



CHARGE Accounts

The mission of the CHARGE Syndrome Foundation is to lead and partner to improve the lives of people with CHARGE syndrome locally, nationally and internationally through outreach, education, and research.

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President's Message

Another successful conference is behind us. I can't thank our Board, Advisors, sponsors and all our fabulous volunteers enough for taking us Deep in the Heart of CHARGE. It was great to see so many new families in attendance and catch up with old friends. I can't wait to see all of you in Arizona! It is going to be a Grand Adventure.

While conference will always be an important part of the Foundation, we have so much more to offer. Our new webinar series starts in November. We recently committed more funds to support family gatherings and regional conferences. Stay tuned for information about events in your area. We funded another four research grants and will open up applications again next year! Our new EWRAP grant recipients have all received their awards and we look forward to giving more individuals with CHARGE the chance to play in 2020!

The ongoing success of the Foundation depends on the hard work of our volunteers and the generosity of our donors and fundraisers. As we approach the end of 2019, there are a multitude of ways to insure a bright future for our CHARGE family. You can participate in our current Charge It for CHARGE campaign, become a member, participate in our upcoming #GivingTuesday campaign, host an event, volunteer on a committee or run for a seat on the Board. We can't do it without you!

Enjoy another excellent newsletter. As always, please reach out with any questions or comments info@chargesyndrome.org.

David

David Wolfe, President

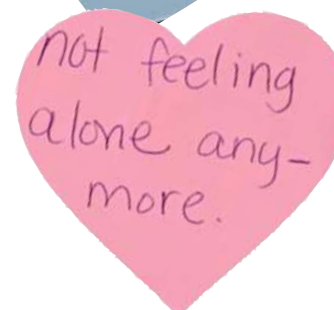
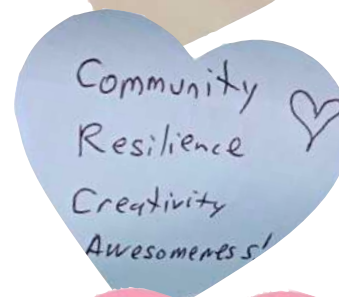
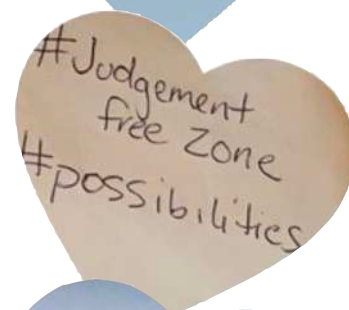
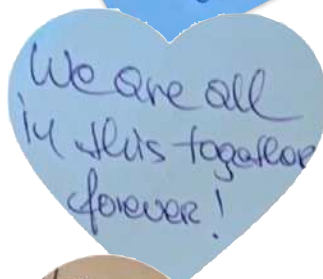
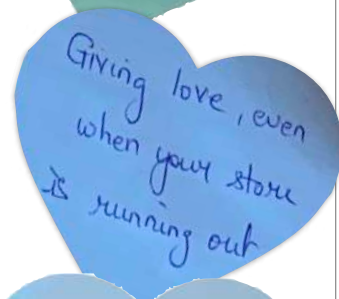
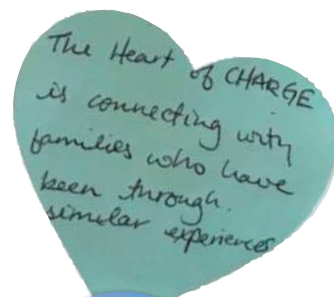
Deep in the Heart of CHARGE

If you've attended a CHARGE conference, you know the experience is much like a family reunion with all your favorite relatives. Even if you are meeting someone for the first time, you know you have a true connection and kinship. The sense of community is very strong and our conference theme, "Deep in the Heart of CHARGE," nicely captured that feeling.

Conference attendees were asked to give thought to what the "Heart of CHARGE" meant to them individually and to write down their takeaways and "aha" moments from the Conference experience. It didn't take long for the "Heart of CHARGE" wall to be covered in paper hearts with attendee's personal inspirations. The messages were each unique but it is probably no surprise that several words came up over and over again: family, support, acceptance, belonging, resilience, hope, and love.

The CHARGE Conference is an unforgettable experience and the "Heart of CHARGE" was more than a theme. It was way to recognize the importance of what it means to be together and what we mean to each other.

