# **Vision Access**

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

> Volume 23, Number 3 Winter, 2017

Published Triennially for Members in These Formats: Large Print, Email, and Audio CD.

Copyright © 2017 by the Council of Citizens with Low Vision International, a not-for-profit organization affiliated with the American Council of the Blind.

Council of Citizens with Low Vision International 1703 N Beauregard Street, Suite 420 Alexandria, VA 22311 (800) 733-2258 <u>www.cclvi.org info@cclvi.org</u> Views expressed in Vision Access by contributors do not necessarily reflect the views of the editor or of CCLVI. All rights revert to individual contributors upon publication.

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:

CCLVI Attention: Mike Keithley Editor 191 East El Camino Real #150 Mountain View, CA 94040 editor@cclvi.org

Publications Committee: Joyce Kleiber, Sarah Peterson, Patti Cox, and Mike Keithley. Formatting: Christine Chaikin.

Join our Social Networks:

CCLVI is now on Twitter at twitter.com/CCLVI\_Intl and Facebook by searching for "Council of Citizens with Low Vision International." Questions? Email <u>fb@cclvi.org.</u>

Please email <u>membership@cclvi.org</u> to change the format of your Vision Access magazine or update your postal address. Alternatively, you may also make such changes via telephone by calling our office at

(800) 733-2258.

### **Table of Contents**

From the Editor
President's Message 4
Scholarships5
Dues Notice
ACB Midyear Meeting7
Lets Talk Low Vision Conferences 8
ADA Movie Captioning and Audio Description
Rule Published 10
In the Palm of Nature 10
RSVA Sagebrush Conference 14
Dinner Table Syndrome: Tips and Tricks14
Historic Accessible Book Treaty Takes Effect18
The Importance in Telephoning Your Representatives When Lobbying on an Issue
State Resource Handbooks Available 23
McKinleyville California Has a Champion/Advocate and Support Group for the Blind and Visually Impaired
Request for Contributions 27
CCLVI Officers and Directors 28
CCLVI Local Chapter Affiliates 29
CCLVI Membership Application

### From the Editor By Mike Keithley

It's raining and cold while I'm writing, and company is coming in an hour. I'm thinking of a Redwood tree in Cuesta park in Mountain View, CA that I often visit with Star on morning walks.

It's not much more than a sapling ("I hope to have a bass voice soon!") so it hasn't been around much; but it's fun saying hello, putting my arms around the rather spongy bark and noting the morning moisture.

And in the summer time there's that wonderful resinous smell as the sun shines on the greenery. I believe there really is more oxygen under that tree at that time.

There isn't much to report of CCLVI happenings in the winter time, so the Organization News section will be rather small.

Plus Sarah Petersen has lots of job- related work so a profile will have to wait for the spring issue.

But we do have a wonderful article from Richard Rueda about his adventures in Italy, which will brighten the landscape a bit.

**Enjoy!** 

## **Organization News**

### President's Message By Leslie Spoone

**Dear CCLVI Colleagues:** 

Happy New Year from your CCLVI family. We are looking forward to another wonderful year in 2017.

Our CCLVI Board is working on several initiatives for the upcoming year. We have an exciting schedule of topics for "Let's Talk Low Vision" with Dr. Bill that include "Weathering the Storm" on emergency preparation and "How To Be Handy around the House." The E

Communications Committee has established a new 800 number, which will go into effect in April and save CCLVI money.

This new number will be (844) 460-0625, and is effective April 1.

As to the old number, one of CCLVI's affiliates may inherit it.

Plans are underway for the 2017 convention in Reno and the Fundraising committee is excited to host the third annual CCLVI Firecracker's walk team.

I am looking forward to representing CCLVI for the first time at this year's Mid Year President's meeting in Washington DC and reaching out to the 115th Congress to promote low vision electronic magnification devices through Medicare.

We continue to hold Board meetings on the following bimonthly schedule: January 4, March 1, May 3, June 7, July 1, September 6, and November 1; and welcome our members to call in and participate.

The call-in number is (712) 432-3447 code 182019. Meetings begin at 8:30 PM ET.

Let's keep up the good work for CCLVI. Best Regards Leslie Spoone CCLVI president <u>president@cclvi.org</u> (407) 929-9837

### **Scholarships**

## **CCLVI Scholarship Announcement**

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

Application materials must be received by March 1, 2017.

Scholarship monies will be

awarded for the 2017 - 2018 academic year.

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

Applications will be available to submit online from January 1 until March 1 at 11:59 pm Eastern Standard Time. Questions may be directed to legally blind, maintain a 3.3 GPA and are involved in their school/local community.

Apply for a 2017 Scholarship with ACB!

The American Council of the Blind (ACB)

Applications may be submitted beginning November 1, 2016 and all materials must be received by 11:59 PM Eastern on February 15, 2017.

annually awards approximately

20 scholarships of up to \$3,500

to vocational/technical school

students, entering freshmen,

undergraduate and graduate

college students who are

To read the scholarship guidelines and complete an online application, please visit www.acb.org/scholarshipapplication.

If you are interested in applying, or know someone who is, please contact Dee Theien by phone at (612) 332-3242 or by email at <u>dtheien@acb.org</u> for more information.

We look forward to receiving your application materials!

### Dues Notice By Jim Jirak

It's that time of year to pay dues and renew memberships to CCLVI.

