WINTER 2019 vol 29 issue 1

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.

The CHARGE Syndrome Foundation, Inc.
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Buffalo Grove, IL 60089
800-442-7604
www.chargesyndrome.org
info@chargesyndrome.org

President's Message

Spring is in the air and that means registration for our 14th International CHARGE Syndrome Conference in Dallas is now open. Plus, we are accepting applications for conference scholarships and the Ethan Wolfe Recreational Assistance Program, until **April 1**. Don't delay, ACT NOW!

Scientific and Clinical Research Grant applications are also being accepted. Visit our website for information and application.

What do a 13 year-old runner, a professional football player, and a 13 year-old boy who has CHARGE have in common? They all used their skills to raise money for the Foundation. Read about their stories, words of advice from our Director of Outreach, things to plan for before your child with CHARGE reaches 18 and much more in this informative edition of CHARGE Accounts.

Looking forward to seeing many of you in Dallas.

David

David Wolfe, President

Join us in Dallas, August 2-5!

Registration Now Open!

14th International CHARGE Syndrome Conference

August 2-5, 2019
Dallas, Texas

Register & Pay By April 1 to be Eligible for Early Bird Prizes!

BOOK YOUR HOTEL ROOM TODAY!

https://book.passkey.com/event/49757510/owner/863/home

CONFERENCE SCHOLARSHIP APPLICATION

Foundation members are eligible to apply for scholarships to assist with the cost of attending conference

Apply Today! Deadline: April 1

CLICK HERE

Not a member? Join Here.

CHARGE It For CHARGE

THE CHARGE SYNDROME FOUNDATION

EARN ONE FREE CONFERENCE REGISTRATION FOR EVERY $3000 RAISED

Qualify by June 1

THERE'S STILL TIME!

CLICK HERE TO GET STARTED

DONATIONS NEEDED

SILENT AUCTION & BASKET RAFFLE

The more prizes we have, the more fun for everyone!

We welcome all donations, including themed baskets ($50 value) for adults and for children and bigger ticket items such as sports tickets and electronics.

Questions? Contact deanna@chargesyndrome.org

Donation form available here
Letter to donors available here

We're actively seeking volunteers with sign language skills to support our campers and to assist during our evening events.

Please share the details and application with your teachers, therapists, friends and family members.

What You Need to Know Before Your Child Turns 18

Don't wait until your child with special needs turns age 18 to begin planning. Becoming a legal adult leads to many changes in available benefits, needs, and your ability to act on your child's behalf. Here are just a few of the many items for your to-do list

Government Benefits

If your child receives SSI (or SSDI as a minor on a parent's work record), then when your child turns 18, the Social Security Administration will automatically review his or her file. The SSA uses a different test to determine benefits eligibility for adults than for minors. The adult test asks whether your child has a lasting physical or mental impairment that "results in the inability to do any substantial gainful activity." Your child could lose benefits or need to appeal a denial because of this different test.

On the bright side, the income requirements are different too. Minors' eligibility for SSI turns on financial requirements that include their parents' income and resources. Adults' eligibility looks only to their own income and resources. Your child may therefore **qualify** for SSI even if he or she did not as a minor.

Keep in mind, if your child has not received it before, you cannot actually apply for SSI or Medicaid until the first day of the calendar month after he or she turns 18.

Government Requirements

Now is the time to get a state-issued identification card or driver's license and to make sure you have your child's Social Security card. You will need these cards to apply for many services. Also, your child may need a bank account to accept SSI checks or employment checks (these should be separate accounts). You also could help your child register to vote and, if he is male, he must submit Selective Service paperwork.

Practical Steps

If your child has intellectual disabilities, we recommend that your child take an adult IQ test between the ages of 17 and 18. The Social Security Administration considers IQ test results in figuring out whether your child qualifies for benefits. Obtaining a test result of 70 or below may make qualifying easier.

