

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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The CHARGE Syndrome

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President's Message

I n just a little more than 2 months, we will be Taking CHARGE in Orlando! As we approach our 13th conference, I reflect on how far we have come as a Foundation, and look to the future.



I am extremely proud of how we have evolved. The

Ethan Wolfe Recreational Assistance Program continues to put smiles on our members' faces. When I see an individual with CHARGE riding their own adaptive bike, going to swimming lessons, riding a horse or just participating in any recreational activity that makes them happy, I am glad the Foundation could help make that happen.

Our Scientific Advisory Board and Clinical Advisory Board are both in the middle of accepting <u>grant applications</u>. Six years ago we did not even have these boards! Our Director of Outreach and special advisors respond to emails and phone calls on a daily basis to help our families navigate the complex CHARGE world.

Admittedly, the tremendous expansion of our programs does not come without its challenges. As we grow, the costs to fund these programs and time commitments for the small handful of volunteers that make everything happen have skyrocketed. We need everyone in our CHARGE family to get involved!

There are many things you can do to help lighten the work load. If you are attending conference, please <u>register today</u>. <u>Pre-order</u> your conference merchandise now. Help us make our Saturday night party a little more fun by <u>donating cool baskets</u> or items for silent auction. Build on the excitement of conference and <u>participate</u> in Charge It for CHARGE or host a fundraiser. Let your voice be heard by <u>becoming a member</u>.

Together there is so much we can accomplish. Enjoy the newsletter. See you soon!

Davíd

Conference Prep and Insight

from Julie Brandrup, Parent and New Board Member

here is no such thing as being too prepared for Conference. No matter what you think you know or have seen before, there will always be something new to remind you that nothing compares to a CHARGE gathering – so much support, so much learning, so much inspiration. Our 13th International CHARGE Conference should be no exception and once you've registered and made hotel reservations, it's a good opportunity to think about what you're hoping to take away from conference ... and possibly give back, too.

For our attendees, the CHARGE family, we know that just leaving the house for a few days can be difficult. So, after traveling to another state and spending a lot of money to get there, it feels amazing to look around and see so many people who just "get it" without even saying a word. Also a comfort is knowing that the people planning and running the conference have been in the shoes of most attendees and are ready to give everyone the best experience possible.

What has been fun for me this year thinking about Conference (my 7th) is seeing it from the planning side of the Foundation Board. With this new insight, I have a few tips that may help attendees get more out of conference – but there are also important realities to share about this special event. So as we look towards July, here's the list:

- The CHARGE website can make your conference planning much easier. Visit the conference section early and often. The Program Agenda is there for you now: www.chargesyndrome.org/ for-families/conferences/conference-program/ If you can choose what sessions to attend before you arrive, then your overwhelmed-conference-self will thank you. #onelessthing
- If you are really on the ball, you can also download the presentation handouts to your iPad or tablet – or print them out to put in a binder (great for note taking) before you go. Yes, in a perfect Wi-Fi world, you could do this on-site but in hotel land, meeting space Wi-Fi runs about \$50,000 and that's not an option for our conference budget. #buttherewillbeblendersatlunch
- Seriously, don't be overly dependent on hotel Wi-Fi. It will be available free in your individual guest room but it won't be super fast with 1,400+ trying to use it at the same time. #therewillalsobeafridgeineveryroom
- Now here's something that can't be emphasized enough. If you are at Conference, we need you to be a Foundation member. We are a genetically significant syndrome and an impressive



organization – but compared to other rare conditions, CHARGE is being overlooked for funding sources (grants, research, etc.). If that frustrates you, it should. Funding agencies look at membership and compared to the 1,400+ in attendance at Conference and the 5,000+ we have on Facebook, our Foundation membership is only a fraction (about 550). CHARGE syndrome should not be overlooked and if you agree, the most important thing you can do is help reflect

our true numbers through official membership. It's \$30 a year - and hey, you'll get a shiny ribbon for your badge at conference. #countmein

Speaking of badges, your conference badge is like a golden ticket. Each attendee will receive a badge and your choice of how to attach it (lanyard or clip) at check-in. The badge must be worn at all sessions and events and especially at meals. Wearing your badge at all times makes life much easier for everyone to know you belong with us. Wearing it all the time also



makes it easier to not lose. Believe it or not, lost badges have been a pesky and costly issue at Conference so that's why they get a whole bullet point's attention. #aintnobodygottimeforthat

It's not really a secret but here's a hard-to-believe insight about ***** PLEASE SUPPORT OUR * costs: The Foundation pays about \$200 beyond what attendees pay for registration for every person who comes to Conference.

