

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

## Volume 27, Number 1, Spring, 2020

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Council of Citizens with Low Vision International Attn. Linda Allison 6010 Lilywood Lane Knoxville, TN. 37921

> (844) 460-0625 www.cclvi.org cclvi@cclvi.org

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Vision Access welcomes submissions from people with low vision, from professionals such as ophthalmologists, optometrists, low vision specialists, and everyone with something substantive to contribute to the ongoing discussion of low vision and all of its ramifications.

Submissions are best made as attachments to email or may also be made in clear typescript. Vision Access cannot assume responsibility for lost manuscripts. Deadlines for submissions are: March 1, June 1 and September 1.

Submissions may be mailed to, Vision Access Editor, editor@cclvi.org

Vision Access is available to listen to on the CCLVI Information line at (773)-572-6315 and then pressing 2.

Publications Committee: Joyce Kleiber, Ken Stewart, Tom Lealos, Christine Chaikin, and Mike Keithley.

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# (There are "DID YOU KNOW?" sections added as filler)

## **Editor's Corner** by Robert Spangler

Hello everyone, I hope this edition of "Vision Access" finds you in good health and safe from this Covid-19 situation. While I am not the editor, I have taken it upon myself to work with the publications committee to see that we get something out to you.

The committee has worked hard to see that the members of CCLVI get a newsletter for the Spring of 2020. We have changed our schedule to better reflect the annual period. We will now have a Spring, Summer and Fall issue and will be asking for your input. What I would like to see is more articles from our members. If you have a recipe that you like and would like to share send it in and we will have a section specifically for recipes. Have some Tip's & Tricks you feel others would benefit from to help them cope with low vision, send them in and we can start a Tip's & Trick's section. This is your "Vision Access" and it should have members input.

Hope you enjoy the articles we have for you.

#### ORGANIZATION

## **FROM THE PRESIDENT**

by Sara Conrad

Dear CCLVI,

I am delighted to write this letter and tell you about the great things happening in CCLVI! I'm especially excited to share with you insights from the ACB Leadership Meetings this February. In this letter, I will share a few details about CCLVI's current projects and information about upcoming opportunities.

ACB held its annual leadership meetings and legislative seminar in February. CCLVI was well represented! Many of our board members and officers attended all or parts of the weekend. I had the opportunity to participate in the ACB board meetings, affiliate president's meeting, and legislative seminar. ACB's staff put together a great conference. I highly encourage you to listen to the ACB radio archive recordings of these sessions. Issues of importance to our low vision community were certainly highlighted throughout the meetings. VISION ACCESS 4 Spring 2019

CCLVI is also gearing up for the ACB Conference and Convention, in July! This will be a virtual convention. Jim Jirak and his convention planning team have great sessions prepared for you.

I also want to share a bit of personal news with all of you. I am excited to say that I said, "Yes!" to my fiance's proposal on Valentine's Day. I am over the moon excited to spend my life with such a wonderful man.

I have amazing colleagues in CCLVI and trust that the organization will have opportunities to thrive in the future. I am looking forward to advising the board as the immediate past president. I also want to publicly thank Leslie Spoone for her thoughtful mentorship and leadership as the immediate past president the last two years.

As we move forward with the remainder of this year and into the next year of CCLVI, we will have many opportunities to grow and change. I encourage all of you to participate in CCLVI calls and events. Together, we will learn new things and push forward to even greater success. I encourage all of our members to consider more involvement in CCLVI as we continue our great successes. I will be reaching out to the membership about committee chair and committee member assignments very soon. Please consider how you can use your skills to help the low vision community!

Thank you for your support over the years. I look forward to the many opportunities we have to grow together!

All the best,

**CCLVI's Response to COVID-19** by Sara Conrad

Update April 1, 2020

CCLVI is working hard to respond to the rapidly changing situation as our world faces COVID-19. While there are more questions than answers at this time, I want to provide a brief update as well as information for you to get answers as they come. ACB has cancelled the in-person national conference and convention this July. Instead, ACB is working hard to plan a virtual conference this year. CCLVI is planning ways to engage our members in new ways.

