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
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*
WE CAN’T WAIT TO SEE YOU AGAIN!
15th International CHARGE Syndrome Conference
July 16-19, 2021
JW Marriott Phoenix Desert Ridge, Phoenix, Arizona
Thank you for your valuable contributions to the success of our conference.

Presenters, Exhibitors, Sponsors, Interpreters, Photographers and Volunteers

2019 Conference Handouts AVAILABLE HERE
The Third Class of Sandra Davenport CHARGE Syndrome Fellows

by Megan Schmittel 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 overarching 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 …

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.

Attending 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…

Continued on the CHARGE Syndrome Foundation website
We all have many questions about all aspects of CHARGE and more questions arise every day. Research helps answer some of those questions. As the largest worldwide gatherings of professionals, families and individuals with CHARGE, the Biennial International CHARGE Syndrome conferences are ideal for conducting research and for presenting research findings.

At the 2019 conference in Dallas, there were more than 20 presentations based on research done at previous conference, including a range of behavioral and educational topics, social skills, growth and genetics (see page 36 of the Program Book for a complete list). Dr. Donna Martin, chair of our Scientific Advisory Board also presented about the information and publications that have resulted from the more than $1 million in research grants awarded by the CHARGE Syndrome Foundation.

Looking towards the future, there were 10 research projects enrolling subjects in Dallas. They ranged from online questionnaires to testing of motor skills to in-depth interviews, covering a multitude of ages and topics (see page 37 of the Program Book for a complete list). These 10 projects enrolled more than 250 participants (many people participated in multiple studies). Watch for email blasts describing publications and presentations at future conferences.

Are you feeling left out? Many of these projects are still enrolling participants (several can be completed online). Here are the projects which are still enrolling subjects:

1) Fathers’ Experience with CHARGE. Recent decades have brought increasing research on fathers’ roles in families and their contributions to children’s development and education. This study focuses on fathers of children with CHARGE syndrome. CHARGE syndrome is a highly complex and low incidence. This project aims to gain insight into the fathering experiences of families with children with deafblindness focusing on a subset of fathers of children with CHARGE syndrome.

Any Dads and other male parental figures of children/ young adults with CHARGE syndrome. If you are interested in participating in a Skype Interview (45 minutes), please follow this link: https://forms.gle/ B7jFEEyKamTwRmXc6 or contact Jerry Petroff petroff@tcnj.edu 856-577-2400

2) Early Childhood Home Environment and Motor Skills. How might the home environment affect motor development? Parents of children age 18 months to 42 months are invited to complete a questionnaire, 15-30 minutes. Contact Pamela Haibach-Beach pbeach@brockport.edu

3) Gut Microbiome in CHARGE. Is the gut microbiome different in individuals with CHARGE compared to those who do not have CHARGE (especially their brothers and sisters)? Complete a questionnaire and send in small stool samples (we’ll send you the kit to mail back to us). If your child with CHARGE is age 2-18 years (and especially if there is a sibling control). Contact Emily Chedrawe emily.chedrawe@dal.ca 902-489-1887

4) Genetics Research – looking for other genes that cause CHARGE features. If DNA testing has not been done or if CHD7 testing was negative, you may be eligible. Questionnaire and saliva collection kit (to be mailed back) for people with CHARGE features, their parents and siblings. All ages. Contact michiganCHARGEresearch@med.umich.edu

5) Social Play in Elementary Age (completed grades 1-6). Parents get a short video training; then answer a questionnaire. More info here: https://cmich.co1.qualtrics.com/jfe/form/SV_dgakPXjA6sDKiyN or contact Megan Schmittel schmi2m@cmich.edu 636-359-3291

6) Attitudes About Sex Education. What were you taught? What should be taught and when? Confidential questionnaire just to get your opinions. Adults with CHARGE (18 and over) and parents of individuals with CHARGE (all ages). Parent survey: https://msstatecoe.co1.qualtrics.com/jfe/form/SV_0xG37v549o8DMah Individuals with CHARGE 18 years and older survey: https://msstatecoe.co1.qualtrics.com/jfe/form/SV_4MTQooUttwwlJVH

7) Self-Injury Behavior. We want to learn more about these behaviors - frequency, severity and body site of self-injury. Parents of children over 1 year of age. Questionnaire. For a link to the online survey, contact Lyndsay Fairchild (laf2592@msstate.edu) or Laura Quintero (lmq8@msstate.edu).
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

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.

A Day to Remember
SEPTEMBER 21, 2019

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.