Making the conference affordable is a priority for the Foundation, so that's why you hear so much about fundraising. #chargeitforchargemakesiteasy

- Related to the financial reasons above and also for liability insurance requirements, only registered-for-conference, badge-wearing people can be at sessions, events, and meals. We'll be checking. This has been brought up as a sticky situation because Orlando is a destination where many of us may bring extra people along for theme parks. Those extra people may not understand why they cannot pop in for a buffet, evening activity, etc., so please register them. #yourmommamaylooklikeacrasher
- Remember to bring a sweater or jacket because the meeting rooms are usually freezing. #orbuysomechargeawarenessmerchandise
- Bring some Kleenex to share for the tears around the room as we applaud the amazing examples we'll see and hear from the platform - and maybe for the first time attendee who is seeing the breadth of CHARGE for the first time and feeling overwhelmed (we've all been there, right?). #welcometotheclub
- Lastly, as a new board member, I've discovered the people in charge of the conference are not actually the superheroes I assumed them to be. They are just like the other attendees with jobs, interests, and issues that compete for their energy, including the unique



demands that come with having a family member with CHARGE. So why do these mere mortals volunteer (as in not paid) for all the work they do and what is their secret? The answer is YOU ... the Conference attendee. You are the inspiration because you have gone the distance in so many ways to be at Conference. #nobetterplacetobe

This year, I will proudly wear the bright-colored shirts of my fellow Board members. I hope to serve the attendees well, and also sit alongside you as much as possible to learn and be inspired. I can't think of anything more gratifying than knowing that despite all the different people, from all the different places, and all the different ways life can get in the way, we have all found a way to gather together for the same simple goal: to improve the life of someone with CHARGE syndrome. That is what Conference is all about!

> Would you like to join the board and help plan future conferences? Talk to us in Orlando. We don't bite.

Presenter Handouts will be available at the **Conference Information Page** approximately 2 weeks prior to conference

Paper handouts will not be provided



We need volunteers to help out with many different aspects of conference, especially signing volunteers for camp.

Click here for volunteer application





DEADLINE



CONFERENCE REGISTRATION: Everyone must be registered and wear name tags at all times in order to participate in meals and events. Register and pay by June 1 to avoid late fees. Click here.

CAMP REGISTRATION: If your child will be attending camp during conference, you **MUST** register with our childcare company **ASAP** so that the childcare company can appropriately staff for our conference. This requires a separate registration form to be completed. **Click here** to complete the Corporate Kids Events registration form.

PRE-ORDERYOUR CONFERENCE MERCHANDISE see page 10

APPLY TO HOST A DAVENPORT FELLOW see page 5

QUALIFY FOR THE CIFC INCENTIVE PROGRAM see page 11

TO DO ASAP!

MAKE HOTEL RESERVATIONS: Use THIS LINK to reserve your room

BECOME A MEMBER OF THE FOUNDATION: We depend on the support and commitment of our members to help create a better, more understanding and accepting world for all individuals with CHARGE. To join or renew, click here.

DONATE A BASKET: Our fun-filled silent auction is always one of the highlights of Saturday night's CHARGE-A-Palooza festivities. We combine a basket raffle with a traditional silent auction. The more quality baskets and items we have, the better your chance to win!. Visit the Conference Events page for the donation form or contact Neal Stanger for additional information.

Still Have Questions?

Visit the Conference Information Page Watch the Conference 101 Webinar & Read the Conference Newsletter

Planning Ahead?

