

Spring 2016



Ohio Connection

American Council of the Blind of Ohio
3805 N. High St., Ste. 305
Columbus, OH 43214
1-800-835-2226

ACB-OHIO'S ADVOCACY EFFORTS IN OHIO AND BEYOND

By Katie Frederick

It's that time of year when members of the American Council of the Blind head to Washington, D.C., to meet with congressional staff and discuss legislative priorities. During our visit to the nation's capital, ACB-Ohio delegates will bring four issues to the attention of our state's representatives and senators. Two of the 2016 legislative imperatives likely sound familiar to many readers since we have brought them to the attention of congress over the past several years.

We discussed the Medicare Demonstration of Coverage for Low Vision Devices Act of 2015 (H.R. 729) with Hill staff last year and it's one we will make a case for again this year. This is bipartisan legislation to overturn a 2008 ruling by the Centers for Medicaid and Medicare that excludes low vision aids such as magnifiers and video monitors from Medicare reimbursement. The full



Katie Frederick and Rob Rogers visit Sen. Portman's office

text of the background paper is available at: <http://www.acb.org/li-LowVision>.

Our second legislative priority is the Alice Cogswell Anne Sullivan Macy Act. Reintroduced as H.R. 3535, this legislation will improve special education and ensure that children who are blind, visually impaired, deaf-blind, deaf, and hard of hearing receive the services they need in their k-12 education setting. For more information about H.R. 3535 visit www.acb.org/LI-CogswellMacy.



Katie Frederick and staffers outside of Sen. Sherrod Brown's office

On February 10, 2016, President Obama sent a package to the United States Senate asking for, among other things, ratification of the Marrakesh Treaty. This is the third legislative priority Ohio's delegates will address with our senators, allowing people who are blind or visually impaired access to and sharing of accessible materials around the world. More information about the Marrakesh Treaty may be found here: www.acb.org/LI-Marrakesh.

The final 2016 legislative imperative seeks advocacy from the House of Representatives urging that the Department of Justice issue a notice of proposed rulemaking (NPRM), pertaining to Title III of the Americans with Disabilities Act. As technology continues to evolve, it is crucial people who are blind or visually impaired have equal access to web content and web developers

make their content accessible to all individuals. To read more about this issue visit www.acb.org/LI-ADA-Accessibility.

On the home front, ACB-Ohio is currently playing an active role to ensure funding for early intervention services and support is increased throughout our state. On February 10, I emailed a letter to directors of the Ohio Department of Health and the Department of Developmental Disabilities urging increased funding for children from birth to age three and their families who are impacted by blindness or visual impairment. There are a few pockets of the state where these crucial services are available, but many Ohioans' needs are unmet. If you have not done so, I strongly encourage you to let leaders of Ohio's Department of Health and Developmental Disabilities know how important it is for children in the critical first three years of life to receive support. I want to thank Kay Clarke, a provider and member of the Early Intervention Provider Network, for bringing this issue to my attention. If you send a letter expressing the importance for increased funding, please notify me in the ACB-Ohio office so I can follow up and work with others and advocate as necessary. If you are unable to send an email letter of support, please call the office; I am more than happy to send a

note of support on your behalf. Please email letters to:

Kim Hauck
DODD Assistant Deputy Director
Kimberly.Hauck@dodd.ohio.gov

Nathan Dedino
ODH Interim Part C Coordinator
Nathan.Dedino@odh.ohio.gov

Michele Frizzell
ODH Bureau Chief of Health Services
Michele.Frizzell@odh.ohio.gov

Richard Hodges
Director of ODH
Richard.Hodges@odh.ohio.gov

Here is the letter I sent in support; please use it as a guide and include your own story or express the need for increased funding. Thank you in advance for your advocacy assistance as ACB-Ohio works to improve the quality and equality of life for people who are blind or visually impaired around Ohio and beyond.