By now, all non-chapter affiliated life members, at large members, and professional members should have received their renewal notice for the coming year.

As chair of the Membership Committee, I am responsible for gathering and submitting accurate contact information on all members to our parent organization's national office.

My goal as membership chair is to have the certification process complete and submitted by midnight eastern time no later than 4 days prior to the submission deadline, or March 11.

#### CCLVI at (800) 733-2258 o<u>r</u> scholarship@cclvi.org.

Please submit the information listed below to our CCLVI treasurer \*NO LATER THAN\* 11:59 PM eastern time, February 15. your name the correct postal address, including the zip code plus four, if in the United States.

the correct telephone number and specify whether it is a landline or cell.

the correct email address visual status (IE: blind or low vision or fully sighted).

preferred format for the ACB Braille Forum and Vision Access.

Even if there is no change, specify and don't assume. preferred method of contact (IE: telephone or email.).

Indicate whether you are a life member.

For your convenience, the dues structure is: 15.00 Members at large

\$75.00 Annual Professional Membership \$300.00 Life membership: which can be paid in 3 annual installments, plus affiliate dues if applicable.

\$500.00 Professional Life Membership

Concerning dues payment, CCLVI is pleased to announce that if you wish to join for the first time or renew you're membership online; you may do so by visiting <u>http://www.cclvi.org/member</u> <u>ship-form-0</u> where you will be directed to pay via PayPal.

Alternatively, the membership application found in this publication can be sent to: Linda Allison, CCLVI Treasurer 6010 Lilywood Ln Knoxville TN 37921-4111

Please be advised that any information provided to the membership committee will be shared with our parent organization, ACB.

If you have any questions, please either email me at <u>membership@cclvi.org</u> or call Kathy Casey in our office at (800) 733-2258.

### ACB Midyear Meeting from the acb-leadership list

Our phones have been ringing with requests for information about the 2017 midyear meeting. Below you will find the dates, the schedule of events, the hotel information and room rates. More information about the meetings and agendas will be available in the coming weeks. We hope you'll join us!

The American Council of the Blind's annual midyear meeting and legislative seminar will take place from Saturday, February 25, 2017

to Tuesday, February 28th, 2017 in Alexandria, Virginia.

2017 Schedule of Events: Saturday, February 25: Board Meeting.

Sunday, February 26: Affiliate Presidents' Meeting. Monday, February 27: Legislative Seminar. Tuesday, February 28: Meeting with Legislators on Capitol Hill.

Hotel Information: Crowne Plaza Alexandria Room rates (pretax): \$114 per night.

Address:

901 N. Fairfax Street

Alexandria, VA 22314. Phone number: (703) 683-6000. Crowne Plaza of Alexandria Website: <u>www.ihg.com/crowneplaza/ho</u> <u>tels/us/en/al</u> exandria/axecp/hoteldetail?c m\_mmc=Googl eMaps-\_-CP-\_-USA- -AXECP.

### Lets Talk Low Vision Conferences

Each month, the Council of Citizens with Low Vision

, International (CCLVI) provides a forum addressing topics of concerns to people with low vision 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 be part of the conversation, please call: (712) 432-3447, and enter the code 145330.

2017 Schedule:

Tuesday, January 17: CCLVI's Scholarship Program and Succeeding in College with Low Vision: Dr. Bill touches on CCLVI's Fred Scheigert scholarship with the chair of the Scheigert committee and recent scholarship recipients who share their recommendations for success in college. Tuesday, February 21: Nutrition, Exercising and Healthy Lifestyles in the New Year: Dr. Bill interviews CCLVI President and Certified Aerobics Instructor Leslie Spoone who will provide tips for staying physically fit in the new year.

Tuesday, March 21: Tax Tips and Preparation: This lecture will describe special tax deductions for people with low vision.

Tuesday, April 18: The "How To's," Being Handy Around the Home, At Work and in the Community: From fixing things, upgrading your home to finding handyman life hacks, this show will explore unique ways persons with low vision can maintain independence and learn from others. Dr. Bill interviews Larry Turnbull, ACB Radio Manager, who will provide tips for those so inclined to "do it yourself" in the home.

Tuesday, May 16: CCLVI and You: An Up-close and personal look at what's to come at our convention in Sparks, NV this summer. Dr. Bill interviews Jim Jirak and others involved in the elaborate planning of the 2017 CCLVI convention programming.

Tuesday, June 20: Best of the Best: Applications and Useful

Tips and Tricks for Mobile Phones and Tablets: Dr. Bill interviews Julian Vargas. This mobile technology specialist discusses the latest in useful tricks and tips for mobile devices.

Sunday, July 2: LTLV Is Live in Sparks, NV: Psychological Impact of Vision Loss: Be sure to join us live from the sight of the 2017 ACB Conference and Convention as we present a live in-person Lets Talk Low Vision series presented by Vickie Parker, M.A.

Tuesday, August 15: Parenting with Low Vision: Dr. Bill interviews Parenting Expert Julie Johnson, who will provide an informational session for low vision parents raising their children.

Tuesday, September 19, 2017: Weathering the Storm and Emergency Preparedness: Dr. Bill interviews FCB President Jim Kracht and Second Vice President Doug Hall on emergency preparedness issues for people with low vision.

