



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

Spring is around the corner and change is in the air. Thank you to Pam Ryan and Julie Brandrup for your many years of service on the board and to our large extended family. While we will miss you on the board, we know you will continue to support the Foundation and look forward to seeing you at future conferences. We are pleased to announce that Anne Swenson and Allie Jones have joined the board. If you are not familiar with Anne and Allie, please check their [profiles here](#). We look forward to all the new and exciting ideas that they will bring to the board.

This edition of CHARGE Accounts highlights some of the great accomplishments of individuals with CHARGE. Whether it is fundraising or awareness, our families continue to spread awareness about CHARGE while raising valuable funds for the Foundation. A special thank you to all of our Facebook fundraisers from last year. Together you raised more than \$64,000 to support Foundation programs!

Remember, Rare Disease Day is February 29. Please check out this issue for ideas how you can raise awareness about CHARGE. CHARGE is rare, but together we can make it well known in our communities!

Just in time for spring fun, the applications are now available for the 6th annual Ethan Wolfe Recreational Assistance Program (EWRAP). EWRAP offers assistance to individuals with CHARGE to purchase recreational equipment or participate in recreational activities. Every individual with CHARGE deserves a chance to play.

Hope everyone stays healthy this flu season! Enjoy the newsletter.

David

David Wolfe, President

Carson Rocks Rare Disease Day!

As we all know, the last day of February is Rare Disease Day. In 2019, Carson was healthy enough to be in school and wanted to do something for CHARGE. Carson is 8 years old and was born with CHARGE syndrome. He is the only child in our county that we are aware of. We have been very open to raising awareness so that people are not “afraid” and are more open to choosing kindness. In 2018 we read “We are all wonders” to the kindergarten classes and wanted to support Rare Disease Day but unfortunately, from the first week of January until the end of the school year, Carson was too sick to be in school.

In 2019 a new principal at the school was very eager to support Rare Disease Day and CHARGE syndrome. The students along with the staff all wore jeans and the staff and a few students, including Carson, wore a t-shirt that one of the volunteers made! We did “Pennies for CHARGE” and all of the students were so excited to bring in their pennies! With that said the school raised around \$870! WOW! The school is very excited to do this bigger this year! The school is very accepting of Carson. They make going to school so much smoother for Carson and he enjoys going every day to see his friends! The staff all love him and when he’s out sick they all miss him and are concerned!



Carson is always willing to explain CHARGE whenever someone asks “what’s wrong with him.” He is very proud to be him!

— Jesse Beals



**It’s easy to host an awareness event in your community
on Rare Disease Day or any day.**

Share your personal story and raise awareness of CHARGE syndrome!

Host an awareness booth or table at: a county fair or festival, sporting events, hospital lobby or cafeteria

Make a presentation about CHARGE syndrome to: school clubs, scout troops, service organizations (Lions, Kiwanis, Rotary etc.)

Plan a fundraising activity: workplace dress down day, fun run, bake sale, golf outing

Share Your Awareness Story with the Foundation: email to info@chargesyndrome.org

CHARGE Syndrome in the News: What Do I Say?

When one of our favorite support groups, Children's Harbor of Alabama, asked if our daughter, Adele, would like to be part of their patient/player special event with the UAB Blazer football team, we thought it was a not-to-miss opportunity. In an inspirational match-up, 99 Children's Hospital patients were paired with the 99 college football players. The patients get to watch practice up-close, meet their player, and receive recognition at the Homecoming game – with the highlight being each player wearing a customized jersey with their patient's last name on the back. Later, the patient receives the jersey as a souvenir – and Adele wearing that jersey was foremost in our mind when we said “yes.” I could just picture her on high school Jersey Day telling stories of how her player, UAB's star running back Spencer Brown, scored a touchdown with “Brandrup” across his back.

What I did not picture was myself as the lone parent spokesperson at the press conference about the event. Adele was excused from school to attend and followed every word with the help of the sign language interpreter. As you know, It's not easy to explain CHARGE syndrome, especially not when you are paired with a college football coach and a CEO and a line of news cameras is pointing at you. I started with our personal story and connection to Children's Harbor and why we appreciate their work. But when it came to putting CHARGE syndrome into a tidy nutshell, it seemed very important to get it right. I did not want miss an opportunity for awareness for CHARGE as a whole but also felt I needed to keep it specific to Adele. I really needed a fill-in-the blank CHARGE blurb.