Photos by Buller Photography, Kaylea Carpenter, Kristin Buciak, Hollie St. Arnauld



Celebrate
BOTH
Difference
&
Similarity

sibling
support

✱
ALWAYS
Presume !!!
Intelligence!
♡ Anna
Kouri

The Best
Family
Reunion!

The only
place we
can be a
true version
of ourselves

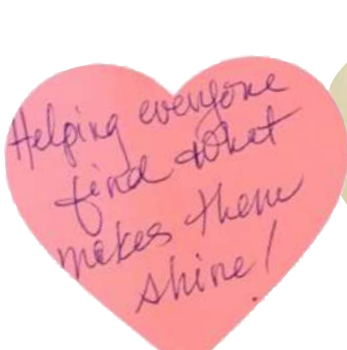
**WE CAN'T WAIT TO
SEE YOU AGAIN!**

**15th International
CHARGE Syndrome
Conference**

July 16-19, 2021

**JW Marriott Phoenix
Desert Ridge,
Phoenix, Arizona**





**2019 Conference Handouts
AVAILABLE HERE**

THANK YOU

**Presenters, Exhibitors,
Sponsors, Interpreters,
Photographers and Volunteers
for your valuable contributions to
the success of our conference.**

The Third Class of Sandra Davenport CHARGE Syndrome Fellows

by Megan Schmitt and Sara Espanet

Another group of Sandra Davenport Fellows has become part of our CHARGE Family! 14 Fellows who were chosen from a wide group of international applicants attended the 14th International CHARGE Syndrome Conference in Dallas in August. The 14 included young professionals and graduate students in education, behavior, medicine, genetics, audiology, and neuroscience. Their interest and experience in CHARGE varied widely and they all benefited from the diverse professional perspectives. Each Fellow was matched with a family with an individual with CHARGE at conference. They got to know the family, share a meal with them, and spend half a day volunteering in Camp with their family's child. In each of the next several issues of the newsletter, we will present reflections from the Fellows. We start with articles by Rebecca Darden-Perry and Elaine Ritter.

Elaine Ritter

Elaine is a Postdoctoral Research Fellow (cellular and molecular neuroscience) in the lab of Dr. Donna Martin at the University of Michigan. Her research is focused on defining roles of the CHD7 gene in the development of neural crest lineages that contribute to the development of the inner ear. These roles may underlie hearing and balance deficits seen in individuals with CHARGE. She presented a poster of her research at conference.

The International CHARGE Syndrome Conference was unlike any other professional meeting I have ever attended. As a PhD researcher working in a lab, conferences that I normally attend are geared entirely toward research, and the focus is typically on a broad field. Those meetings tend to be rather large (many thousands of attendees), and it's easy to fall into a void in the typical research science meeting. With so many people and so many topics, you can feel somewhat isolated, and it can be a struggle to find and connect with others with similar interests and goals. The CHARGE Conference was a very welcome "break from the mold" – smaller, more focused, with an over-arching goal of improving the lives of individuals with CHARGE syndrome. I had the privilege of presenting my work to people who are personally and emotionally invested in CHARGE research. Having attended dozens of conferences over my career, I can truly say it was a unique and wonderful experience ...



Elaine (center) with Holden and other Fellows

Continued on the CHARGE Syndrome Foundation website

Rebecca Darden-Perry

Rebecca is a PhD candidate (special education) and currently a teacher of the deafblind in North Carolina. She anticipated that attending the conference as a Fellow would accelerate her knowledge and understanding of many areas of CHARGE, which would be useful both for her doctoral work (which is on CHARGE) and in the classroom.

Atending the CHARGE conference as a Davenport Fellow forever changed my life. When I first arrived at the Conference hotel and met the other Fellows, I was nervous and excited at the same time. Being the first Fellow that is deaf/hard of hearing was exciting and challenging. After introducing myself and meeting the other Fellows, I learned quickly we all had a desire to learn as much as possible about individuals with CHARGE. Some of us were new to CHARGE and others were not, but we all wanted to delve deeper. I feel like we formed a bond during the conference that will never be forgotten. Everyone genuinely cared about one another and all the Fellows tried their best to communicate clearly with me, which meant the world. I feel honored to have been Fellow and look forward to attending future conferences as a Fellow, and perhaps one day be on the CHARGE Syndrome Foundation board...