Tuesday, October 17: Medical Advances: Dr. Bill reviews the most significant advances for the most common eye diseases.

Tuesday, November 21: Holiday Gifts for Children and Adults with Low Vision.

Tuesday, December 19, 2017:

## **Quality of Life**

### ADA Movie Captioning and Audio Description Rule Published as distributed on the acb- leadership list

The Justice Department has published in the Federal Register a final rule revising its Americans with Disabilities Act (ADA) Title III regulation to further clarify a public accommodation's obligation to provide appropriate auxiliary aids and services for people with disabilities. the Federal Register's website and on the Department's ADA website. The rule will take effect on January 17, 2017.

For more information about this rule, please visit the Department's ADA website at ada.gov or call the ADA Information Lines: Voice: (800) 514-0301;, TTY: (800) 514-3083.

The Final Rule is available on

### In the Palm of Nature By Richard Rueda, CCLVI Second Vice President

Snapshot of a multisensory and deeply tactile experience in the outdoor wildlife of Italy's Abruzzo, Lazio e Molise National Park. Readers note: Richard Rueda is an avid world traveler. He has low vision and has experienced the world both through sound, touch and limited sight. With a deep respect for diverse culture and an appreciation for wine, coffee and local native rituals, the following is a brief snapshot into a September 2016 excursion in the outdoors and natural elements of Italy.

This past September I was honored and fortunate to be among six individuals participating with the newly formed Diakron Institute, a non-profit whose mission is to mediate the cross-cultural and interdisciplinary exchange of relevant and diverse human perspective. During the eight-day adventure, the experiences of nature in the raw, with its vast depth, smells, sounds and sights, left me in deep fascination and awe, all the while wanting to extend the trip indefinitely.

This was an eco-cultural multisensory journey deep in the country side of Italy's Abruzzo, Lazio e Molise National Park, about 2 and ½ hours outside of Rome. This was a true immersion deep within nature.

Although we had comfortable lodging, we were never far removed from the animals that roamed the grounds and deeply forested mountainside.

A typical morning included waking up with hot and strong Italian coffee and witnessing cows and horses just outside our window. If we were quick enough lacing up our shoes, we could be outside in mere moments and pet both the cows and horses happily grazing.

Our week also included extensive hiking throughout the national park learning about nature and the ecology of the region. Often us blind participants were handed various natural materials including plant leaves, barks from native trees, wild berries, mushrooms, and other artifacts of the area to touch and smell. On one of our adventures just outside the park, we met with a local wildlife expert who walked us through a path introducing plants and other wild grasses and leafy greens that are edible when adventuring in the wild. The emphasis was also on alternative ways to remain health conscious.

We frequently met with naturalists, ecologists, archaeologists and locals to humbly gain insight and perspective on how the locals interact with native animals and other species in the region with minimal impact to the environment. During some of our excursions we happened upon the red deer.

In early autumn, the red deer rut season is at its peak. This is when the male deer seeks to mate with the largest harem. It was not uncommon to be as close as 50 yards from the active rut and yet not disturbing their activity.

We also learned from the local park rangers and locals who frequently walk the park paths that there were two active bears in the region. The widely accepted attitude about the bears was "chill." In fact, there has been no attack from bears recorded in more than a hundred years. Yet, one of the local bears fondly referred to as Gemma, (ChehMuh) was known to be a party animal who would ransack garbage cans and fruit trees and gardens of area homes in the village.

Not only did we immerse ourselves among the wildlife and native landscape, our itinerary included frequent visits to local taverns and small family dining and coffee establishments. It is no surprise that the Italian culture adores its caffeine ritual of cappuccino, coffee and yes, vivid tasting wines. Wine and cheese tasting throughout the region is a must and is deeply rooted as a part of the cultural thread.

There are no Starbucks in Italy. I say this to underscore that Italy largely appreciates locally owned establishments from lodging to food and more. Our tours of these smaller eateries and coffee houses were often met with getting to know the barkeep and learning without pretentiousness the lay of the land, how food and beverages is deeply honored and served.

Two of my favorite finds during our adventure were that of sampling Sheep's milks cheese and a locally produced liver sausage. The flavors and texture were simple yet powerful. I do not believe that throughout the eight-day adventure, we went without bread during any meal. Fortunately, our active hiking explorations kept us from gaining too much.

A common sign of gratitude in parts of Italy is that of sticking both thumbs into one's own cheeks with fingers of each hand rolled inward and making a twisting motion. This is the equivalent of saying with gratitude that food and beverage consumed is wonderful. During our travels, we witnessed the graceful aged, yet environmentally sound layout of the small villages dotted throughout the region. Often spanning an entire block, many of these tall stone buildings would house local eateries, homes and other small businesses. When there were sidewalks, often they were short and narrow. I had to stop myself from walking outside to the virtually nonexistent sidewalk, so that I would not be run down by a car or carriage.

Other highlights included closely researching on foot local animal life. To that end we had opportunities to gently observe and touch recent undisturbed tracks of deer, wolf and bears. Nathan Ranc, our trip leader guided us through the plaster cast steps of that of tracks of a red deer. After the deer tracks were plastered and dried, it provided for us a three-dimensional, hands on the footing of a typical red deer. In late evenings on our trip, we would venture throughout various known locations in the national park to listen to wolves howling. Led by Nathan, we went to various locations, both in remote forests and closer to settlements, with the hope to hear the wolves. During one of our late night listening attempts, we heard a short yet powerful wolf howl surrounded by a cacophony of barking doas.