I'm not sure all the words came out right but I must have done okay because the day before the game, I was asked to do an even shorter version live in the press box at halftime on ESPN (it was pay-per-view so you probably missed it) and to be honest, I was so nervous I barely remember what I said.

In the end, Adele's favorite part was seeing the physical therapy area of the football facility and witnessing so many tough guys getting worked on and just hoping to recover enough to play. Like most of our kids, I think she could relate more to injury and behind-the-scenes grit more than she could to the touchdowns and game ceremonies. But hopefully she will also remember her mom overcoming her nervousness to go on camera to say thank you to the organizations that help us and also to bring awareness to CHARGE syndrome.

Our kids are deserving of attention – their determination and ability to overcome medical and developmental challenges can be inspirational in a world of negative news stories. If you get asked to participate, go for it – and hopefully these suggestions of what to say will cause you less stress in the spotlight – and also bring accuracy and awareness for CHARGE!

— Julie Brandrup



Everyone Deserves a Chance to Play!

Over the past 5 years, EWRAP, the Ethan Wolfe Recreational Assistance Program, has helped over 50 individuals with CHARGE ride bikes, trikes, and horses, swim, play music, and go to camp.



This year, we want to give even more people the chance to play!

The CHARGE Syndrome Foundation is pleased to announce the 6th Annual EWRAP. Thanks to ongoing support from the Wolfe family and friends, individuals with CHARGE will have the opportunity to purchase appropriate recreational equipment or participate in recreational activities. Every EWRAP award honors Ethan's memory.

For details about what the program covers and who is eligible, please see [EWRAP Application](#). The application deadline is April 1, 2020.

Awards will be made by May 1, 2020. Please send any questions regarding the program to EWRAP@chargesyndrome.org.

COMMENTS FROM PRIOR RECIPIENTS



Lacey got her tandem bike from EWRAP a few years ago. Before we weren't able to go bike riding as a family but now we can, thanks to EWRAP. Lacey enjoys riding and especially loves the wind blowing in her face! It is great exercise for her too and all of us! Bike riding is a wonderful family activity that we all can enjoy together including Lacey! We really appreciate what EWRAP has done for our family!

—Laurie Suter, mom to Lacey

We applied for the Ethan Wolfe Recreational Assistance program two years ago. My son Noah had outgrown traditional trainer wheel bicycles. Even though he had tried very hard to learn, was unable to ride a two wheel bike, due to vestibular issues. When I decided to apply, I talked to Noah about how he would like to possibly have a bike with three wheels that he could ride. He said " I would love it ! When I could ride a bike before, I remember it felt just like flying".

We were blessed to receive a bike that Noah loves! We are so grateful! He enjoys this bike and this past summer was able to ride 3 miles independently, at least 2 or 3 times a week.

— Sondra Dean,
mom to Noah



Family Engagement in Action

David Brown educates in AZ and SC

I have loved learning from David Brown since our first encounter, and every time I have another opportunity, I learn more and more and more. On December 6 and 7, 2019, the Arizona Deafblind Project brought him to Arizona for a day of sharing his wisdom with families and educators interested in deafblindness, plus an evening where families and individuals impacted by CHARGE syndrome were able to gather with David. Thanks to financial support from the CHARGE Syndrome Foundation this group was treated to a wonderful meal, enjoyed while soaking up David's wisdom and connecting with others.

Thanks to all who contribute to the CHARGE Syndrome Foundation with time, money, and other resources to make events like this possible.

— Kim Lauger, Arizona State Liaison

“Most people focus on the child’s disabilities, but close attention to their abilities can reveal more about the difficulties they face as well as the strategies they use to function effectively.”