The 14th CHARGE Syndrome Foundation Conference will be held at the beautiful Hilton Anatole in Dallas, Texas, August 1-4, 2019

2017 Davenport CHARGE Syndrome Fellows Announced

From a broad field of very well-qualified applicants, we have selected 11 young professionals from all over the world who each have a growing passion for CHARGE to be the 2017 class of Davenport CHARGE Syndrome Fellows. Fellows will come to conference to meet with each other, with other professionals and to meet families. They will eat meals with us, go to presentations and volunteer in camp. Several will be doing research and/or presenting their research at conference.

WANTED: HOST FAMILIES TO BE MATCHED WITH FELLOWS

To make the most of their experiences, we will be matching each Fellow with a host family. Host families must:

- I) Have a child with CHARGE who will be in Camp
- 2) Be willing to be in touch with their Fellow by email prior to Conference
- 3) Meet their Fellow at the opening reception Thursday evening and
- 4) Have at least one meal during Conference with their Fellow.

Below is a short introduction to each Fellow and some suggestions of what sort of family might make a good host. We welcome inquiries from ANY family interested in hosting a Davenport Fellow: Please send an email to Pam Ryan <u>pam@chargesyndrome.org</u> telling us a bit about your child and your family, where you are from, and if you have a preference to be matched with a particular Fellow. Also please include your phone number if possible. Deadline: June 1.

Emily Fassi is a genetic counselor in St. Louis, Missouri. She has been interested in CHRGE since she began working with Meg Hefner on the CHARGE database (CSCDP) prior to her graduate training in genetic counseling. Emily presented information on the database at the 2013 Conference in Arizona. In Orlando, she will present a poster on Milestones in CHARGE with CSCDP data. As a Davenport Fellow, Emily hopes to more fully understand what family like is like in CHARGE-land and how genetic counselors can best assist families and to establish herself as a genetics professional within the CHARGE community. She is happy to be matched with any family who is OK with her asking lots and lots of questions.





Dieuwerke Dijk is a physician from the Netherlands. She is currently doing subspecialty medical training on children with intellectual disabilities with Dr. Conny vanRavenswaaij. This area of training is unique to the Netherlands, where they recognize that healthcare professionals need to be able to connect with the patient to determine the issues. Her current research interest is growth in CHARGE syndrome: growth charts for CHARGE, growth hormone issues, body proportions. Dieuwerke will be collecting data on body proportions in Orlando. She is looking forward to meet with families and individuals with CHARGE. A good host family for Dieuwerke might be one whose child is on growth hormone or has growth issues.

Lauren Fogarty is a medical student at Dalhousie University in Halifax, Canada. She has a master's degree in neuroscience and has experience volunteering with a number of recreational and therapeutic programs. As part of her medical training, Lauren is doing research with Dr. Kim Blake looking at what diagnostic imaging has been done in children with CHARGE. Lauren will be presenting a poster and collecting data on her project at the conference. She is hoping that, as a Fellow, she will have the opportunity to interact with professionals and families in ways that will help her become a better pediatrician. A Canadian family might be interested in hosting Lauren.



Charlotte Reimer has just about completed her 4 year training to be a speech-language pathologist (SLP) in El Cerrito, California. Her interest in CHARGE started with her very first client as a student – a 10year-old girl with CHARGE, which also led her to discovering

the California Deafblind Project. This child taught Charlotte that everyone has the desire to communicate and everyone has the right to communicate. Charlotte has made it her goal to help each of her clients find and express their personal voice. She is looking forward to her first CHARGE conference and would like a host family with a young child who uses AAC or speech, preferably from California or the west coast so she can keep in touch after conference.

Alex Donovan is currently a candidate for a PhD at King's College, London. He is studying craniofacial development and cell biology with Dr. Albert Basson. Before starting his PhD, Alex volunteered at Swiss Cottage School for children with complex learning difficulties and

studied genetic and developmental causes of autism spectrum disorders (ASDs). Now he is studying mice in hopes to learn more about executive functioning in people. He will be presenting a poster of his work in Orlando. Alex attended a CHARGE Family Day in England in 2016 and is looking forward to hearing more about family experiences with CHARGE and meeting more professionals in the CHARGE world. A family with a child with autistic like features might be a good host for Alex.