Legal Steps

If your child needs significant help with activities of daily living, now is the time to start working on the guardianship process. The courts take time to process guardianship petitions, so talk to a lawyer about preparing now. You may instead need to help your child get a **power of attorney**.

Estate Planning for Your Extended Family

When planning for your family's future, don't forget that extended family members may need to change their plans too if they want to help your child with special needs. This article describes some common **situations** that arise when well-meaning relatives want to include your child with special needs in their estate plans and explains how to redirect these efforts to best benefit your child.

Often, relatives want to leave the child with special needs bequests in their wills or make gifts to them. Bequests made directly to a child with special needs can be extremely problematic for government benefits eligibility. If the will leaves the child with special needs a sum of money or a piece of property, or if the will leaves money to a support trust, the child could become ineligible for government benefits. The government takes into account inheritances and other resources (including traditional support trusts that do not have special needs trust language in them) when determining eligibility.

Gifts and bequests without careful planning can cause major problems for the recipient and the family of the child with special needs. So, how can a well-meaning, generous relative help out? Relatives may want to seek legal advice to ensure that their estate plans line up with your own and maximize benefit to the family member with special needs.

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For additional helpful articles:

https://www.rubinlaw.com/category/blog/

What About Adults?

By Sheri Stanger, Director of Outreach

So your child with CHARGE syndrome is no longer a child. You've put a lot of energy towards a good education for 21 years but now they've aged out of children's services and are no longer in school. If you are like many parents, you are probably asking "What's next"? This little article doesn't purport to answer all your burning questions and my focus will not be on the transition process. The transition services period, which technically begins at age 14 years old, can be a very scary time for a parent that has a child with CHARGE syndrome. It can lead to added anxiety for the teenager/young adult as well as anxiety for the parent(s)/guardian(s). The information I'm providing is useful to all but it is directed towards the parents whose adult child has already aged out of school and is living at home. What resources are available to assist you in providing your adult child with a meaningful life? There are no easy answers to our burning questions but there are some resources and supports to assist you along the way.

Helen Keller National Center: Helen Keller Services enables individuals who are blind, visually impaired, deaf-blind or have combined hearing and vision loss to live, work and thrive in the communities of their choice.
https://www.helenkeller.org

This part of the website will provide information for "on campus" opportunities:
https://www.helenkeller.org/hknc/campus-services

HKNC Nationwide Services Regional Representatives: If you have not yet reached out to your Regional Representative, please consider contacting them.
https://www.helenkeller.org/hknc/nationwide-services

HKNC DB Immersion Experience: On Campus Training Program for Adults with deaf-blindness with additional disabilities:
https://www.helenkeller.org/hknc/hknc-services-individuals-who-are-deaf-blind-additional-disabilities

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CONTACT ME: sheri@chargesyndrome.org

HKNC National Community of Practice (NCOP): This is a network of agencies around the country that learn, share information, develop resources and competencies and create best practices with and for people with deaf-blindness. This is a list of partners by state and national organizations:
https://www.helenkeller.org/hknc/national-partners

NDBEDP – National Deaf-Blind Equipment Distribution Program: This program enables people with deaf-blindness to access free equipment for distance communication.
https://www.helenkeller.org/hknc/national-deaf-blind-equipment-distribution-program.
For a complete list of contacts for your area:
http://www.icanconnect.org

NFADB Adult Life Facebook group: This closed group is run by the National Family Association for Deaf-Blind (NFADB) and focuses on issues surrounding adults with deaf-blindness.

CHARGE Syndrome Foundation website: The Foundation has a section on Adulthood with links to various organizations that are specific to deaf-blindness and general disability agencies that can assist you at the local level.
https://www.chargesyndrome.org/for-families/adulthood/

Adult life is a huge and complex topic. This is information to help get you started. In my experience, it's critical to stay connected to other parents that have an adult child with CHARGE syndrome and the local resources in your area that can assist you with housing, day habilitation programs and self-directed services, vocational services, mental health issues, recreational and respite options and continuing education. If you'd like a list of parents from your state, province or country, please email me to request one. Many of our children will need some form of ongoing support as adults and there are agencies in place to assist. As parents and caregivers, we need to share information and resources with each other. As advocates, we need to ensure that the adult service agencies know about CHARGE syndrome to meet the growing needs of our population.