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/

Mariane Adiaheno
Alyssa Akinremi
Kimberleah and Bode Akinremi
Catherine Allen
Tracy and Mark Allred
Bryan and Melissa Alston
Megan Anderson
Linn Antonsen
Norbert and Joan Archibeque
Cindy and Michael Archuleta
Denise Babbitt
Lara and Johnny Baggs
Isabel Bahena
Alyssa and Meagan Beaty
Stephanie Becker
Tina Benner
Svenja Bergner
Kim-Kristina Bergner
James Bidmead
Marissa and Bradley Binnebose
Kayla Biscamp
Suzanne Boer and Marcel Janssen
Patreea Boone
Amanda and David Bowdoin
Gloria and Zack Bowles
Maggie Bowles Heller
Katelyn Brennan
Janice and Boyd Bridgewater
Jonna and Jacob Broadway
April and Melvin Brooks
Elizabeth Brown
David Brown
Katrin Brunig
Meghan Bryant
Lucas Bryson
Kristin and Brian Buciak
Peter and Amy Bucklin
Michael Burger
Stacy and Ronald Charlebois
Sharon and John Chatham
Alexis Cheek
Lena Ciccotelli
Lauren Clark
Nerina Clarkson
Margaret Clements
Stacey and Tony Cline
Dan Close
Kerri and Jeremy Cochran
Andrea Cost
Andrew Coughlin
Jessica Courtne
Sean Courtne
Jerry and Alison Cowling
April and Jeremy Cranall
Shawnie Cunningham Plourde
Zack Dabs
Karri and Bob Dagley
Sondra and Jamie Dean
Lois Dean Garrett
Richard Deaton
Sharah Dilley
Chip Dixon
Danny Dunne
Audrey and William Dwyer
Ahmed El Amrani
Dikrayat Zerrai
Victoria Elizabeth
Ashley Elles White
Laura Epperson
Marti Evans
Kayla and Luke Fairchild
Lee Fairfield
Yvette Farmer
Morgan Farthing
Steve Feldkamp
Starla-Octavia Ferguson
Jason Fernandez
Anna Floyd
Laura Forsch
Layla Frias
Anne Gallegos
Jody Gartin
Beatriz Gavarret
Cody Gearheart
Christina Gilland
Paul and Noel Gilman
John Glave
Tee Good
Michelle and Randy Goodwin
Zianna Granillo
Blaize Grant
Trish Gray
Anyssa Green and Justin
"Cody" Green
Nikki Haas-Hackett
Maria and Pat Halloran
Daniel Hansen
Peggy Harris Denson
April Harrison Vaughan
Michelle Henderson
Sheri Hendricks Drewett
Nikki Hernandez
Monica and Jerome Hieb
Stacie and Bryan Holder
Tina Hopson
Elizabeth Horner
Shaunie and Monte Hoskins
Robin Hues
Christine and Stephen Huff
Andrew Huff
Casey Hughes
Brenda Iqueda Molina
Nytrons Joanna Misini
Linda Johnson Rider
Nate Jolly
Ray Joseph
Cathie and Jeff Josephson
Mabel Juliff
Debra Kahley Witwer
Naomi Kates
Kristen Kimball
Matt King
Monica Kinney and Justin Bmabie
Steven Kistner
Catherine Kouzmanoff
Rick Schatzabel
Nick Krull and Shantel Piper
Karim Kulas and John J. Kulas
Nikki Lacey
Minnie Lambert and Douglas
Delaney
Diana Lambert
Christine Lang
Shakira Lango
Tiffani and Kenneth Lanting
Ngoc Le
Melissa Legere
Joanne and Michael Lent
Brett Lesley
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Christopher and Michelle Lin
Maria Lindquist
Sara Lisenby
Nyssia Littles
Brittany Loebrer
Anthony Johnson
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Scott and Marianne Lynn
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Scott Manahan
Chloe Marie
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Olympia May-Hudson
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Tamina and William Mayberry
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Patricia McClintock
Allison McEvain
Rhonda McGuffie Wood
John and Elliot McLean
Kristal McPherson
Poonam and Amrit Mehta
Anna Meshina
Dallas Messer
Katrina Michel
Ashley Mikayla
Lori Miller

SAVE THE DATE
#GIVINGTUESDAY
DECEMBER 3, 2019

continued on next page
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!  

Leah and Ryan Miller  
Savannah and Dennis Milnes  
Mike Mohler  
Blake Morgan  
Kathy Moscato Farese  
Sara and Dean Moseley  
Amy Murray  
Stephanie Nai  
Lily Nash  
Tami Newman  
Julie Nichols  
Rafael Nieves  
Marissa Nolan and  
Michael Hochstuhl  
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Adriana Olgueruas  
Launie and Ben Ormsby  
Maria Otero Munoz and  
Erick Hernandez  
Mia Palermo  
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Michelle Ramirez and Dax  
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Anita Ross  
Seth Rossi  
Kathleen Rossi  
Inger and Richard Russell  
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Jenna Schiller  
Courtney and Jens Scholl  
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Sheila Steele  
Allison and Max Steinhauser  
Deanna and Bill Steinhauser  
Breanna Stewart  
Adam Stone  
Michelle Sutton  
Sasha Swayne and Kurt Frost  
Emma Sweeney  
Alicia Tardiff  
Barbara Teller  
Tianna Thomas and Travis  
Schenfeld  
Anna and Richard Thompson  
Michelle Touceda  
Colleen and Chris Turpin  
Tay Tyler  
JoLea Urrutia  
Jenn Viveros  
Jane and Douglas P. Von Dohre  
Margaret Walker  
Kayla Walters and Charles Gray  
Marie Walters  
Ronna Watts  
Gabrielle Weiler  
Pamela Weimer  
Caetlin Weindel  
Carrie and Mark Weiss  
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Aubrey Williams  
Candice and Alex Wilson  
Philip Wismer  
Heather Wolf  
Carmen Wong and Vincent Cham  
Denise Wright  
Paiton Wright  
Jill Zwerling  

*as of September 26, 2019
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.
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)