Dear _____,

As a leader of The American Council of the Blind of Ohio, a consumer group consisting of members impacted by blindness or visual impairment, I am writing urging support for bridging a critical gap in Ohio's early intervention

system that impacts hundreds of families throughout our state. Despite the fact that all states who receive federal funds to operate early intervention programs are required to fund vision services to support families of young children with vision loss, the Ohio Department of Health, (ODH), has failed to implement a system of services and supports statewide. While vision services are provided through private agencies in a few pockets of Ohio, most families are not reached or connected to these services and agencies.

As an individual born premature, resulting in blindness, I was fortunate to have vision support services available to me as an infant. The support and services provided to my family and I proved invaluable and positively contributed to my future development. Through support and services my family and I received, I learned nonvisual ways to explore my environment, interact and communicate with others, and early literacy skills through the use of braille. Many times, as was the case with my family, parents and other caregivers are unsure where to turn when they learn their child is blind. As a result of early intervention services, my family learned to cope with and adapt to meet my unique learning style. Approximately 90 percent of learning and

(Continued on page 12)

BEHIND THE SCENES—ACBO'S BOARD OF DIRECTORS

By Vicky Prahin

As a member of ACBO, you receive a copy of this newsletter each quarter, hear about events and legislation, and might attend the annual convention in the fall. It's easy to take all of this for granted, but do you ever wonder how the work gets done and who does it?

At the convention each year, attendees elect officers and members of the board of directors to two-year terms. These people then represent all members.

ACBO has five officers: president, first and second vice-presidents, secretary, and treasurer. All of these are elected and serve two-year terms, limited to two consecutive terms. In addition, we have an executive director who does most of the administrative work, oversees accounting, and represents ACBO on councils and committees and at various meetings of organizations involved in serving the blind and visually impaired. That person does many of the jobs which would otherwise fall on the shoulders of the officers. I could not effectively act as president without the help and support of our executive director.

The president and both vice-presidents must be blind or visually impaired. The president serves as Chair of the Board of Directors, conducts meetings of the Board and membership, acts as official spokesman when necessary, appoints committee chairmen, serves on all committees as required, and tries to keep everything running smoothly. If the president cannot fulfill these duties for any reason, the first vice-president will step up and act as president; if that officer is unavailable, it falls to the second vice-president to fulfill the obligations of the president's position. Most of the time they both offer general support and take on some of the responsibilities of the president so that everything that needs to be done can be done efficiently.

The secretary has the job of preparing minutes for each meeting of the Board of Directors and keeping all of those records up to date. The treasurer, of course, oversees accounts and prepares reports of those accounts. The treasurer must prepare a budget each year and see that we function within it. If all of these do their jobs effectively, it makes mine that much easier.

So, if the officers do all of this, what do the 11 directors do besides having an important-sounding title? The directors decide on policies between conventions, support the president and executive director in fulfilling their responsibilities, and chair the 14 committees to carry out the business of ACBO. They also contribute financially to help provide programs and further our mission.

What do these committees do? The Convention Program Committee, with the help of the Site and Exhibit Committees, plans the annual convention, identifying topics of interest, finding speakers and presenters, locating a venue which is accessible and affordable, and inviting and organizing exhibitors and vendors. These committees start work in January or February because it takes months to work out all of the logistics. Even so, the last-minute cancelation of a speaker, the discovery that the hotel has no room numbers which are in braille or large print, or a decision to hold some activities in another building can throw everything off and require frantic shuffling and reorganization.

The Awards Committee is charged with requesting and considering nominations for the seven awards ACBO offers. Both tasks are difficult. Sometimes we only receive one or two nominations; sometimes we receive so many for one

award that it's hard to make a choice. We would much rather have the latter problem, so send those nominations in!

The Scholarship Committee has a similar chore, getting the word about our seven scholarships out to students, gathering applications and references, and choosing winners.

Other committees plan the summer and winter sports retreats, stay informed about national and state legislation, update membership records and find ways to attract and retain members, and oversee how we fund the organization and spend those funds.