Focus on Fundraising

Emmet's Run for CHARGE

As part of his Bar Mitzvah, Emmitt Gerstein was required to perform a public service project. Emmitt wanted to do something to help his brother, Tomer, who has CHARGE, and it was an easy choice for Emmitt when he decided to recruit friends and family to participate in a 5K run/walk to raise awareness of CHARGE Syndrome and seek contributions to the CHARGE Syndrome Foundation. On November 18, 2018, forty people joined the 5K on a very chilly morning in Washington, DC, while other friends found other 5Ks around the country. Participants received a shirt with the Foundation's logo and "Emmitt's Run for CHARGE" and together raised over $2,500 for the Foundation. Back at the Gerstein house after the run, participants enjoyed brunch and Tomer signed "thank you for your help" to the group.

THANK YOU!

Dymonte Thomas of the Denver Broncos

for choosing the
CHARGE Syndrome Foundation
as your "My Cause My Cleats" charity

and thanks to the anonymous bidder,
the Foundation received a donation of $1963!

Dymonte Thomas' cleats represent the CHARGE Syndrome Foundation, an organization that promotes awareness and research for CHARGE syndrome, for My Cause My Cleats in 2018.

Dymonte Thomas' cleats represent the CHARGE Syndrome Foundation, an organization that promotes awareness and research for CHARGE syndrome, for My Cause My Cleats in 2018.

> *"I met two families with children with CHARGE Syndrome and wanted to support the kids and families and raise awareness for the illness. I promised the families I would help them and will be dedicating My Cause My Cleats to do so."*

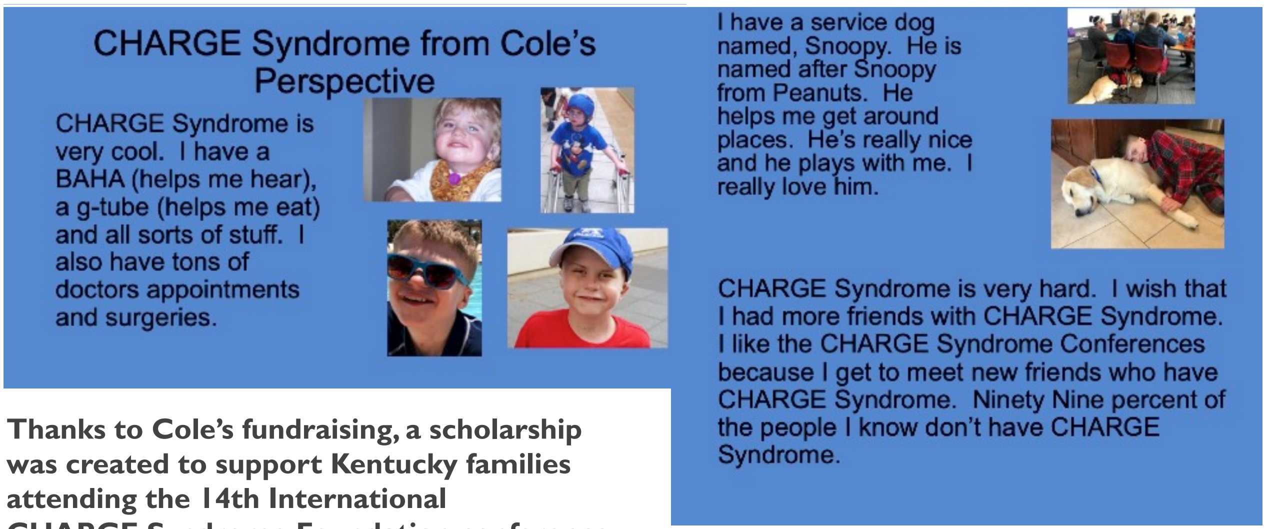
Good Friends Co-Op CHARGE Syndrome Fair & Fundraiser