CHARGE using mouse models. Hui met many families at the 2015 CHARGE conference in Chicago and is looking forward to meeting more families and professionals in Orlando. Meeting families provides a real world context for her research. Hui will eventually take her expertise back to China with her. A family interested in China might be a good host for Hui.

Chathuri Illapperuma is a PhD candidate in School Psychology at Mississippi State University under Dr. Kasee Stratton at the Bulldog CHARGE Lab. She is from Sri Lanka, where she developed an interest in sexuality education, a taboo topic in Sri Lankan society. She is hoping to be able



to develop curricula to explain sexuality education to atypical children, including those with CHARGE syndrome. At conference, Chathuri is hoping to have many true conversations with individuals with CHARGE, their families and professionals about this topic. She will be part of the team presenting with Dr. Stratton and hopes to take what she learns back to South and South East Asia at the end of her studies. A family with interest in sexuality education in CHARGE would make a good host family for Chathuri.



Kareem Tawfik is an ENT physician about to begin a Fellowship in Pediatric Otology and research at Cincinnati Children's Hospital in Cincinnati Ohio. He is training with Dr. Daniel Choo, co-director of the CHARGE Center at Cincinnati Children's. Kareem is interested in children whose MRIs do not show evidence of a cochlear nerve and yet get benefit (sound awareness) from a cochlear implant. He sees many children with CHARGE in clinic and is looking forward to meeting families at a more personal level and meeting other CHARGE professionals. Kareem would like to be hosted by a family whose child has a cochlear implant or auditory brainstem implant. **Bree Kaufman** is a PhD candidate in School Psychology at Central Michigan University in Mt. Pleasant, Michigan under Dr. Tim Hartshorne. With Dr. Hartshorne, Bree has attended the 2015 CHARGE conference in Orlando and the 2016 CHARGE conference in Australia. Bree's research, through Dr. Hartshorne's CHARGE Lab at Central Michigan, is focusing on degrees of severity in CHARGE. She will have a poster and may be collecting more data on her project in Orlando. A good host family for Bree might be one who has a slightly older child and has thought about what severity means in CHARGE.

> **Megan Connaughton** is a teacher in the Deafblind Program at Perkins School for the Blind in Watertown, Massachusetts, where she has worked for eight years. She holds a Master's of Education Degree from Boston College in Severe and Multiple Disabilities with a concentration in Deafblindness and is fluent in Spanish and ASL. Megan has worked with students with CHARGE from ages 3-22 and is currently teaching preschool students, ages 3-6. Her interests in the field include early communication and literacy skills, and strategies and adaptations for students with additional physical disabilities. Megan enjoys cooking in her spare time, and carries that interest over to school, where she teaches adapted cooking lessons to her preschool

class. She would like a host family with a preschool age child – ASL or Spanish welcome.

Zachary Bird is a Board Certified Behavior Analyst (BCBA) who works in the Deafblind Program at the Perkins School for the Blind. Zach, who has been working at Perkins for a little over a year, has come to know many of the intricacies that make up CHARGE Syndrome. One of Zach's goals in graduate school was to take his expertise in behavior analysis and apply it to populations outside of autism. He wrote, "More than 95% of behavior analysts currently employed in the field, work with individuals with autism. It's important to me that I am able to interact and disseminate behavior analysis where it's not as common and help make progress with those individuals." If you have a child with behavior issues, you might be a good host family for Zach.

Again, if you are interested in being a host family for a Davenport Fellow, please send an email to pam@chargesyndrome.org by June 1. Tell Pam a bit about your child, your family, and where you are from. Let her know if you have a preference for any particular Fellow(s).

Donate a basket for Saturday night's CHARGE-A-Palooza More baskets = More Winners = More Fun for Everyone!

We need baskets for adults and for kids of all ages and abilities, with a value of at least \$50 (date night, game night, spa day, chocolate lovers, sensory toys, etc.). We are also accepting high-end items, such as timeshares, fine jewelry, airline tickets, electronics, and sports memorabilia.



Please let us know before conference if you will be bringing a donation with you.