As you can see, being an officer or director is more than a title. When you consider nominating someone to one of these positions, ask that person if he or she is willing and able to accept the responsibilities involved, and ask yourself when voting if you truly believe that the person you vote for has the qualifications and abilities to perform the duties of the position. Good officers and a strong Board of Directors are vital to keeping ACBO running smoothly and carrying out our mission. You can learn more by reading ACBO's constitution and bylaws, available on our website, www.acbohio.org.

CONNECTING THE DOTS: OHIO'S FIRST DEAF-BLIND BRAILLE PROGRAM

By Elizabeth L. Sammons

- Who?** Adults with low or no vision and hearing
- What?** Learning basic braille
- When?** June 12-24, 2016
- Why?** Labeling/messaging; increasing independence
- Where?** Ohio School for the Deaf, Columbus

That's the plan in a nutshell! Last year's Workforce Integration Task Force reported: "Ohioans with disabilities often lack critical vocational and career planning skills and the appropriate training opportunities to acquire them are not always widely available." The report recommends that Ohio should ensure that pre-vocational and vocational training be available and accessible for blind, deaf, and deaf-blind Ohioans throughout the state; and that "Ohio should explore ways to better leverage the facilities, programs, and services available in order to create immersive and hands-on training opportunities for blind, deaf and deaf-blind communities."

In response, Opportunities for Ohioans with Disabilities (OOD) has set aside

special funding for a two-week class, and is now recruiting those who have lost their auditory literacy, their visual literacy, or never had high literacy and wish to be able to read and write basic braille. We believe this will lead to more possibilities of getting a job and increasing independence.

Literacy is an essential skill in virtually any job. As adults, learners seldom have school or other hands-on sources of braille instruction, making it nearly impossible to pursue braille on their own, so I am coordinating this program, which I call "DoDots." Learners need fire in the belly to restore their ability to read, and the physical, mental and emotional ability to go through what is basically braille boot camp. There is no age limit. Learners may be current or former OOD consumers, but this is not necessary for participation in this program.

We expect learners to come from two basic categories – those who will learn through ASL and those who will use English. Interpreters, orientation/mobility trainers, and experienced teachers, some of whom will be volun-

teers, will lead the program, as will service support professionals (SSP's) for those who need them. The first such program in the country, DoDots is still evolving. I urge VR professionals working with current or former consumers who have dual sensory loss to email or call for details, including an application, since recruiting appropriate learners will be among the top challenges of the program.

Elizabeth.sammons@ood.ohio.gov

614-438-1260

RECREATION ROUNDUP

By Jill Noble

In addition to sponsoring an annual statewide conference, ACB-Ohio supports two recreational programs each year. The goal of the Winter Sports Retreat is to give adults who are blind or visually impaired the opportunity to try cross-country skiing as well as other outdoor winter activities.

This year, there wasn't enough snow to ski. Some of our most experienced ski guides tested the conditions early on and quickly determined that, instead of gliding through the snow, their skis collected a lot of mud within minutes. Even though cross-country skiing and snowshoeing were out for this year, our volunteer guides organized several

ACBO Community Shares Campaign Codes

State of Ohio 19003

City of Columbus 60240

Franklin County 60240

Ohio State University 60240

Columbus State 1061



winter hikes, shopping trips, and, for the first time, a trip to a nearby resort where they were able to snowtube. If you have never participated in the Winter Sports Retreat, I hope that by now I have piqued your curiosity enough to join us in 2017.

A big thank you to our friends who volunteered their time and talent during the weekend as well as providing participants with the much-needed transportation to the event.

Look for an article about the Summer Sports Retreat in the next issue and a few informational tidbits about the 29th Winter Sports Retreat.

2015 SCHOLARSHIP WINNERS

By Jenna McCartney

ACBO awarded four scholarships during our 2015 conference and convention. The recipients are from all walks of life, in a variety of majors, and very deserving of the scholarships given.