One of the unique challenges ACB and CCLVI are facing is how to keep the integrity of our elections and voting. Neither ACB nor CCLVI can hold virtual elections or voting due to restrictions in each organization's constitutions. As such, both ACB and CCLVI will keep the same officers and board members for the coming year. Any officer or board member who is up for re-election or terming out in July may choose to resign his or her position. I plan to stay on the ACB board and as your **CCLVI** president for another year to ease this transition. If a vacancy is created due to a **CCLVI** officer or board member resignation, we will appoint someone to fill that position until voting can occur in-person next year.

A small group of CCLVI leaders are helping me consider the many issues that may need to be addressed. We are considering ways to support individual needs as well. As CCLVI makes decisions and answers your questions, there are several ways for you to access the rapidly changing information.

- CCLVI email
- · Phone at 773-572-6315
- . CCLVI's Facebook page
- . CCLVI.org

We will do our best to update information as quickly as possible. Thank you in advance for your patience. If you have questions regarding CCLVI's response to COVID-19, please email me at President@cclvi.org

Please know that I am thinking of each and every one of our members. We will get through this time together. I firmly believe that struggle brings opportunity to grow for the better. I'm happy to be surrounded by ACB and CCLVI leaders who hold this same belief.

Be well.

Sara Conrad CCLVI President **VISION ACCESS** 

## KCCLV

Low Vision Support in Kentucky by Carla Ruschival

The Kentucky Council of Citizens with Low Vision is a chapter of both CCLVI and the Kentucky Council of the Blind (KCB). Organized in February, 2017, KCCLV became an affiliate of KCB a month later.

"KCCLV is a very active chapter. With a membership of 25 to 30, it sponsors in-person and telephone support groups where people can share tips and ideas for living with low vision. Programs sometimes include speakers and product

demonstrations; they always include tips, information and a chance to discover helpful apps, low-vision devices and services.

KCCLV's telephone support groups meet the first and third Wednesday of each month at 8:00 PM Eastern; join the calls, no matter where you live, by dialing (669) 900-6833 and entering the code 3572595193. This is a Zoom Line, so you can also join from your PC or cell phone.

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KCCLV's in-person support groups meet from 1:30 to 3:30 PM on the second and fourth Thursday of each month at a community center in Louisville. Attendees come from southern Indiana as well as from Louisville and surrounding counties.

We are now working to build a support group in Oldham County, east of Louisville. Our goal is to establish more in-person groups around the state.

The KCCLV Board includes Shirley Cain (President, Bellevue); Amanda Selm (Vice President, Louisville), Debbie Persons (Secretary, Louisville), David Smith (Treasurer, Louisville), Phyllis Caywood (Director, Mt. Sterling), Zora Schultz (Director, Cedar Park, TX), and Alan Schrebtienko (KCCLV Representative to the KCB Board, Sellersburg, IN).

For more information about KCCLV, call (502) 895-4598 or email kcb@kentucky-acb.org.

## VISION ACCESS 10 Spring 2019 CCLVI ANNOUNCES ZOOM MEETINGS

For several months we have had issues with our conference lines used for our Board meetings and Let's Talk Low Vision. The Board decided to try Zoom for the March "Let's Talk Low Vision" to see how it would work. Zoom greatly improved the quality of the call and provided the LTLV team with an excellent recording that can be shared on our CCLVI Message Line and on our website.

The LTLV team has scheduled the remaining 2020 schedule to be on Zoom. the schedule and meeting information is on the website as well as below.

To join the LTLV meetings: Join Zoom Meeting https://zoom.us/j/793242226 Meeting ID: 793 242 226 Dial in (312) 626-6799 Meeting ID: 793 242 226 VISION ACCESS 11 Spring 2019

The May CCLVI Board meeting will be held using Zoom. Time: May 12, 08:30 EDT

Join Zoom Meeting https://zoom.us/j/896397845 Meeting ID: 896 397 845

Dial by your location (312) 626 - 6799 Meeting ID: 896 397 845

Watch your emails for additional Zoom meeting announcements.