Hi! My name is Cole Herrick and I am a 13 year old boy who has CHARGE Syndrome. I like Mario, Gemmy singing toys, technology, dogs, pizza, jokes, cartoons and books. CHARGE affects me because it is not easy. I have to use lots of extra stuff. Some things that I have are a BAHA, a g-tube, a wheelchair and a service dog named, Snoopy. He is named after Snoopy from Peanuts. I have had thousands of surgeries. I like my doctors but I do not like my surgeries.

My mom told me that we were going to do a fundraiser for the CHARGE Syndrome Foundation. At first, I did not want to do this but my mom made me because moms always like to make their kids do stuff that they don't want to do. Then, we went to the CHARGE Syndrome Foundation website to get ideas. I decided to get donations and teach people about CHARGE Syndrome by writing a letter to family and friends. And, O Boy, it was a huge success! I felt like a You-tuber who just hit One Million subscribers when I met my goal of raising $1000.00 in 1 day and of course, my jaw dropped and my mind was blown.

After this fundraiser, we did a fair and fundraiser with my Good Friends Homeschool Group to raise money for the Kentucky CHARGE Syndrome Association. We had pie face, Connect Four, face painting, an art silent auction with art made by kids in my homeschool group, water balloons, ring toss and the ice bucket challenge. It was a massive success!

Even though my mom made me do these fundraisers, it made me feel happy and proud. I actually had fun. I liked reading and responding to people's comments on my fundraiser page and seeing how much money I raised for the CHARGE Syndrome Foundation. For the homeschool group fundraiser, it was awesome because it was about me and it was fun. I really liked raising money for CHARGE Syndrome. Anyone can totally do it!



CHARGE Syndrome from Cole's Perspective

CHARGE Syndrome is very cool. I have a BAHA (helps me hear), a g-tube (helps me eat) and all sorts of stuff. I also have tons of doctors appointments and surgeries.

I have a service dog named, Snoopy. He is named after Snoopy from Peanuts. He helps me get around places. He's really nice and he plays with me. I really love him.

CHARGE Syndrome is very hard. I wish that I had more friends with CHARGE Syndrome. I like the CHARGE Syndrome Conferences because I get to meet new friends who have CHARGE Syndrome. Ninety Nine percent of the people I know don't have CHARGE Syndrome.

Thanks to Cole's fundraising, a scholarship was created to support Kentucky families attending the 14th International CHARGE Syndrome Foundation conference in Dallas.

To apply, contact shawneherrick@gmail.com | Deadline April 1

If Cole Can Do It, So Can You!

Everything the Foundation does to serve families and individuals living with CHARGE is made possible with your support.

Make a Donation

Become a Member or Start a Fundraising Campaign

Sandra Davenport CHARGE Syndrome Fellows: Reflections from the 2017 Conference

by Meg Hefner

The Sandra Davenport CHARGE Syndrome Fellowship program was established in 2015 as a way for the CHARGE Syndrome Foundation to educate and encourage young professionals who are involved in the world of CHARGE. The Fellowship provides a scholarship for the young professional to attend both Professional Day and the biennial International CHARGE Syndrome Conference. Our hope is that their Fellowship experiences will help them become professionals more expert in CHARGE and encourage them to continue to be involved with CHARGE research and with the Foundation. This is the final installment of Reflections from 2017. Click here for information about past Fellows and applications for the 2019 Fellowship program, click here.

Would you like to be matched with a Fellow in Dallas? Go to page 9 for more information.