Rebecca, right, with her roommate Sarah

Continued on the CHARGE Syndrome Foundation website

[Click here to read more from Elaine and Rebecca and additional information about the Sandra Davenport CHARGE Syndrome Fellowship Program](#)

Make An Impact. Make A Difference.

WE'RE LOOKING FOR A FEW GOOD BOARD MEMBERS

Our conferences and other programs would not be possible without a team of skilled, dedicated volunteers. Members of the Foundation are invited to apply for a position on the Board of Directors.

[Click here for information and application](#)

DEADLINE: December 20, 2019

Leadership - Energy - Passion

12th Charge It for CHARGE!

Join now and make your impact today!

Use the power of email and social media to raise money for the Foundation.

All funds raised allow the Foundation to continue its support, outreach, awareness, and research. With about an hour of your time and the e-mail addresses of friends, family, and colleagues, you can help us reach our goal.

[Click here](#) to begin your fundraising campaign or to make a donation to another participant.



September 21st marked the CHARGE Syndrome Foundation's Second Annual "A Day to Remember." Our community honored those with CHARGE who have passed away by performing acts of kindness.

[Click here](#) to see how our community celebrated and remembered those lives we have lost.

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You shop. Amazon gives.

Start your shopping each time
at **smile.amazon.com**

Amazon will donate a
percentage of your purchase
to the CHARGE Syndrome
Foundation

Focus on Fundraising

THANK YOU!

to everyone who has created a Facebook fundraiser in the past year
Your support of the Foundation is greatly appreciated.



**Facebook makes it easy to start a fundraiser
 to celebrate your birthday or any other occasion:**

<https://www.facebook.com/fund/chargesyndromefoundation/>

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 Dallas Messer
 Katrina Michel
 Ashley Mikayla
 Lori Miller

continued on next page

**SAVE
 THE DATE**

**#GIVINGTUESDAY
 DECEMBER 3, 2019**

Take a Dip for CHARGE

There are many ways to create awareness of CHARGE and fundraise for the Foundation. At conference in August, we rolled out our new DipJars. These jars are easy to display and allow people to donate with a quick "dip" of their credit card. Jigisha Tamakuwala is using one of the jars at her dental practice to make people aware of CHARGE and collect donations. Everyone that walks into her office now knows a little more about CHARGE syndrome!

If you are interested in having one of our DipJars at your place of business, please e-mail us at: info@chargesyndrome.org



THANK YOU FACEBOOK FUNDRAISERS!

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Heather Wolf
Carmen Wong and Vincent Cham
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Paiton Wright
Jill Zwerling

**as of September 26, 2019*

October is National Disability Employment Awareness Month

by Valerie Muck

October is National Disability Employment Awareness Month (NDEAM). This year's theme is 'The Right Talent, Right Now.' **NDEAM** celebrates the contributions of workers with disabilities and educates the public regarding a workforce inclusive of persons with disabilities' skills and talents.

My son Steven was diagnosed with CHARGE syndrome at birth (it was just an "Association" in 1992!) Steven "came of age" in Ohio. He was involved in a vocational training program (Project Search) and he had a comprehensive Individual Transition Plan. Transition while in Ohio was relatively easy, as there was sufficient interface between the school district and the county. In addition to job placement and job coaching services, we also received transportation assistance.

In 2015, I transferred to the Pentagon. If you have moved a child with disabilities, you know the pressures of finding new doctors and support services. As we no longer had the school district in our corner, we dealt directly with the county for adult services. Job placement? Nope. Job coaching? Nope. Transportation? Nope. There were lengthy waiting lists for all of the services we needed. We eventually found my son a job volunteering at a thrift store about 8 miles from our house and, with no transportation assistance, we paid out-of-pocket for a taxi.

Last year we moved to Michigan. We've worked with the county and Michigan Rehabilitative Services to find my son meaningful employment. Job placement? Yes! Job coaching? Yes! Transportation assistance? Yes! Even though the services are available, it has still been a lengthy process and we have faced set-backs matching my son's skills and talents to long-term, meaningful employment. And transportation options within a relatively rural county are also challenging.

