention. Fortunately for me, there was a new

addition to the practice and he requested permission to examine me. His diagnosis was juvenile macular degeneration and he suggested that my parents take me to Louisville, Kentucky, to be examined at the Lion's Eye Clinic. So, in January 1972, I and my parents spent my ninth birthday at the Lion's Eye Clinic. Ultimately the diagnosis was confirmed and later would be reconfirmed by an ophthalmologist in London, England who examined me when I was twelve years old.

Life goes on and so it did. We had a diagnosis. Now what? The former army doctor remained my ophthalmologist until he retired in the late 1990's. His advice to my parents was simply in the form of a choice. My parents were told, "you can either coddle her and make her a burden on society, or treat her as any other child and make her do." My parents chose the latter. I did everything that my sister, who is not at all visually impaired, did. It goes without saying that there were many trips to the emergency room resulting from my desire to prove that I was no different from my sister. Long story short, my method of coping with my progressive vision loss was to pretend like it wasn't there.

By the time I was twelve, I was legally blind. Seeing the chalkboard from the front row was increasingly more difficult. My grandmother gave me a pair of beautiful opera glasses. They were so pretty and compact. Unopened, they were flat and only about one inch thick. A spring release opened them to reveal lenses. They were strong enough for me to easily read the board and compact enough to carry discretely in my purse. That was my first real adaptive device that I ever used in school.

Junior high and high school were a different animal altogether. Where elementary school was a pleasant and nurturing environment in which I was a straight A student, junior and senior high were a constant struggle. My mother spent a lot of time either on the phone or in the face of school officials in an attempt to push them to fulfill their legal obligation under the law. At one point, she threatened the system with legal action and ultimately got their attention. My mother was a very fervent advocate for my education.

Following high school, I was introduced to Voc Rehab and, after a brief stint at Arkansas Enterprises for the Blind, I enrolled at the University of Tennessee. At nineteen, I had become more comfortable in my own skin and less embarrassed by my visual status. I was also learning to speak up for myself and advocate for reasonable accommodations for tests etc. Voc Rehab had provided me with a V-Tek Voyager and it was my most useful device at the university. I purchased a Smith Corona electric typewriter with a moving carriage. This was the perfect combination with my Voyager. I would place the typewriter under the camera and the carriage would move underneath it and I could see what I was typing. This was something that I had not previously experienced. It also allowed me to make my own corrections - another first.

My next most valuable device was a four-track player/recorder called a Tokman. I sometimes used it to record lectures, but mostly I used it to play my textbooks from the company now known as Learning Ally. It was fairly lightweight and compact. It fit easily in my backpack and I could do reading between classes.

Thanks to those two pieces of technology and a lot of hard work, I graduated with my Bachelors degree, cum laude.

Most of my adaptations in life revolved around education until my late twenties. It was at that time that I married and became a mother. Between the ages of ten and twenty, I had spent a lot of time babysitting for extra money. I was no stranger to taking care of children. However, when they hand you that tiny baby and send you home, it's a totally different ball game. The biggest issue I faced was measuring medication for my son. I had my husband mark the medicine dropper with a sharpie and I could see the contrast to fill the dropper with the correct dosage. The next obstacle was the thermometer. I purchased a basic digital thermometer which I could easily read under my Voyager. By the time my daughter came along in 1995, I had things pretty well figured out.

Fast forward a couple of years to my first job since my daughter was born. I had finished my Masters degree when my son was three and I had not been in a position to work. I was offered an interim position at a local college because their French instructor was out for an extended illness. A few months after this position ended, my husband began a series of contract programing jobs which would result in multiple relocations over the next two years.

Life went upside down and backwards. In 1999, I was a single mother of two and back in Tennessee. I ended up with two teaching positions at two local colleges and, with the help of family and friends both old and new, I went about the business of raising my children. My teaching positions gave me the luxury of being home when my children left and returned. Thanks to coordinating

with other parents and sometimes family, my children were able to fully participate in after school and extracurricular activities. It was also at this time that I learned about and began using paratransit.

Throughout my nearly forty years of existence at this point, I had had little or mostly no interaction with other visually impaired people. Once I began using the local paratransit system, my exposure to other visually impaired individuals grew. I had heard tell of a woman in my neighborhood who hosted a gathering of other blind people on a monthly basis. One day, I was picked up and there was another lady on the van. Long story short, I was seated next to the lady that I had been told about on several occasions. She invited me to one of her gatherings. It was at that gathering, in February of 2012, after ten years of hearing about it, I joined her group. That group is the East Tennessee Council of the Blind and I am the current president. That group that I fondly call the “crazy people” profoundly changed my existence.

That same year, I experienced another drastic and unexpected change. I lost my teaching position that I had held for the last twelve and one half years. Thanks to one of the members of my chapter, a retired Randolph Sheppard vendor, I ultimately enrolled in the vending program in 2015. I now have my own facility and am enjoying the whole process. So far, my only adaptive equipment is an ID Mate hand-held talking barcode reader. With this device I can identify 99% of the products in my warehouse. I also have one in my kitchen at home. It is one of the most useful devices that I have found.

If you had told me twenty years ago that I would be the president of anything, yet alone the treasurer of two different groups and a

director on the board of yet another group, I would have asked you what you'd been smoking. Add to that my five trips to Washington, DC and every convention since 2013 and am still shocked by my own level of involvement, especially since I didn't even know that it existed before 2012. I also never expected to be a vendor or a grandmother of three precious little people, but I wouldn't have it any other way.

The take-away? We deal with the life we are given. Life is a series of inconveniences, adjustments, compensatory maneuvers seasoned with victories, joys and satisfaction. We monitor and adjust to meet the needs of our existence and travel forward in hopes and with the intention of arriving where we are supposed to be.

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> .

CCLVI Coffee Break:

Join Kathy Farina and Tom Lealos for a morning chat.

Each Friday morning at 11:00am Eastern.

Meeting ID: 838 9349 7160

Passcode: 432483

Ham Chat:

Want to know about Amateur Radio, or just want to meet others. Join us each Thursday evening at 7:00pm Eastern.

Meeting ID: 883 1823 6600

Passcode: 360613

CCLVI Game Night:

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

Meeting ID: 857 3352 6427

Passcode: 257307

CCLVI Board of Directors Meetings:

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

Meeting ID: 896 397 845

Passcode: 338938

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 8:30pm Eastern

Meeting ID: 793 242 226

Passcode: 270147

KCCLV Low Vision Support Calls:

Scheduled for the first and third Wednesdays of each month these meetings are informative for all low vision individuals across the United States. Join our Constant Contact list to receive information on joining these meetings. Meeting reminders are sent the week of each event.

Want to get involved?

CCLVI has several committees that can give you opportunities to get involved in the many aspects of the organization. Our committees are a great way to start. If you are interested in joining a committee, you can contact the CCLVI President, Patti Cox, at patti.cox@cclvi.org or contact the committee chair.

CCLVI committees:

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sara.conrad@cclvi.org

Constitution and Bylaws Chair, Robert Spangler.
secretary@cclvi.org

Convention Chair, Shirley Cain.
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eCommunications Chair, Robert Spangler.
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VISION ACCESS is Published six times a year in These Formats: Large Print, 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. Access@cclvi.org.