Everyone Deserves a Chance to Play 3rd Annual Ethan Wolfe Recreational Assistance Program (EWRAP)

EWRAP was created and funded in 2014 through generous gifts from the Wolfe family and friends in memory of Ethan Wolfe. The program provides families with funding for recreational programs or to purchase recreational equipment

Congratulations to this year's recipients!

James & Brayden - Bike Trailer Daniel, Tyler, Chantelle & Lacey - Adaptive Bike Micah - Summer Camp Alexis - Swimming Lessons Bryce, Delilah & Ryder - Hippotherapy



From James' Family:

We received the WeeHoo tandem bike on May 5th. I managed to quickly put it together in time to pick James up from daycare that same day. It's a fantastic piece of equipment! Well built, incredibly easy for James to get in/out and the travel bags have lots of room. We've had some really crazy weather lately (one day sunny, the next pouring rain...) but we've already managed to get out for our first family ride along the sea walk! Thank you so very much. We look forward to all the adventures this summer will bring.





From Chantelle I love my trike and riding felt so natural. I was smiling the whole ride home. I am so happy!

From Brayden's Family:

Today we took our new trailer for a test ride at nearby Ojibway Island. We thank you all so much for the many adventures to come and so many exciting memories that will most definitely be made. We were limited in Brayden only being able to ride his adaptive trike at our neighborhood park. We can now enjoy bike trails, state parks and camping...Yogi Bear Park Campground being our 1st adventure of many! The trailer will allow Brayden to not only have



fun but will certainly bring so many life changing adventures in our lives. EWRAP has played a huge role in enriching my son's life. Thank you with all of my heart!

Look for applications for the 4th Annual EWRAP at the beginning of 2018

The Importance of Movement for Individuals with CHARGE Syndrome Appropriate Physical Education Service in Schools: Laws and Knowledge Ву

The Individualized Education Program (IEP) should address the impact of the dual sensory loss on motor development and provide interventions to improve overall motor function for individuals with CHARGE syndrome. One area related to motor development within the education system is general physical education and adapted physical education. Educational techniques and interventions within special education are specifically designed to meet the unique needs of the students, which may include adaptations when appropriate in the content, methodology, or delivery of instruction [Individuals with Disabilities Education Improvement Act (IDEA), 2004]. Special education instruction includes physical education under IDEA, 2004, Public Law 108-466 regulations. Therefore, physical education should be specially designed to meet the unique needs of individuals with CHARGE syndrome.

Within the physical education class, students should learn about the following as defined by IDEA, 2004: Physical and motor fitness, skills in aquatics, dance, and individual and group games and sports (including intramural and lifetime sports); as well as special physical education, adapted physical education, movement education, and motor development.

Early interventions and appropriate instructional strategies are critical components in the success and participation of a student who is deafblind. Highly qualified adapted physical educators are professionals from standard-based physical education teacher education programs who can design, implement, and evaluate motor skills and fitness of students with disabilities especially from low incidence populations.

Qualified teachers demonstrate effective teaching strategies, specifically to adapted physical education that provide access and opportunities to build on previous experience and knowledge. Therefore, quality teaching must also include the knowledge of learners, which comprises of individual characteristics, background experiences, and prior knowledge. Moreover, highly qualified adapted physical education teachers must possess a comprehensive content knowledge in disability studies, assessment methods, special education law, development of IEPs, adaptations, and modification for physical education, behavior management, individual teaching and learning styles, inclusive practices, instructional design and planning, professional leadership,

By Dr. Beth Foster

IDEA, 2004, Public Law 108-466

(1) Special education means specially designed instruction, at no cost to the parents, to meet the unique needs of a child with a disability, including--(i) Instruction conducted in the classroom, in the home, in hospitals and institutions, and in other settings; and

(ii) Instruction in physical education. (Part B,

Section 300 / A / 300.39 / a / 1) (i) Instruction conducted in the classroom, in the home, in hospitals and institutions, and in other settings; and

(ii) Instruction in physical education. (Part B, Section 300 / A / 300.39 / a / 1)

(2) Physical education means--(i) The development of—
(A) Physical and motor fitness;
(B) Physical and motor fitness; and
(C) Skills in aquatics, dance, and individual and group games and sports (including intramural and lifetime sports); and
(ii) Includes special physical education,

adapted physical education, movement education, and motor development. (Part B, Section 300 / A / 300.39 / b / 2)