Our accommodation, the Casone di Colleciglio, a historic waypoint for shepherds, which is integrated in the landscape along the shore of Barrea Lake in Abruzzo, was our home for the eight-day trip. Surrounded by wildlife, dirt roads and animals literally at our front door, our ears feasted on the red deer rut, cows and horses and birds off in the distance.

Our group size was small yet comfortable. Meeting staff and participants from across Italy, France, Greece and the United States, we shared similarities in lifestyles on blindness, guide dogs as well as how things are accomplished differently. We learned of each-others passions, love for coffee, wine and eclectic music. Often conversations would move on deep into the night around the large indoor rustic fireplace.

This is what the Diakron hopes to achieve in its mission and on this inaugural adventure, the outcome could not have been better planned.

This was the first of what is hoped to be many more multisensory travels planned for by the Diakorn staff.

Having been a part of many non-profit travel organizations during my lifetime, I have not seen a more respected and deeply committed group of people plan and passionately both share and experience together the journey.

I certainly departed from the trip with a far greater and deeper profound knowledge for the simplicity of the European and Italian lifestyle.

Also, as an unintended outcome of this extraordinary travel event, learning about the wins of planting and preparing organic food for consumption doubled my commitment to buying organic as often as possible.

For more information about the Diakron, visit <u>www.diakron.org.</u>

# RSVA Sagebrush Conference from Ardis Bazyn as distributed on the ccb-presidents list

Hi all,

The 2017 RSVA sponsored Sagebrush National BEP Training conference is coming

soon-- February 13-17, 2017 in Los Vegas. The announcement letter, exhibitor letter and the sponsorship letter are all available on the RSVA website at www.randolphsheppard.org. Please forward this announcement to friends and colleagues. The attendee registration goes up on January 1.

If you have questions, please email\_ <u>abazyn@bazyncommunications</u> <u>.com</u>or call me at (818) 238-9321.

If you need a tentative agenda, let me know.

### Dinner Table Syndrome: Tips and Tricks By Becky Frankeberger as distributed on the sasi email list

{Editor's note: The audience for this article is hearing impaired people. But since many of them have low vision, I thought it appropriate here.}

Greetings from the Office of the Deaf and Hard of Hearing!

2016 is drawing to an end. Many of us are now starting preparations for family gatherings during the upcoming holiday season. We would like to share some tips and tricks for communicating with your loved ones while being sensitive to hearing loss. Most of the 430,000-plus individuals in Washington state who have some form of hearing loss, whether they identify as deaf, Deaf, DeafBlind, Hard of Hearing, or Late Deafened, will experience something called Dinner Table Syndrome during the holiday season.

What is Dinner Table Syndrome, you ask? When a person with hearing loss is in a room full of hearing people, yet feels completely alone and invisible, this is Dinner Table Syndrome. Imagine a long table covered with food and people chatting or playing Trivial Pursuit.

In the midst of the chaos is a person with hearing loss, watching everyone else laugh and joke and argue and share news, but not having the same access to these conversations as their peers.

Often a person not

understanding the flow of the conversation will ask what is going on at the table. The responses they receive vary: "I will tell you later," "never mind" or "it's not important." If they are lucky, they will receive a brief summary of the entire conversation in a way that prevents the person from participating in it. This is Dinner Table Syndrome (DTS).

As a result of DTS, people with hearing loss often become isolated, lonely, frustrated and/or angry. They may feel unimportant or invisible to their hearing family members.

They may cope with this by seeking refuge in whatever way feels safe to them, such as spending time reading books or surfing the Internet during the family gathering.

In the weeks leading up to the holidays, people with hearing loss often begin to anticipate Dinner Table Syndrome with trepidation.

The holidays are a stressful time for everyone, especially for those who have hearing loss. Hearing people, especially family members, may not realize how their loved one feels being left out at the dinner table or in conversations since it doesn't impact them in the same way that it impacts their loved one.

Breaking down the barriers to communication will lead to improved connections and healthier interactions with your loved ones. Naturally, the best way to do this is to learn how to

communicate with them. If they are American Sign Language users, learning even the most basic sign language will go a long way. If they are hard of hearing, remember to always make sure they can see your lips. Don't cover your mouth or turn away during a conversation, even if their lipreading makes you selfconscious.

When you do that, you effectively cut them off.

For your loved ones who rely on hearing and speaking, be sure to enunciate clearly and speak at a normal pace. Do not slow down or over-enunciate words. Do not shout. Pause in between sentences, repeat new words or names that may be difficult to understand, check in often to make sure your friend is engaged and following the conversation.

If you are hosting a gathering, make sure there is good lighting being distributed from above you in the room where the party is being held, as well as anywhere people may congregate throughout the house. Be mindful that low seated lamps on coffee tables will often impede sight lines. If you are talking to someone with hearing loss, be sure to check behind you for any bright lights that may make it difficult to see your face clearly. If

the light is in front of the person with hearing loss, they are seeing silhouettes, not your actual lips. Ideally, the light should be behind the person with hearing loss so that it is shining ONTO whatever they are looking at. Be sure to have a room in the home that is well lit, has seating, and is quiet, for your hard of hearing loved ones to have side conversations with others one-on-one. Have some hands-on activities like nonverbal board games, crafts, cookie decorating, etc. available for folks to play. Write down a list of tasks that need to be done for the party,

and have everyone cross things off the list when they are done, rather than having this be all verbal. This will empower your loved ones to participate in a way that is accessible to them and does not draw attention.