Megan Connaughton, Teacher, Perkins School for the Blind

There are times when you experience something that will stick with you for the rest of your life; for me, the 2017 CHARGE Conference was one of those experiences. I was fortunate enough to not only attend my first conference, but to do so as a Sandra Davenport Fellow. As a teacher in the Deafblind Program at Perkins School for the Blind, where I have had the privilege to work with many students with CHARGE over the past few years, I thought I knew what to expect, but I could never have anticipated the incredible experience that was waiting for me. While I knew how passionate and supportive the CHARGE community is, it was amazing to see it first hand, in such great numbers. From the moment I registered in Orlando, I saw individuals with CHARGE and their families embracing around me, like a great family reunion was taking place. Young children in walkers and gait trainers zipped around while teenagers caught up with friends they hadn't seen since the previous conference. It was clear that I was in the midst of an incredible community, and I was lucky to be part of it.

As a teaching assistant and then teacher for eight year at Perkins, I have had the pleasure of working with what I considered to be a diverse group of students with CHARGE, ranging in age from 3-22. About three minutes into the reception the first night, I realized there was an even wider world of CHARGE beyond my experience! I met individuals and their families from around the country and beyond, and heard their stories and experiences. Everyone I met was kind, and happy to chat about everything from their experiences with CHARGE to their plans for the rest of the summer. I loved seeing families look so relaxed, enjoying their time and feeling true belonging with their "extended family."

As a Davenport Fellow, I started by attending Professional Day, which felt a little intimidating. I was pleasantly surprised by how much I understood, while learning new information in many fields. It was a great opportunity to get a "taste" of what was coming in the following days of the conference, and allowed me to attend more sessions than I would have been able to if I had just gone to the main conference.

One of the key "take-aways" for me at Professional Day was seeing the flaws pointed out in the IEPs presented during the IEP process study overview - it made me feel for the families who do not have access to quality IEPs, even after fighting for their child at every step of the process. With all of the other stresses in the lives of these individuals and families, fighting for a quality education should not be one of them. It made me proud to be a teacher to my students, and made me wonder if there is a way experienced teachers could help collaborate with families to provide insight into the process. I was also surprised to learn about the surge in the push for the intervener model to be used.

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Megan with Ethan

EWRAP

Everyone Deserves a Chance to Play

The Ethan Wolfe Recreational Assistance Program (EWRAP) provides grants to assist individuals with CHARGE syndrome to participate in recreational activities.

Learn more about EWRAP

Applications Now Open

The Ethan Wolfe Recreational Assistance Program (EWRAP) has helped dozens of individuals with CHARGE have fun and we're looking forward to helping even more people attend summer camp, ride bikes, trikes & horses, swim, and dance!

Apply by April 1 Click Here

Megan Connaughton

I had not realized how much traction it was gaining in the U.S. In areas where students do not have access to educational specialists in CHARGE or deafblindness, this could be the way to ensure students are accessing the quality education that they deserve.

After easing into the conference at Professional Day, I was eager to start attending the main conference. Each night, I read through the presentation descriptions and carefully picked out a range of sessions to attend. I made sure to branch out of my comfort zone, attending sessions to gain new information, to learn from a different perspective, and in areas I was unfamiliar with. I was surprised how simply being in the sessions seemed to open me up to new ideas for my students back at Perkins. Presenters would say something on their topic that would somehow channel its way to a specific thing I had been stuck on with one of my students, helping me to come up with new plans for the upcoming school year. In fact, scattered throughout my notes from all of the sessions I attended are starred items detailing plans for individual students. It was literally as if attending the conference was "recharging my CHARGE knowledge" and boosting my creativity and problem solving for my classroom.

Of all of the sessions I attended, the one that stands out the most to me was the sibling panel. I was drawn to this session because of my desire to build strong relationships not only with my students with CHARGE, but also with their families. In reading the description of the session, I realized that relationships built between teachers and families at school are between the teacher, student and parents, as opposed to the family as a whole. I was interested to hear firsthand from siblings of individuals with CHARGE, as they are an often underappreciated yet integral part of their sibling's life. Hearing the panel discuss the highs and lows of life with a sibling with CHARGE was extremely real and touching, and it was incredible that they were willing and able to share their experiences. Leaving that session, I started thinking of ways to include siblings more at school, and would love to work with others at Perkins to create a siblings group for students with CHARGE.