Benjamin Horton

A student attending Capital University Law School, Ben received the Max Edelman Scholarship. He wishes to become a lawyer to fight for the rights of people with disabilities.

Jenny Ham

Jenny received the David Newmeyer Scholarship. She is a sophomore at the University of Cincinnati majoring in social work and is pursuing a double minor in Spanish and international human rights.

Jessica Rabenstein

The recipient of the Linwood Walker scholarship, Jessica is a junior at Cedarville University. She is majoring in social work, has volunteered in Brazil and studied in Uganda.

Joseph Chadbourne

Joe is a student at the University of Akron, majoring in accounting with a minor in Spanish. He received the Joann Fischer Scholarship and plans to obtain an accounting job in a large law firm after college.

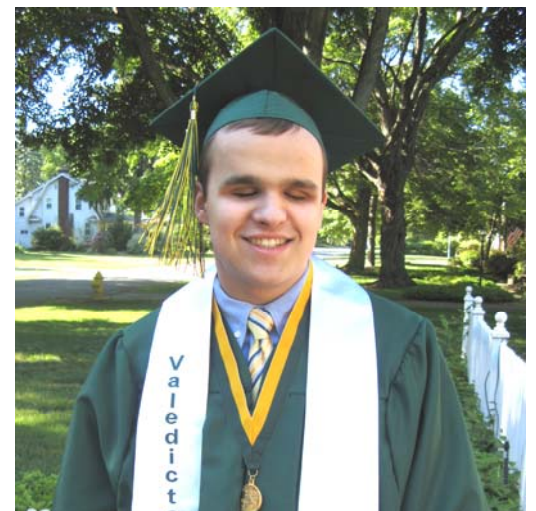
Congratulations, winners, and good luck in your future endeavors. Information about the 2016 scholarships will be available shortly.



Jenny Ham



Jessica Rabenstein



Joseph Chadbourne

ADVOCACY THAT HITS CLOSE TO HOME

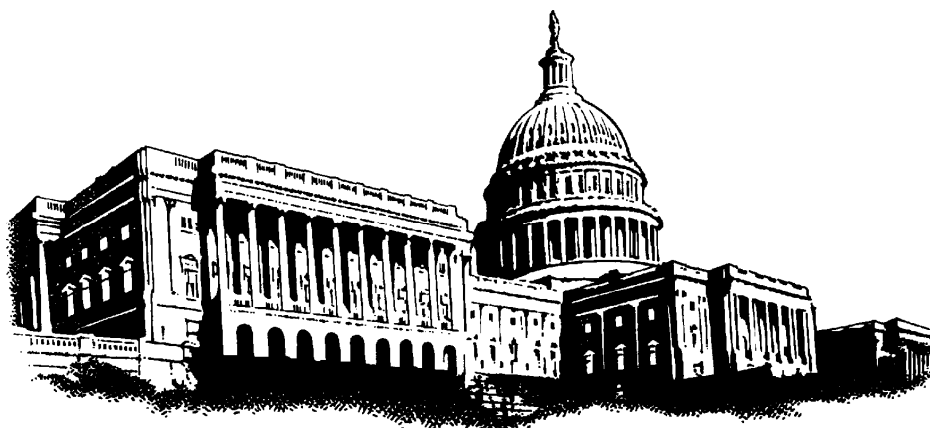
By Carl Kienzle

For many years I have made the trek with others to Washington, D.C. to advocate for issues affecting those with visual impairments and blindness. It has always been a bonding time with many from our state and national organization and also quite a learning experience. I have always found the training in advocacy and the practical experience of putting those newfound skills to practice exciting, scary and very rewarding! It's fun to sit in congressional offices and be a part of the legislative process as a citizen in our great country. It's also an awesome responsibility to "put our best foot forward" for our peers like us, who have physical challenges and need to voice our common needs.