For example, if your sister (who has a hearing loss) comes up to you and asks what needs to be done, and you are in the middle of doing something else and don't have time to pause and communicate with her, you will likely say "nothing, go relax." A few minutes later, she will watch you tell someone else to carve the turkey or grab the gifts from the garage, and wonder why you didn't give her this task.

Having a written list of tasks or being more mindful of this will help your loved one be a part of the celebration.

Check in ahead of time: send an email or text message to your loved ones asking what you can do to make things more comfortable. Ask them if there is a specific seat that is better for them to be able to see others.

Be sure to turn on the captions on the television BEFORE they arrive. Make sure the WIFI username and password is written down in an accessible place, and let them know what it is before they ask. If your loved ones are residents of Washington state, they can visit ODHH's website at <u>www.dshs.wa.gov/altsa/odhh</u> <u>/telecommunic</u> ationsequipment-distribution for more information on getting these devices. You can also call ODHH at (800) 422-7930 (V/TTY), (360) 902-8000 (V/TTY), (360) 902-0855 (Fax), (360) 339-7382 (VP) or e-mail <u>odhh@dshs.wa.gov.</u>

Also, many of these types of equipment listed on the ODHH website can be purchased at Amazon.com or through the manufacturer's

websites. Be sure to check with your loved ones first to make sure this device will work for their communication needs.

Another resourc<u>e is</u> <u>www.harris</u>comm.com for a variety of assistive equipment and cultural needs.

For people with hearing loss who are fluent in English, you can also use speech- reading Apps on your phone.

Be sure to pick one with high reviews. The App will transcribe spoken word into English. However, your friends still need ways to communicate their thoughts with you, either by typing, writing, or speaking if their speech is clear.

You can also use Apps (some reputable ones are "The ASL App" by Ink and Salt with Nyle DiMarco, and "ASL Dictionary from NTID") to learn some basic sign language.

Be sure to choose deaf instructors for the most accurate signs. Another option is to hire an ASL interpreter.

It may feel cost prohibitive, but it is worth it. You would be surprised at how many people are willing to chip in a few bucks.

Check in with other hearing relatives ahead of time to collect money to hire an ASL interpreter for the party.

It will make your loved one's day to know they have full access to communication for the entire time they are at the party.

You will get to know your loved one in a whole new way with an interpreter facilitating clear communication. Contact ODHH for resources on hiring ASL interpreters.

Be proactive. Be assertive.

Show them that you are thinking about them.

When making introductions, don't say "this is my cousin Judy, she's deaf." Model the communication method that works best for Judy when introducing her to other people at the party. Speak slowly, make eye contact, slow the conversation down and make sure the lighting is good.

All parties will appreciate the modeled behavior and it will make communication more efficient and less awkward.

Don't get upset with your loved ones if they choose to withdraw and read a book or get on their phone. This is their coping skill. Be supportive by offering them a lamp, cup of tea or a pillow.

Show them that they can make themselves comfortable and do what works for them.

Be understanding when they leave early.

Make the effort to talk with them one-on-one and really connect with them, whether it's through writing notes, lipreading, gesturing, even using speech to text on a phone App to

communicate.

They might have traveled a great distance for this event, only to be isolated. Be mindful of that.

Be sure to keep them in the loop if there are updates like the turkey will be out in 15 minutes, mom is making the whipped cream for pie, these are the drink options, which movie do you want to watch, etc.

Make sure they have access to this information and are able to participate in the discussion about choosing things.

Last but not least, eye contact, body language (nodding your head, smiling, those brief moments of connection) make a difference. Take the time to really see your loved one, and it will make a difference.

Have a wonderful holiday season!

## Historic Accessible Book Treaty Takes Effect edited from the ACB leadership list

[the original article is at www.perkins.org/stories/new s/historic-accessible-booktreaty-takes-effect-today.]

In 22 countries and counting,

the Marrakesh Treaty will make more accessible books available for people who are blind. Stalin Arul Regan Devadoss knows how hard it can be for people with visual impairments to get books in braille format.

In August, Devadoss received an urgent request in his native India from a college student who is blind. The student had enrolled in an English Literature class, but only standard print copies of the textbook were available. She needed a braille version--and fast.

"She was falling behind in her class," said Devadoss, who works for a government disability agency. Devadoss was able to help the student contact a braille printing press and get an accessible copy of the textbook she needed to keep up with her sighted classmates.

On October 1, 2016 India and 21 other nations will begin a new era in accessible books.

Through ratification of the Marrakesh Treaty, millions of people who are visually impaired or otherwise unable to read print materials will now enjoy increased access to braille, audio and other accessible book formats. A groundbreaking international agreement, the Marrakesh Treaty creates exceptions to intellectual property law that allows accessible versions of copyrighted books to be produced and distributed, both within countries and across international borders.

As these reforms take effect in the 22 ratifying countries, readers with visual impairments should find it increasingly easy to buy or borrow books in accessible formats.