(3) **Specially-designed instruction** means adapting, as appropriate to the needs of an eligible child under this part, the content, methodology, or delivery of instruction-

(i) To address the unique needs of the child that result from the child's disability; and

(ii) To ensure access of the child to the general curriculum, so that he or she can meet the educational standards within the jurisdiction of the public agency that apply to all children. (Part B, Section 300 / A / 300.39 / b / 3) and assistive technology for physical education. The service and placement of general physical education or adapted physical education should be in the student's least restrictive environment, which allows the student to be safe at all times and be able to achieve successful movement experiences.

IDEA 2004, states that the State must ensure that public agencies in the State comply with the following:

(a) General. Physical education services, specially designed if necessary, must be made available to every child with a disability receiving (Free Appropriate Public Education) FAPE, unless the public agency enrolls children without disabilities and does not provide physical education to children without disabilities in the same grades.

(b) Regular physical education. Each child with a disability must be afforded the opportunity to participate in the regular physical education program available to nondisabled children unless--



(1) The child is enrolled full time in a separate facility; or

(2) The child needs specially designed physical education, as prescribed in the child's IEP.

(c) Special physical education. If specially designed physical education is prescribed in a child's IEP, the public agency responsible for the education of that child must provide the services directly or make arrangements for those services to be provided through other public or private programs.

(d) Education in separate facilities. The public agency responsible for the education of a child with a disability who is enrolled in a separate facility must ensure that the child receives appropriate physical education services in compliance with this section. (Part B, Sec. 300.108 Physical education)

Research your state regulations related to physical education and adapted physical education. Then ask about a motor skills assessment for adapted physical education at your next IEP meeting.

Dr. Beth Foster, CAPE is an Assistant Professor in Adapted Physical Education, Department of Kinesiology and Health Promotion at California State Polytechnic University, Pomona. <u>Click here to read this article with academic references.</u>

CONFERENCE MERCHANDISE PRE-SALE

Now accepting **preorders** of Conference T-shirts, lunch bags, CHARGE logo polo shirts, quarter zips, performance T-shirts, long sleeve T-shirts, sweatshirts, hats, and more!

We will have a limited number of items and sizes at Conference

If you see something you like, order by June 1 and your items will be ready for you to pick up at conference!

CLICK HERE ORDER BY JUNE 1



If you are not attending conference, you can order CHARGE awareness items through the Foundation's website. <u>Click Here</u>

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Focus on Fundraising

I n memory of my son, Felix Owens, and in honor of Lienna Reeves, who is 2-years-old, Megan Reeves (right) and I recruited friends to hold online fundraisers for CHARGE (Mary Kay, Initials Inc. Origami Owl, Posh, Lularoe, etc.) and they donated their commission to the fundraiser. A friend who makes t-shirts sold them and she donated her commission to our fundraiser. Others donated cash. Lularoe matched my friend's commission donation, which was an extra \$102.50. A friend who owns Gracie's Gowns is doing a virtual 5k in June and will donate half the proceeds to the CHARGE Foundation.

It was a lot of fun and we actually ended up raising a little more after we printed the big check, \$2,654 so far. We hope to do more throughout the year and have others donate to our Charge It for CHARGE fundraising page!





Charge It for CHARGE The Online Fundraising Campaign of the CHARGE Syndrome Foundation.

Your support helps fund research, outreach, scholarships and biennial international conferences. You can make a difference!

BECOME A FUNDRAISER SUPPORT A FUNDRAISER

The Deadline for Prizes and Free Conference Registration is June 1

Raise \$2,500* - Earn One (1) Free Conference Registration, Conference T-Shirt & Sweatshirt Earn an Additional Registration (up to 4) for Each Additional \$2,500 Raised

Raise \$1,000* - Receive a Free Conference T-Shirt & Sweatshirt



Raise \$500* - Receive a Free conference T-Shirt *Limit One (1) T-Shirt and One (1) Sweatshirt Per Fundraiser

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by Sara Owens