The past couple of years I have had to put these skills to work in advocating for a loved one in a nursing home and

hospital. One of my elderly parents has dementia and multiple health issues. Hospitals and nursing homes often require a great deal of interacting with professionals who aren't always on the same page. Insurance companies and Medicare create situations that are not always in a patient's best interest. Those pressures on hospitals and doctors create a vital need for advocacy skills from family members and friends.

I always had a knot in my stomach as we approached Capitol Hill each of the first three to five years I participated, but that stress is now replaced with confidence and a great sense of achievement. I would like to encourage everyone to learn how you can make a difference in the lives of others, whether it is with the American Council of the Blind or closer to the home front.



ARE YOU A STICKLER?

By Carl Kienzle

People who are very much into details may be asked that question. My response to that question is "Yes, I am." When I answer "yes" to that question, it has nothing to do with being a "stickler" for details as most would think—but it does relate to the details that affect my body.

When asked that rare question, it is usually while blinded by a bright light examining my eyes. It's usually a resident or other ophthalmologists-in-training unfamiliar with my eye conditions asking me that question. My short answer to them is understood, but to most of the world if they were prompted to ask me that question I would answer with, "Yes I have Stickler's syndrome." So naturally, the next question is what is Stickler's Syndrome?

Stickler's syndrome in layman's terms is a hereditary, progressive connective tissue disorder, which affects multiple parts of the body, and may include one or a combination of the eyes, ears, and joints. Individuals with Stickler's syndrome lack collagen or proteins that "hold" the body together properly. There is no cure for Stickler's syndrome, but its symptoms are treatable. It is also closely related to

Marfan's syndrome. Life expectancy and intelligence are not affected. Surgeries, medications, glasses, hearing aids, along with other medical devices, help those with this syndrome.

It is usually passed on from a parent. If you have Stickler's syndrome, there is a 50 percent chance you will pass it on to your offspring.

A "Stickler" can have one or many of these progressively degenerative symptoms causing retinal detachments, early cataracts and/or glaucoma, early onset arthritis, heart valve prolapse, cleft palate, breathing problems and hearing loss. I have had 15 eye surgeries, numerous sinus surgeries, ear tubes and multiple joint and ligament problems.

I was not born with a cleft palate like many Pierre Robin Sequence Stickler children, but did go through 15 years of speech therapy. I was diagnosed at Ohio State at the age of 14 when I had four retinal detachment surgeries in a five-month period. I did not realize I had Stickler's syndrome until I read it in a medical chart as a young adult.

Since April, 2014, I have had six eye surgeries and my life is changing drastically again. I am no longer able to drive and last January I had two discs fused in my neck. The condition is progressively worsening. I am fortunate to have resources and support through an organization such as the American Council of the Blind of Ohio.

The one thing I take from not being aware of this diagnosis early on is there is early intervention and help. Many of the 7,900 to 9,500 infants diagnosed yearly are now given eye laser treatments to prevent retinal detachments. I have worn glasses from

an early age and hearing aids since my early 30's. Early diagnosis and intervention is very helpful for families and children. If you would like to learn more about Stickler's syndrome there are resources out there.

Resources include:

- www.sticklers.org.
- www.marfan.org/stickler-syndrome
- The Mayo Clinic, Seattle Children's and Boston Children's Hospitals websites
- You can also view a couple Stickler syndrome-related videos on my Google+ web site under my name

CHAPTER MATCHING GRANTS

By Vicky Prahin

Did you know that any chapter of the American Council of the Blind of Ohio may request funding of up to \$500 to match funds raised for a special project? Perhaps some of your chapter's members want to attend a legislative seminar or workshop, purchase equipment to use in a fundraiser, create a scholarship, or support a program which your chapter manages. Perhaps you and a group of friends are ready to establish a new chapter. Simply fill out our short application, explaining what your need is and what funding you already have available, and we may match your funds. You can find information on our website, www.acbohio.org, or obtain a print form by calling our office, 614-221-6688 or 800-835-2226.