"This treaty will definitely help," said Devadoss, who is currently enrolled in Perkins International's Educational Leadership Program. "Access to information is so essential for developing new ideas and building your relationship with the world. It's the right thing to do."

The United States has not yet ratified the Marrakesh Treaty.

The agreement has backing from the Obama administration but still requires approval in the US Senate. Perkins School for the Blind has made advocacy information available for individuals who support everyone's right to read. Kim Charlson, executive director of the Perkins Library, has been working to encourage ratification of the treaty in her role as president of the American Council of the Blind.

"The Marrakesh Treaty will level the playing field and make it possible for people with print disabilities to have access to valuable materials and information," said Charlson. "This translates to education, personal and professional growth and empowerment for everyone."

The treaty is formally named the Marrakesh Treaty to Facilitate Access to Published Works by Visually Impaired Persons and Persons with Print Disabilities.

It was adopted in 2013 at a diplomatic conference organized by the World Intellectual Property Organization (WIPO) in Marrakesh, Morocco. WIPO is an agency of the United Nations that promotes the protection of intellectual property throughout the world.

Perkins President and CEO Dave Power urged every nation to ratify the treaty. Power said technology exists to share any book in accessible formats while protecting intellectual property rights. Such systems are now in place in several countries, he said. "Access to the printed word promotes independence for those who are visually impaired, and inclusion within their communities," said Power.

"Now is the time to make every book available across any border to those who are visually impaired."

### The Importance in Telephoning Your Representatives When Lobbying on an Issue By Daniel Victor

{Daniel Victor is a senior staff editor at The New York Times.}

Kara Waite, an English teacher at Bunker Hill Community College in Charlestown, Mass., made a rule for herself: For every political rant she posts on Facebook, she must pick up the phone and call a legislator. "It's kind of a swear jar for political action," Ms. Waite said recently.

Ms. Waite, who volunteers for liberal causes and who created a widely shared document last week to teach others her methods, figures that a phone ringing off the hook is more difficult for a lawmaker to ignore than a flooded inbox. Activists of all political stripes recommend calling legislators, not just emailing — and certainly not just venting on social media. Several lawmakers, along with those who work for them, said in interviews that Ms. Waite is right: A phone call from a constituent can, indeed, hold more weight than an email, and far outweighs a Facebook post or a tweet.

To understand why, it helps to know what happens when someone answers the phone at a legislator's office.

Even if you don't speak directly to the lawmaker, staff members often pass the message along in one form or another.

Emily Ellsworth, whose jobs have included answering phones in the district offices of two Republican representatives from Utah--Jason Chaffetz, from 2009 to 2012; and Chris Stewart from 2013 to 2014 — said the way your points reach a lawmaker depends on how many calls the office is getting at the time and how you present your story.

In some cases, it's a simple process.

When a caller offered an opinion, staff members would

write the comments down in a spreadsheet, compile them each month and present reports to top officials, she said. If the lawmaker had already put

out a statement on the issue, the staff member would read it to the caller, she said.

But a large volume of calls on an issue could bring an office to a halt, sometimes spurring the legislator to put out a statement on his or her position, Ms. Ellsworth said.

She recommended the tactic in a series of tweets shared thousands of times.

"It brings a legislative issue right to the top of the mind of a member," she said. "It makes it impossible to ignore for the whole staff. You don't get a whole lot else done.

" When her branch in Utah received a lot of calls, she contacted the Washington office and coordinated the messaging, involving the communications director, the legislative director or the chief of staff, Ms. Ellsworth said.

While scripts found on the Internet can be useful for people uncomfortable talking on the phone, she suggested making the phone calls as personal as possible. In some cases, if she was moved by a call, she would pass on the comments to her district director, she said.

"What representatives and staffers want to hear is the individual impact of your individual story," she said. "I couldn't listen to people's stories for six to eight hours a day and not be profoundly impacted by them." Representatives in Congress may not be able to respond to individual phone calls, but your odds may be higher if you contact officials at the local or state levels.

A New York State Senator, Phil Boyle, a Republican, said that one of his staff members would contact him after a constituent called his office, and that he would try to call everyone back. That's a perk exclusive to those who call in, since he sometimes gets more than 300 emails per day, he said.

"I couldn't possibly do that for emails," Mr. Boyle said. When it's a subject in which he lacks expertise, he said, the calls have made a difference. In one case, several retired law enforcement officers called him about a gun control law that was enacted in 2013, worried that they would have to give up their service revolvers. doesn't use firearms much, was unaware of that possibility and proposed an amendment to grant them an exception. Gov. Andrew M. Cuomo granted the exception seven months after the law was passed.

Most calls can be handled by staff members, said Brian Kolb, the Republican minority leader in the New York State Senate. Many callers just want to express an opinion and don't even offer a name, he said.

In other cases, callers who want to talk out an issue more fully could be directed to a staff member who has expertise in the area, said State Senator Liz Krueger, a **Democrat in New York.** Ms. Waite, who has had a calendar reminder for each Monday morning alerting her to "call party leadership," said that first-time callers often fear they will be guizzed or interrogated, but that they generally just need to offer their opinion and basic personal information, like name and city.

She implored people to be courteous, since the staff members might be getting many calls.

"Communicate in a way that someone can't ignore," Ms. Waite said.