#### **CCLVI Toll-Free Number Hours** by Leslie Spoone

Hello Everyone,

Thank you to everyone who has been calling the toll-free number (844) 460-0625 so far. Here are the hours listed below. 9am Eastern and 9pm Eastern 8am and 8pm Central 6am Pacific and 6pm Pacific VISION ACCESS 12 Spring 2019

Please feel free to leave a message with your name, phone number and what time zone you are calling from, so I can get back with responses to everyone's questions.

Leslie Spoone,

**CCLVI Immediate Past President** 

### **KEEPING YOU INFORMED** by eCommunications

Recently, the web hosting package CCLVI uses added a new feature that we feel will help us keep better contact with our members. April 1st we began to setup and develop ways to use Constant Contact.

We will be using it to provide you with our "Vision Access", Let's Talk Low Vision information, and other important updates. If you have any questions please feel free to contact our webmaster at:

webmaster@cclvi.org or calling our toll-Free Number (844) 460-0625.

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#### Fundraising News by Kathy Farina

Perk up your wardrobe, show your organizational pride and support CCLVI. The teespot has items with the CCLVI logo including; 11 and 15 ounce coffee mugs, colorful polo shirts, hats and visors.

Order online at: https://cclvi.webstororder.com

by phone at: (865) 539-8220. by email at: customerservice@theteespot.com

A portion of the proceeds goes to support CCLVI.

Happy shopping!

#### **CCLVI INFORMATION LINE**

The CCLVI Information line is were you can hear CCLVI programs and news. Call: (773)-572-6315

- 1 Let's Talk Low Vision
- **2 Vision Access**
- **3 Sound Prints**
- **4 CCLVI Board Meeting**
- **5 Important Updates**

#### **MEMBERS**

## "Kopings"

by Dr. Bill Takeshita/Tom Lealos

Dr. Bill Takeshita, commonly known as "Dr. Bill," is no stranger to CCLVI members. He is the long-time host of our monthly call-in program, "Let's Talk Low Vision with Dr. Bill," serves on several committees, and has spoken at CCLVI annual conventions over the years. I have known him for about a decade and consider him to be a very good friend.

I have heard his vision loss story and I appreciate his willingness to accept my invitation to share it with you. I believe you will find it to be very positive and inspiring, in keeping with the overall theme of this column. It is written in his own words in the third person, with some first person quotes thrown in. Thank you, Dr. Bill, for telling your story.

Dr Bill grew up in Los Angeles, CA. His parents had a nursery where they raised

plants to sell to landscapers. He found out that he needed glasses in the 1<sup>st</sup> grade after the school nurse did a screening. When he went to the optometrist's office, he fell in love with the doctor, the office, and his new improved vision. "I could not believe how clearly I could see everything." That night, Bill went home and showed his brothers and his father his new glasses. His brothers just laughed at him and called him every name in the book. His father told him how much he liked the glasses. Bill told his family that he decided that he would become an optometrist when he got older. His brothers just laughed and said, "You are going to be working in the nursery!"

Bill studied as hard as he could and he realized that school was much easier with his glasses. He was the top student in his classes and he was later accepted to UCLA where he majored in pre-optometry. He was then accepted to the Southern California College of Optometry where he earned a doctorate degree in 1987. "I was so happy that I graduated the program." While in optometry school, Bill fell in love with low vision rehabilitation. He was so happy to be Bill studied as hard as he could and he realized that school was much easier with his glasses. He was the top student in his classes and he was later accepted to UCLA where he majored in pre-optometry. He was then accepted to the Southern California College of Optometry where he earned a doctorate degree in 1987. "I was so happy that I graduated the program." While in optometry school, Bill fell in love with low vision rehabilitation. He was so happy to be able to improve the vision of so many who were not able to read or drive due to their vision.