(Continued from page 3)

development of children during their first months and years of life occurs visually, imitating actions and expressions learned through watching others. Therefore, it is crucial funding is provided for early intervention services and supports for children and families who are impacted by blindness or visual impairment in Ohio; helping to ensure positive outcomes and future development into confident self-sufficient adults.

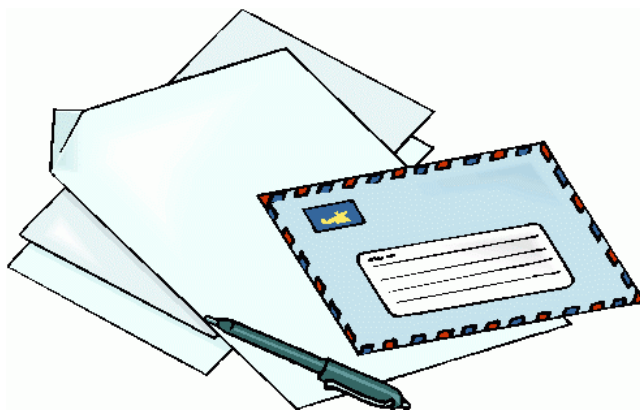
While children who are visually impaired represent one of the smallest groups among children with disabilities, they have some of the most unique and complex needs. Visual impairment or blindness potentially impacts every area of a child's development, including language development, hand skills, independent movement throughout the environment, and literacy without appropriate intervention. For this reason, I believe that access to vision services

and supports, provided by visual impairment professionals, is an essential component within Early Intervention in order for every child to reach their greatest potential.

*Meeting the specialized needs of infants and toddlers with visual impairments and their families must be a 2016 priority in Ohio's efforts to continually improve the effectiveness of its Early Intervention system, be in compliance with federal guidelines, and empower all of the families it has been charged to serve. I am counting on the Ohio Department of Health and the Department of Developmental Disabilities to fund and implement vision services **now** for eligible families throughout our state, including those we serve.*

Sincerely,

*Katie Frederick
Executive Director
American Council of the Blind of Ohio*



BITS & BYTES



BSVI has updated and posted its annual compilation of vision loss and hearing loss resources. The document primarily contains Internet links and other information on general resources, advocacy groups, media and communications access, hearing aid assistance, learning resources and other information. The resources are divided as useful for deafness, blindness and deaf-blind community members. This is a downloadable Word document accessible to screen reader users. <http://www.ood.ohio.gov/Portals/0/VR/Vision%20Loss%20and%20Hearing%20Loss%20Resources.docx>

A new interactive “toolkit” makes it easier for Ohio employers to recruit, hire and retain qualified workers with disabilities. “Hiring Ohioans with Disabilities: A Toolkit for Employers, Managers and Human Resource Professionals” was produced by OOD and the Ohio Department of Job and Family Services (ODJFS). See toolkit here: <http://www.odjfs.state.oh.us/forms/findform.asp?formnum=08036>

Get ready for the tax season! Find hundreds of the latest accessible federal tax forms and publications, plus **assistance for tax filers with disabilities** here: <https://www.irs.gov/Forms-&-Pubs/Accessible-Products#content>

Whether soaring down a ski slope is your ultimate dream or you prefer paddling a canoe on a lake and swimming until sunset, **find the perfect camp** for people with visual impairments at www.aph.org/pe/camps.