Senator Boyle, who said he

### State Resource Handbooks Available for Purchase submitted by Christine Chaikin

I have created 20 screen reader-friendly Resource Handbooks containing resources pertaining to the blind and visually impaired, for use by consumers and professionals. Completed states are: Alabama, Hawaii, Florida, Arkansas, Alaska, Arizona, California, Connecticut, Colorado, Georgia, Texas, New Jersey, New York, Nevada, Ohio, Oregon, Illinois, Kansas, Delaware, and Pennsylvania.

These handbooks are for the residents of the above states

and includes the many organizations for the blind and visually impaired within them, covering areas such as employment, housing, transportation, and more. Each handbook includes contact information on the local, regional, and national levels.

For more information on pricing and formats please contact Insightful Publications by email at <u>insightfulpub@gmail.com</u>, by phone at (808) 747-1006, or visit our website at www.insightful.com.

### McKinleyville California Has a Champion/Advocate and Support Group for the Blind and Visually Impaired By Audrey Demmitt, RN and VisionAware Support Group Facilitator

{Editor's note: This originated from AFB's VisionAware website.}

McKinleyville Low Vision Support Group, also known as "The Bumpers," has been meeting since 1998.

It is a small group in a small town doing important work; providing support to the visually impaired and advocating for their needs in a rural community.

Doug Rose attended this group for 5 years before he stepped up to lead it. He was uniquely prepared for this role by years of experience working for a variety of agencies in the field of blind services. Doug has been blind since early childhood and knows what it takes to live with vision loss. He has been facilitating this group for 8 years. Doug is a long-time advocate for the visually impaired and an active member of the American Council of the Blind (ACB), a national consumer-based advocacy organization working on behalf of blind and visually impaired Americans throughout the country.

The California Council of the Blind is the California affiliate of the ACB, and is a statewide membership organization, with 40 local chapters and statewide special interest associations.

Led by Rose, the group has been successful in many advocacy efforts in the McKinleyville area. There was a time when there were no services for the visually impaired near Mckinleyville. Doug and some support group members are affiliated with the Humboldt Council of the Blind, and they actively lobbied to change that. Now the San Francisco LightHouse for the **Blind and Visually Impaired** operates LightHouse North Coast 3-4 days a week in Eureka, just 12 miles away. This satellite office is dedicated to seniors with vision loss and several group

members have received services there.

In addition, the Humboldt ACB chapter worked to bring accessible pedestrian crossing signals to their community.

After the new pedestrian signals were installed, several people found the time was too short to cross the street safely, so they wrote a letter to give this feedback to the city and the signal time was lengthen on their request. Doug says: "The ACB has a great Pedestrian Safety Handbook which teaches how to advocate for these issues." [The latest Pedestrian Handbook press release is at acb.org/node/626.]

The Humboldt Council of the Blind also successfully advocated for audio description and closed captioning services at a local theater. Doug enlists support group members' help with phone call and email campaigns when the California Council of the Blind needs advocacy work on current legislation.

The McKinleyville Low Vision Support Group meets the last Monday of each month from 11 AM to 12 PM at Azalea Hall Senior Center, 1620 Azelea, McKinleyville, CA. Favorite presentations have included vendor demonstrations of accessible equipment, Emergency Preparedness for earthquakes by the Red Cross, the California Telephone Access Project, and lessons from Low Vision Focus from the Hadley Institute. This group welcomes all ages, eye conditions and family and friends of those who are affected by vision loss.

**Senior Center without Walls** 

Doug facilitates another support group which is quite unique. He volunteers with a program called Senior Center without Walls and leads a low vision support group on a weekly tele- conference call. Senior Center Without Walls is an award-winning program offering activities, education, friendly conversation, and an assortment of classes, support groups and presentations to seniors in the United States, Canada and other locations internationally.

Each week seniors can access over 70 groups by phone or online, all from the comfort of home.

Their mission is to provide community to isolated seniors. The Low-Vision Support Group is called "The Eyes Have It" and it meets every Wednesday from 1:00 PM - 1:45 PM on a toll-free conference call.

There are 10-20 people who call in from all over the US to meet others living with low vision and share solutions and techniques for continuing to live a full life. Doug says many callers live alone and are housebound with multiple health challenges and states "That the phone is their lifeline and allows them to stay connected to others." The group discusses topics like transportation options, Talking Books and vision rehabilitation skills from the Hadley Institute. Doug is working on a hands-on presentation on writing skills. VisionAware will feature this group in the future.

It is obvious that Doug Rose is a champion for people who are blind and visually impaired in his community, making a difference through his advocacy and support group activities.

Though leading this type of support group has its challenges and limitations, it offers a meaningful alternative to seniors who have few options. To learn more about these support groups, contact Doug Rose at <u>dougdrose@suddenlink.net.</u>

## **Science and Health**

### **First Artificial Pancreas Approved**

[Editor's note: This article was distributed by Chris Gray on the ACB leadership list and is edited. Chris writes:

"This is a huge step forward in the treatment of diabetes, currently only for type 1 diabetics but I'm sure that will change over time. Of course, no word about price or its accessibility to a blind user.]