—David Brown

On January 25, 2020 families of children with deafblindness gathered in Charleston, SC for a family training day with David Brown, hosted by the SC Statewide DeafBlind Project. Families came from GA, NC, SC and VA to spend time together and learn from David Brown. Lunch with David Brown was sponsored by the CHARGE Syndrome Foundation, with a CHARGE themed cake provided by a grandma. Minnie Lambert, Family Engagement Lead, along with Kim Lane, NC State Family Liaison, and Michelle Milder, GA State Family Liaison, gave a presentation to the group about the CHARGE Syndrome Foundation and Resources we provide to families. There were 53 lucky people in attendance during this presentation.

—Minnie Lambert, CHARGE Syndrome Foundation Family Engagement Lead



Family Engagement in Action

Michigan Family Gathering

What's the best thing to do when you're feeling stressed and all alone?

Get together with your CHARGE peeps!

That's just what Michigan families did in October. We all headed to Detroit to be with some of the people we love best - our CHARGE family. The CHARGE Syndrome Foundation in collaboration with DB Central (Michigan's Deaf-Blind project) provided a day of information, food and fun!



Highlights:

Isabel Florence from iCanConnect came and talked about the importance of every child having the tools to be able to communicate and demonstrated all that iCanConnect can offer through their free device program. Isabel is very inspirational being a successful deaf-blind adult herself. She is pictured here with her Interpreter.

Activities:

The kids got to participate in a variety of activities that included a photo booth, pumpkin and face painting, games and more! Many members of the Central Michigan University CHARGE lab were on hand to make sure everyone had a great time. There were no complaints about the pizza and cookies that were generously provided by the Foundation.



The Bulzas from Ontario, Canada joined us!



Truly a day that was good for the soul!

— submitted by
Jodie Beavers,
State Liaison
for Michigan

Are you planning a CHARGE family gathering?

The CHARGE Syndrome Foundation can offer financial assistance to support your event. [Click here.](#)

Focus on Fundraising

I recently sent a letter to a local company, TurboCam (Barrington, NH) requesting a donation to The CHARGE Syndrome Foundation. My brother, Andrew Mason, works on their charitable giving committee, and my request was approved unanimously and they are very interested in continuing to support our large CHARGE family.

My brother received a check, but wanted to keep the amount a surprise until he could present it to a Board Member on behalf of TurboCam. New Hampshire State Liaison Laurie Suter was happy to accept the surprise \$2,500 check on behalf of the Foundation.

—by Heather Herod, mom of Kylie (9-yr old with CHARGE).



12th Charge It for CHARGE

CHARGE IT FOR CHARGE IS THE ONLINE FUNDRAISING CAMPAIGN
OF THE CHARGE SYNDROME FOUNDATION
EVERY DOLLAR DONATED HELPS FUND RESEARCH, OUTREACH, AND
CONFERENCES, AND PROVIDES ASSISTANCE TO OUR FAMILIES



- Connect families together
- Send an Individual with CHARGE to conference
- Help purchase an adaptive bike through the Ethan Wolfe Recreational Assistance Program (EWRAP)
- Donate to our Pilot Research Grant Program

Click here to help us reach our goal of \$200,000

*Thank
you!*

Those birthday fundraisers add up!

**Facebook fundraisers generated \$64,600
in charitable donations for the
CHARGE Syndrome Foundation in 2019!**

***Your support of the Foundation and the generosity
of your family and friends makes all the difference!***

Start a Facebook fundraiser to celebrate your birthday - or any occasion:

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

Sandra Davenport CHARGE Syndrome Fellows: Reflections from the 2019 Conference

by Megan Schmittel and Sara Espanet

The Sandra Davenport CHARGE Syndrome Fellowship program was established in 2015 as way for the CHARGE Syndrome Foundation to educate and encourage young professionals interested in CHARGE syndrome, as well as honor Dr. Sandra Davenport for all of her work in CHARGE. The Program provides scholarships for young professionals to attend the biennial conferences. The hope is that Fellows will become an integral part of the next generation of CHARGE professionals, and that they will go home and use their knowledge and experiences to teach other professionals and influence outcomes for individuals with CHARGE syndrome. Each fellow is asked to write up their reflections after the conference. Visit the [CHARGE Syndrome Foundation website](#) for an overview of the Fellows program and reflections from Rebecca Darden-Perry and Elaine Ritter. Here we present the reflections of Rilla Hammett (teacher) and Hallie Smith (Licensed Psychologist and BCBA). Watch for reflections from the remaining Fellows in upcoming issues of CHARGE Accounts.