Join the *AccessComputing* Team

The [*AccessComputing* Team](#) is a community of high school and college students with disabilities who are interested in computing fields, such as computer science and information technology. Team members communicate with support staff and mentors as they engage in electronic mentoring, work-based learning, and other experiences that enhance college and career success in computing fields. Project staff help *AccessComputing* team members locate paid internships and other work and research opportunities as they transition to and succeed in college, graduate school, and employment. [Learn more.](#)

See demonstrations of an app that describes the visual world using artificial

intelligence. View a video showing the reactions of its first users at <https://www.youtube.com/watch?v=h5g82YNmwmU>. Sign up for a free trial for beta users at: <http://aipoly.com/>

Prevent Blindness Ohio offers this new, **online directory, a list of contact information for organizations and services that provide financial assistance for vision care.** Download the directory here:

http://www.preventblindness.org/sites/default/files/national/documents/fact_sheets/Financial_Assistance_IC03%28updated11-14%29_0.pdf>

What will happen to your income, benefits, and health coverage if you go to work? Use this free, **updated 2016 Benefits and Work Calculator** to find out how a job may affect your total income and health coverage. Normally the process requires 20-30 minutes; all results are confidential. More details here: [https://ca.db101.org/planning/\(S\(xidhvy554proc055udqfseyq\)\)/b2w2_start.aspx?screen=start&l=b2w2](https://ca.db101.org/planning/(S(xidhvy554proc055udqfseyq))/b2w2_start.aspx?screen=start&l=b2w2)

The online version of **Nearby Explorer, an app assisting orientation in the visually impaired community, is now available to download for free** from the Amazon App Store. It contains

no onboard map data, so there are no licensing fees to pay. The online version requires a device with a network connection. The original Nearby Explorer is still available through the Google Play Store, and APH plans to continue supporting and developing the original version. The gmail.com original version does not require a network connection. For complete details about Nearby Explorer Online, see http://tech.aph.org/neo_info.htm. To install, see http://www.amazon.com/American-Printing-House-for-Blind/dp/B019PDMFWI/ref=sr_1_1?ie=UTF8&qid=1451314174&sr=8-1&keywords=nearby+explorer+online

ACB Seeking Input re: RedBox

Many of you may be familiar with the company RedBox, which provides a popular service that people use to rent DVDs through machines located at retail convenience and shopping stores around the country. ACB is seeking input from individuals who have experienced difficulty or been unable to use such machines. If this is an issue you would like to weigh in on, please contact Tony Stephens, Director of Advocacy and Governmental Affairs at astephens@acb.org.

AFB Older Workers Survey

American Foundation for the Blind

(AFB) is conducting a survey for people who are blind or visually impaired, who experienced vision loss at age 55 or older, and who continued to work or returned to work after vision loss. The criteria for taking the survey are as follows: (1) You experienced vision loss that started when you were age 55 or older and (2) You continued to work or return to work after experiencing vision loss. AFB will enter your name in a

drawing for a \$100 Amazon gift card if you participate and share your contact information. The survey will help with the development and updating of information on VisionAware for older individuals with vision loss who are seeking to retain jobs or find employment. Link to survey: <http://www.afb.org/Section.aspx?>

[FolderID=5&Mode=Survey&SurveyID=229](http://www.afb.org/Section.aspx?FolderID=5&Mode=Survey&SurveyID=229)



ACB-Ohio Board members Terry Olandese and Lori Woodall as Mr. and Mrs. Claus, providing holiday cheer to people with developmental disabilities in the Cincinnati area last December. Lita Wesley, also a board member, works with individuals who have developmental disabilities, and wanted to provide additional holiday cheer at her company's annual holiday party.



American Council of the Blind of Ohio
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FREE MATTER
FOR THE BLIND



ACB-OHIO DATEBOOK

MAY 6-7

ACBO BOARD MEETING
KALAHARI RESORT, SUNDUSKY, OH

JULY 1-9

ACB NATIONAL CONFERENCE
HYATT REGENCY, MINNEAPOLIS, MN



Thanks to the contributors: **Katie Frederick, Carl Kienzle, Jenna McCartney, Jill Noble, Ann Pimley, Vicky Prahin and Elizabeth Sammons.** The *Ohio Connection* is a quarterly publication of the American Council of the Blind of Ohio. Please submit your material in print or through e-mail, and include your name, address and phone number. Send items for the next issue to acbo.newsletter@gmail.com by **May 15.**