Medtronic Plc will bring to market the world's first artificial pancreas, after US regulators cleared the device for diabetics to automatically monitor blood sugar and supply insulin, replicating what a healthy version of the organ does on its own. The Food and Drug Administration cleared the product, called MiniMed 670G, for patients with Type 1 diabetes who are at least 14 years old. It will let some diabetics turn over part of their daily routine of fingerprick tests and insulin injections to an automatic system.

Along with lessening the burden of a condition that requires constant attention, it also offers hope that better blood sugar control at inconvenient times, such as at night, will ultimately improve long-term health.

"This first-of-its-kind technology can provide people with Type 1 diabetes greater freedom to live their lives without having to consistently and manually monitor baseline glucose levels and administer insulin," Jeffrey Shuren, director of FDA's Center for **Devices and Radiological** Health, said in a statement. The FDA approved Medtronic's product months sooner than investors expected, and without going before a panel of outside advisers that often precedes the introduction of innovative products.

In doing so, the agency also moved faster than European regulators, who are often first to clear medical devices.

**How It Works** 

The MiniMed 670G, which is about the size of a smartphone, wirelessly connects an insulin pump and a glucose monitor. Blood sugar levels are monitored every five minutes by a sensor that reads just under the skin, the FDA said. A computer algorithm then ensures patients have the right amount of insulin, a hormone that's needed to turn blood sugar into energy. Medtronic expects the device to win approval outside the US next summer. Medtronic said it wouldn't be ready to introduce the 670G until the spring of 2017.

**Type 1 Diabetes** 

About 1.25 million people in the US have Type 1 diabetes, where the pancreas fails to produce any insulin, according to the Juvenile Diabetes Research Foundation.

The condition typically presents in childhood, and patients walk a fine line, since too much or too little insulin can be life-threatening. Lax blood sugar control can lead to a host of additional health problems, including heart disease, stroke, kidney and nerve damage and blindness.

Type 2, which is more common, is tied to obesity and typically develops gradually. The Medtronic's device takes on the responsibilities of the human pancreas, which is tasked by the body with producing insulin in precise quantities. While Medtronic previously released a system that could shut off if glucose levels fell too low, it didn't automatically deliver the hormone when blood sugar climbed.

### **Request for Contributions**

CCLVI gratefully accepts contributions from readers and members to help pay for the costs of publishing Vision Access, the costs related to our 800 line and Project Insight, and for funding the Carl E. Foley and Fred Scheigert Scholarships. Please send contributions to

CCLVI Treasurer Linda Allison 6010 Lilywood Lane Knoxville, TN 37921 Phone: (800) 733-2258

#### **CCLVI Officers and Directors**

Officers

President: Leslie Spoone Orlando, Florida <u>president@cclvi.org</u>

First Vice President: Kathy Farina Albany, New York <u>first-vp@cclvi.org</u>

Second Vice President: Richard Rueda Sacramento, California <u>second-vp@cclvi.org</u>

SECRETARY: Robert Spangler Vinton, Iowa <u>secretary@cclvi.org</u>

Treasurer: Linda Allison Knoxville, Tennessee treasurer@cclvi.org

Immediate Past President: Charlie Glaser Stone Mountain, Georgia <u>charlie.glaser@cclvi.org</u>

Directors

Sarita Kimble Philadelphia, Pennsylvania sarita.kimble@cclvi.org

Fred Scheigert Saratoga Springs, New York <u>fred.scheigert@cclvi.org</u>

Zelda Gebhard Edgeley, North Dakota Zelda.Gebhard@cclvi.org

Angelo Lanier North Little Rock, Arkansas angelo.lanier@cclvi.org

Sara Conrad Milwaukee, Wisconsin Sara.conrad@cclvi.org

Patti Cox Louisville, Kentucky patti.cox@cclvi.org

**Other Roles** 

Vision Access Editor: Mike Keithley editor@cclvi.org

Webmaster: Robert Spangler webmaster@cclvi.org

## **CCLVI Local Chapter Affiliates**

CCCLV: California Council of Citizens with Low Vision CCCLV@cclvi.org

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

FCCLV: Florida Council of Citizens with Low Vision FCCLV@cclvi.org

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

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

## MEMBERSHIP Application FORM

All fields marked with an asterisk are required.
*Name:
*Mailing Address:
*City:*State:*Zip Code:
*Phone Number:
E-mail:
*Preferred Method of Contact:
()Phone ()E-mail ()Large Print
()Postal Mail
*Visual Status:
()Fully Sighted ()Legally Blind
()Totally Blind ()Unknown
*Membership:
() \$15.00 Annual Membership
() (\$75.00 Annual Professional
() \$300.00 Life Membership of CCLVI
() (\$500.00 Professional Life Membership

\*Vision Access I would like CCLVI's Vision Access in the following format:

(\_\_)Large Print (\_\_)E-mail

(\_\_)Audio CD (\_\_)Do Not Send

\*ACB Braille Forum I would like the ACB Braille Forum in the following format:

(\_\_)Large Print (\_\_)Braille (\_\_)Cassette

(\_\_\_)Computer Disk (\_\_\_)E-mail

(\_\_)Do Not Send

We offer two methods for payment of your dues.

You may either send check/money order or choose the PayPal option.

Please make your check or money order out to CCLVI.

If you choose to send your payment by mail, please send it to:

CCLVI Treasurer Linda Allison 6010 Lilywood Ln Knoxville TN 37921