Dr. Bill joined a private practice in Los Angeles and he was also named to be the chief of optometry at the Center for the Partially Sighted, a clinic that specialized in helping people with low vision. He loved every part of his work and he worked seven days a week. That same year, Bill married his long time girlfriend, June, and they started their new life together. Shortly after, they had two young children, a girl and then a boy. "Everything that I ever dreamed of was coming true. I had the best life." Unfortunately, Dr. Bill noticed changes to his vision. He went to many retinal specialists and each told him that he had an untreatable eye disease called cone-rod degeneration. "My vision quickly became so blurred that I knew that I had to retire from work as an optometrist. I had to give up my driver's license, and I could no longer see well enough to play sports. I was absolutely devastated. "I just stayed at home and did not want to see or speak with anyone."

One evening, Bill attended his daughter's open house at middle school. He did not want anything to affect his children, so he put on the "good face" and went to the open house. His daughter said to him, "Dad, let's go into this room first." Much to Dr. Bill's surprise he was greeted by Mr. Keith Christian, one of his patients who is legally blind. He told Dr. Bill that this was his classroom and all the students in this room have low vision. Dr. Bill could not believe it. They were all so happy and animated. Keith showed Dr. Bill around the room and all the projects that his students created. Dr. Bill was so impressed and amazed. "I guess that I should learn to do things myself. If these students can do these

things, I can too, " said Dr. Bill. The following Saturday, Keith came by to Dr. Bill and June's home and he began to teach Dr. Bill how to perform everyday activities without vision. Dr. Bill learned how to cook breakfast, walk with a cane, and he also learned to use JAWS, a speech reading program for the computer. Dr. Bill said that it changed his life.

"I had such a negative attitude towards everything, said Dr. Bill. I was so embarrassed of having low vision that I did not want to talk about my vision problem with anyone.

However, after I learned that I could perform daily activities without vision, I became very proud and I wanted to show people what I could do! I was so proud to walk around my neighborhood with my cane and go shopping by myself! It changed my attitude so much!"

Dr. Bill then began to give speeches to various low vision programs and schools of optometry. He felt that as an optometrist, he could help optometrists to become interested in providing low vision care. He learned to travel across the country by himself and he gained more confidence. Later, he was offered a job as an adjunct faculty member at the Southern California College of Optometry. He was so thankful and he quickly accepted the position.

"One of the most helpful thing for me was to speak with other people with low vision.

Initially, people suggested that I join a low vision support group but I rejected the idea. I told them that I did not have a psychological problem. Today, I realize that I did have a psychological problems. I enjoy participating in the chats and discussions provided by CCLVI and ACB and they help me to learn how to over come new obstacles in my life. I have learned that even without vision, I have the greatest life ever!"

#### **DID YOU KNOW?**

there are only 4 words in the English language which end in 'dous' (they are: hazardous, horrendous, stupendous and tremendous) VISION ACCESS 20 Spring 2019 One of My Greatest Fears by Patti Cox

One of my greatest fears is that I will wake up in a very cold place, lying on a metal table, with nothing but a sheet across my body. If you guessed that I would be in the morgue, you are right.

I have an eye disease called aniridia. Aniridia is the absence of the iris, the part of the eye that gives it color. Without an iris, the pupils are always fully dilated. Most people with aniridia have glaucoma, nystagmus and cataracts, among other conditions. My step-daughter was on the way to the hospital one evening and I rode in the ambulance with her. I was permitted to ride because I do not drive at night and have this eye condition.

The ambulance driver and I were talking about my eye condition and I explained to her about my greatest fear. I asked her what would happen, since my pupils are fully dilated, if I were in an accident and not breathing. She told me that they usually would pronounce me dead. I asked her if VISION ACCESS 21 Spring 2019

people ever just start breathing on their own, and she answered yes.

It was imperative that I obtain a medical ID bracelet - one that I could put as much information on as possible. I should include the following information on it:

- My eye condition and what it means;
- Allergies;
- Emergency contact information.

To say the least, I ordered a medical bracelet the next day.

The last thing the paramedic told me was that if I have a living will, I should take a look at it and make sure I have everything spelled out. If I have a Do Not Resuscitate (DNR) order, they cannot use any life-saving measures. She said I should consider not having a DNR. If I do not want to be put on a ventilator to keep me alive for any reason, then I should be specific.