Rilla Hammett

Rilla Hammett is a teacher in the Deafblind Program at Perkins School for the Blind, located in Boston. Rilla hoped that she would gain valuable information as a fellow at the 2019 CHARGE Conference to help her better serve her students.

For the past three and a half years I have had the pleasure of being a teaching assistant in the Deafblind program at Perkins School for the Blind. Over the years I have learned a lot about CHARGE. I thought that Perkins would teach me just as much as I needed to know about CHARGE. However, my ignorance became so clear when I had the chance to attend the 2019 CHARGE conference in Dallas, Texas. It had been my dream to attend the conference since I started at Perkins and my excitement was through the roof when I found out that I would be able to attend as a Davenport fellow. While I knew that I would learn a lot as part of such an amazing opportunity, I had no idea how much the conference was going to humble me, help me grow, and make connections that I never knew were even possible... [Click to read more](#)

Hallie Smith

Hallie Smith, PhD is a Licensed Psychologist in the Pediatric Feeding Disorder Program at the Kennedy Krieger Institute in Baltimore, MD. Hallie received her Ph.D. from Mississippi State University (MSU), where she was an active member in the Bulldog CHARGE Syndrome Lab. At the 2019 CHARGE Conference, Hallie hoped to connect with families who have children that may have difficulties with feeding.

When preparing for this conference, I honestly did not know what to expect. I had been to one conference previously and had a great time, and loved meeting individuals with CHARGE syndrome for the first time. At the conference in Chicago, I was still in graduate school, still training to be the professional I am today and had no idea what the next four years would bring. For me personally, me coming to the conference this year, as a professional, sharing the research I have been doing with other professionals and families, was an incredible experience. It was something I had hoped I could do when I was at the conference in Chicago, and now it was actually happening! I felt so fortunate that I was able to share the experiences and the work I've been doing with families and professionals. I had told myself that if the things I was sharing at this conference helped one family, in some way, that would be all the reinforcement I needed! And, I definitely did get that experience. I had the opportunity to consult with a sweet family and provide recommendations, resources, and support to them. It was incredible to get to work with this family and get to know them on a personal level as well... [Click to read more](#)

[CLICK HERE TO READ MORE FROM RILLA AND HALLIE](#)

Understanding CHARGE Syndrome

Free Online Course presented by the
CHARGE Syndrome Association of Australasia



Delivered by the world's foremost experts, this course offers university-quality education on the latest knowledge and research on CHARGE syndrome.

This course will improve understanding and awareness of CHARGE syndrome amongst health and educational professionals and will strengthen the capacity of families and care givers to create and contribute to personalised CHARGE syndrome management plans. CSAA is very proud to be involved in this excellent educational tool on CHARGE syndrome.

MODULE 1: INTRODUCTION MODULE

- Overview of CHARGE syndrome and major and minor diagnostic features

MODULE 2: THE NERVOUS SYSTEM

- Function of the cranial nerves
- Impact of CHARGE on the nervous system
- The CHARGE checklist
- Feeding scale

MODULE 3: EARLY COMMUNICATION & MULTI-SENSORY IMPAIRMENT

- Early communication
- Deaf-blindness/Multi-sensory impairment
- Proprioception and Vestibular Senses
- Causes of Paediatric Vestibular Disorders
- Head/Neck trauma
- Vision & Retinal Detachment
- Hearing & Auditory Devices

MODULE 4: BEHAVIOUR & PAIN

- Behaviour in CHARGE
- The Behaviour Triangle for CHARGE
- Pain behaviour in CHARGE

MODULE 5: ADULT YEARS & BEYOND

- Medical Issues into adulthood
- Assessments
- Person-Centred Planning
- Life beyond school
- Social and Emotional Development

REGISTRATION NOW OPEN!

<https://understandingchargesyndrome.org>

Course starts: 4th April 2020

Effort: 5 weeks, 2 hours per week (self-paced)

COST: FREE

(Certificate may be purchased upon successful completion)

**15th
CHARGE
Syndrome
Conference**

**Marriott
Phoenix
Desert Ridge**

*We hope you
can join us!*