Every parent hopes their child will find competitive, integrated employment within their community. Parents also want their child's compensation to be comparable to the compensation of a non-disabled worker performing the same tasks (including the same benefits and opportunities for advancement). Nirvana, right? When nirvana isn't quite possible, there are organizations that provide non-competitive employment opportunities to individuals with disabilities. Two organizations I am familiar with, Production Services Unlimited (Southwest Ohio) and Work Skills Corporation (Livingston County Michigan) provide non-competitive employment opportunities within their distinctive 501(c)3 non-profit organizations. Both organizations offer training that allows employees to develop job skills and soft skills. My son worked at Production Services Unlimited. It was a very positive experience, and he was eventually placed in an enclave where he received minimum wage for part-time employment. We recently contacted Work Skills Corporation as a potential option for my son now that we are in Michigan.

Some of our family's toughest challenges relate to employment opportunities. Our situation is a bit unique, as we've lived in three states since my son graduated from high school in 2014. Three states and three vastly different experiences.

Parents, caregivers and individuals with CHARGE should research employment services within their community, county, and state. It's never too early to start. Additional information about NDEAM can be found at whatcanyoudocampaign.org.

Valerie was recently interviewed for a podcast to highlight National Disability Employment Awareness Month (NDEAM), as well as to raise awareness of CHARGE syndrome. [Listen here](#).



Steven ready for work at
Dorothy Lane Market in Ohio

iCanConnect

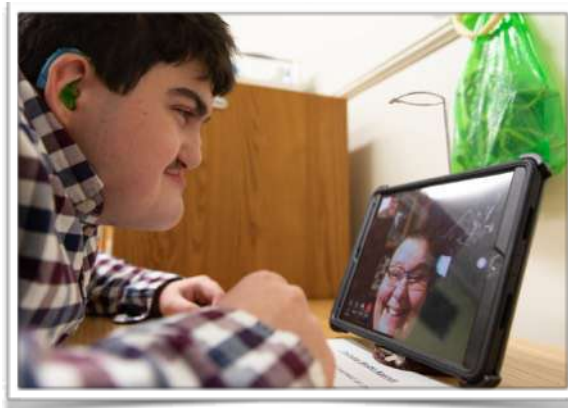
Helps Individuals with Deafblindness Communicate

If you or someone you know has both significant vision and hearing loss, you may be eligible for [iCanConnect](#), the National Deaf-Blind Equipment Distribution Program. iCanConnect is a national program with local contacts that provides free distance communications equipment and training to individuals who meet federal disability and income [guidelines](#). Examples of the types of distance communication equipment the program provides includes computers, phones, mobile devices, signalers, braille devices, and software.

iCanConnect serves people from a wide range of backgrounds, including individuals who have CHARGE syndrome, like 15-year-old Andrew Delaney from South Carolina (above, right). Andrew attends school out-of-state and uses the iPad he received through iCanConnect to stay in touch with his family while he is away. "It's given him independence," says his mom, Minnie Lambert. "He texts me to say when he's going to call. We FaceTime on the same days every week, and he can call us and talk at his discretion. iCanConnect is our lifeline."

To learn more about iCanConnect, contact your local program [representative](#) who can answer questions and help guide you through the process. Individuals who are interested in receiving equipment and training through iCanConnect will need to submit an application, which is available to download from your local program iCanConnect webpage, or one can be sent to you.

To start, visit the [See if You Qualify](#) section of the iCanConnect [website](#) for more details. To qualify for the program, the individual must have significant **combined** vision and hearing loss. In addition, the participant's household income must be within 400



percent of the federal poverty level. Participation in programs such as Medicaid and SSI also qualify.

Once the application is completed, submit it to your local iCanConnect representative. Make sure to include a disability verification form signed by a professional who attests that the applicant's hearing and vision loss meets iCanConnect's [disability guidelines](#). The individual will also need to submit proof that he or she meets iCanConnect's [income guidelines](#). Once accepted, each program participant will receive an individualized assessment to identify distance communication goals, equipment, and training plans. Then the equipment will be installed and training will begin.

iCanConnect helps people with significant hearing and vision loss connect with friends, family, community, and the world. To find your local program contact, learn more about iCanConnect, or to apply for the program, please visit www.iCanConnect.org or call 800-825-4595.

by Marcia Brooks, Director,
Perkins National Deaf-Blind Equipment Distribution Program (iCanConnect)