I want everyone to know that it is very important to think about how your eyes can make a difference in the care you could receive. If you have an eye condition like

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mine, it is so important to make sure that you have some kind of identification in plain sight. First responders look on your body for identification before they look at your phone or wallet. It will make a difference in how they care for you.

#### **CCLVI** Chat

Join CCLVI leaders and guests on the monthly CCLVI Chat.

CCLVI Chat scheduled Zoom meeting. 08:00 PM Eastern Time Apr 27, 2020 08:00 PM May 25, 2020 08:00 PM Jun 22, 2020 08:00 PM

Join Zoom Meeting https://zoom.us/j/95023608739

Meeting ID: 950 2360 8739 One tap mobile +13126266799,,95023608739# US (Chicago)

Dial by your location +1 312 626 6799 US (Chicago) Meeting ID: 950 2360 8739

## **Request for Contributions**

CCLVI gratefully accepts contributions from readers and members to help pay for the costs of publishing Vision Access and other programs of CCLVI.

Please send contributions to: Linda Allison. **CCLVI Treasurer** 6010 Lilywood Lane Knoxville, TN 37921 Phone: (844) 460-0625.

Or you may donate using PayPal by visiting our website at cclvi.org

#### **CCLVI Local Affiliates**

California Council of Citizens with Low Vision CCLV@cclvi.org

Delaware Valley Council of Citizens with Low Vision DVCCLV@cclvi.org

Kentucky Council of Citizens with Low Vision kcclv@cclvi.org

Metropolitan Council of Low Vision Individuals, Greater New York MCLVI@cclvi.org

New York State Council of Citizens with Low Vision NYSCCLV@cclvi.org

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## **CCLVI Membership Application**

**Council of Citizens with Low Vision International, An Affiliate of the American Council of the Blind.** 

| Name                                 |  |  |  |  |
|--------------------------------------|--|--|--|--|
| Address                              |  |  |  |  |
| City State Zip Code                  |  |  |  |  |
| Country                              |  |  |  |  |
| Main Phone                           |  |  |  |  |
| E-Mail                               |  |  |  |  |
| Preferred method of being contacted: |  |  |  |  |
| Phone email                          |  |  |  |  |
| Membership Status: I am              |  |  |  |  |
| New member at large.                 |  |  |  |  |
| Renewing member at large.            |  |  |  |  |
| Life member of CCLVI.                |  |  |  |  |
| Life member of ACB.                  |  |  |  |  |
| <u></u> Supporting Organization      |  |  |  |  |

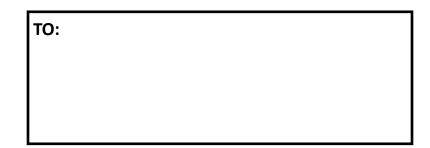
Visual status: I am ... \_\_\_\_ blind or visually impaired \_\_\_\_ sighted **Publication Formats:** I wish to receive the CCLVI publication(s), Vision Access in: \_\_\_ Large print \_\_\_ E-mail Audio CD \_\_\_\_ Do not send Please send the American Council of the Blind ACB **Braille Forum in:** Large Print E-mail Braille \_\_\_ Digital Cartridge \_\_\_ Do Not Send **Payment:** \$ \_\_\_\_ Annual At-Large Dues \$15.00 \$ \_\_\_\_ Life Membership Dues \$300.00 (in full or installments) Can be paid in three (3) annual installments, plus chapter dues if applicable.

- \$ \_\_\_\_ Supporting Organization: \$75.00
- **\$** \_\_\_\_ Additional Donations
- \$ \_\_\_\_ Total Amount

Return this application along with payment to: CCLVI, Attention: Linda Allison Treasurer, 6010 Lilywood Lane, Knoxville, TN 37921-4111 Phone: 865-766-0477

#### **RETURN TO:**

Council of Citizens with Low Vision International Attn. Linda Allison 6010 Lilywood Lane Knoxville, TN 37921 FREE MATTER FOR THE BLIND OR HANDICAPPED



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.