> *It was literally as if attending the conference was "recharging my CHARGE knowledge" and boosting my creativity and problem solving for my classroom*

There were many perks to attending the CHARGE Conference as a Davenport Fellow. Being a part of the Fellowship program allowed to me to meet and interact with the other Fellows, which included people in the clinical and research fields that I never would have had the opportunity to meet otherwise as a teacher. It is so easy to get pigeon-holed in your own area, which for me means thinking almost exclusively about the educational implications of working with people with CHARGE. Although I knew there were many other perspectives to consider, I never truly stopped to think about other things happening in the field, and how they were happening, such as researching the CDH7 gene in mice. If I had attended the conference without being a Fellow, I undoubtedly still would have learned a lot, but

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With more than 1000 attendees,
including more than 200 individuals with CHARGE,
the 14th International CHARGE Syndrome Conference
presents a unique opportunity for research.

If you might be in a position to conduct research at the 2019 Conference in Dallas, please submit a draft proposal as soon as possible. Click here.

Megan Connaughton

being able to meet, collaborate and review what we had learned at the end of each day gave me an opportunity to even further expand on what I learned.

Family match and volunteering in Camp

A great aspect of being a Fellow was being matched with a family. I was honored to be matched with Ethan, a four year old from Florida, and his family. Working with preschool-aged students with CHARGE, I was anxious to meet Ethan and get to know him. His family was incredibly supportive, and his mom, Michelle, was extremely welcoming. Chatting with her about Ethan felt so comfortable and natural. Learning that Ethan was able to read familiar things, in spite of not being taught how, directly related to what I am seeing with one of my current students, and I was amazed when his mom told me about it. I was shocked to hear of the issues Ethan's family is experiencing due to lack of state and insurance resources. Things that would be necessary and beneficial to Ethan, such as GI specialists and access to a BCBA, are not covered by insurance. Unfortunately, Ethan was sick and unable to attend camp the day I was volunteering, but I was able to spend time with him and his family during a lunch. I hope to stay in contact with them. Because Ethan was not in Camp, I put my signing skills to use, working with Lorne, a 15-year-old from California. Together we explored the fire truck brought in for campers to experience. Volunteering at camp was definitely one of my favorite parts of being a Fellow - it was a great way for us to meet and work with individuals with CHARGE. The Davenport Fellow Program was an incredible experience, and I would highly recommend it to other teachers working with students with CHARGE.

The 2017 International CHARGE Conference was both everything I hoped it would be and nothing I expected. There was no way I could have prepared myself to be immersed in such an incredible group of people. The lines between family and professionals were blurred, with everyone simply being a member of what is affectionately referred to as "CHARGE Land." I gained not only new information, but new experiences that will influence how I teach current and future students with CHARGE. I hope to gather and eventually present preschool-specific strategies for students with CHARGE, ranging from where to start when they first enter a classroom, to the skills that need to be taught to build a foundation for future learning. I feel incredibly lucky to have been able to attend the conference as a Davenport Fellow, and I am counting the days until the next conference.

Would you like to be matched with a Fellow?

The 14th International CHARGE Syndrome Foundation Conference in Dallas will include the third class of Davenport CHARGE Fellows, our way of encouraging young professionals to become more involved in the CHARGE world. As part of the Fellow experience, we will match each Fellow with a family at conference. This is your chance to get to know a young professional with a growing passion for CHARGE and introduce her or him to your family.

We will be looking for families who:
1) are coming to conference,
2) will have a child in Camp, and
3) want to be matched with a Fellow.

What does this involve?
1) Get in touch by email before conference to introduce your family,
2) Meet up at the opening reception,
3) Eat at least one of the conference meals together, and
4) Generally spend some time together to help your Fellow understand life with a child with CHARGE.

If you are interested in being a Fellow Host Family, watch for more information in the next newsletter and in Conference email Blasts.

Meg Hefner & Pamela Ryan, Davenport Fellow Advisors