



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

PASSION, ENERGY and LOVE filled every moment of our 13th International CHARGE Syndrome Conference. We came together from all over the world. 1,200 people from diverse backgrounds; 100% committed to our friends and loved ones with CHARGE. This was my 8th consecutive conference and yet I am still amazed by what can occur when we Take CHARGE together.

We are so fortunate to have so many professionals who donate their time to CHARGE. Our physicians, therapists, researchers, educators and interpreters make sure all of our attendees receive the most current information about CHARGE. Conference blends the perfect combination of learning, sharing and fun in a whirlwind weekend.

As you read through this fantastic edition of CHARGE Accounts, I am confident you will be ready to Take CHARGE beyond Orlando. I would like to see everyone who wants to attend a conference in Dallas in 2019! In the meantime, please contact us at info@chargesyndrome.org for ways that you can get involved with the Foundation.

David

David Wolfe
 President

A New Friendship

by Molly Roberts

The National Charge Syndrome Conference is our family reunion, and we would not miss the opportunity to connect and learn from other families and professionals. Our experience at this year's conference was unprecedented and the relationships we made impacted us in a fresh new way.

This year we left Christian's siblings at home. We focused on him and made some remarkable memories. Dad, Christian and I boarded a plane, super early in the morning and made our way to Florida. As usual, as we pulled up to the hotel we started recognizing faces and immediately felt at home. Home is not where you are, it is who is there. So, regardless of what state we are in, these incredible, unique, patient, loving individuals create a sense of acceptance and I immediately feel like we belong.

The social opportunity on the first night of conference set the pace for the rest of the weekend. Typically, Christian prefers to stay on his iPad and not socialize; however this night we encouraged him to at least say hi and share his name with his peer group. Quickly he met Andrew, another teenager with CHARGE Syndrome. They had a lot in common – interests in How to Train Your Dragon and iPADS. These two boys sat by each other and communicated through sign and their iPADS until the hotel staff had to close the room. Their interaction was unprecedented and we decided that creating opportunities for their connection to grow would be the focus of our weekend.

The next day Christian attended camp for the morning session, but pretty quickly started asking for his "friend" Andrew. For the rest of the weekend Andrew and Christian sat next to each other in sessions, they signed, shared pictures and messages through texts and watched movies on the iPad. The boys kept each other entertained, laughing out loud



Christian, left, with his friend Andrew.

at their inside jokes. The much anticipated event of the night was Signing Time with Rachel Coleman. The room filled with people, the little ones danced and the big girls sang along. All the while, Andrew and Christian seemed unfazed and engrossed in their own world, but not alone, a world of two boys who completely understood each other. Later that evening moms went out for lady's night, but the real party was in room 608 where the boys kept the connection alive.

As usual, the session content was amazing. The speakers are always top notch and we have come to expect always gleaned new information to bring home to our communities. However, it was Christian's new friendship with Andrew, which was so unexpected and made this year's conference our best one yet.

We left Andrew and his mom with big hugs and the promise to maintain contact. We plan on seeing them at the next family reunion, in our home state of Texas in 2019.

SAVE THE DATE!

14th International CHARGE Syndrome Foundation Conference

WE'LL SEE YOU IN DALLAS!



August 1-4, 2019

A Fun Start to Conference!



“This was our first conference and we were blown away with how organized and positive our experience was. All the volunteers were so friendly and we felt like we were meeting our ‘family’ for the first time.”



So Much to Learn



“We truly enjoyed the entire conference. We appreciated the opportunity to attend because we learned how to better advocate for our daughter, met the most amazing people from around the world, and came back home with numerous take-aways!”



**Couldn't Make It To Orlando?
Wish You Could Have Attended EVERY
Session?
[Conference Handouts Available Here!](#)**



All in Celebration of our Children with CHARGE





Philip Wismer



THANK YOU ...

To our conference sponsors and fundraisers, our amazing interpreters, dedicated volunteers, knowledgeable and inspirational speakers and Buller Photography for capturing so many special moments.

[Click here to see all the conference photos.](#)
Password: charge2017

Thank You Donors!



Diamond Fundraisers - \$10,000+

Bernard, Ben & Elizabeth
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The Second Class of Sandra Davenport Fellows

by Meg Hefner

Another group of Sandra Davenport Fellows has become part of our CHARGE Family! 11 Fellows who were chosen from a wide group of international applicants attended the specialist and founding member of the CHARGE Syndrome Foundation in Orlando. The group included specialists and graduate students in education, behavior, medicine, genetics, research, speech and language, and school psychology. Their interest in CHARGE was as varied as their professional lives and they shared openly, allowing others to appreciate their different perspectives on why they applied to be a Fellow and attend Conference.

Who are Sandra Davenport Fellows?

Dr. Sandra Davenport is a deaf-blind specialist and founding member of the CHARGE Syndrome Foundation. In recognition of her lifelong work, the CHARGE Syndrome Foundation named the Fellowship in her honor. The Fellowship provides a scholarship allowing these young professionals to attend the biennial conference. They are chosen based on specific criteria, including how they are already connected to CHARGE. The hope is that they will become an integral part of the next generation of professionals in CHARGE syndrome. They will go home and use their knowledge and experiences in their chosen fields to assist families, teach other professionals, and influence educational outcomes for individuals with CHARGE syndrome.

What was new this year?

Based on feedback from the first class in 2015, we added a new component to expand their CHARGE experience: Each Fellow was paired with a host family. They met the family, shared a meal with the family, spent their volunteer

time in camp with the child or young adult with CHARGE from their family, and in some cases, even went with their family to Disney World! Several of our 2017 Fellows who did research had never before met a person with CHARGE syndrome, and the family connection was an unexpected high point for them.

How did the Davenport Fellows find their CHARGE family?

Meg Hefner and Pam Ryan, the Fellowship mentors, “put out a call” to our CHARGE families asking if they would like to “host” a Fellow, including a short bio of each Fellow in the Spring 2017 CHARGE Accounts newsletter. What did “host” mean? It meant that they would be willing to share at least one meal with their Fellow and share the ups and downs and insight as to what life was like for them in their CHARGE world. “Hosting” only meant giving time and sharing their family; the Foundation financially supports the Fellows. If you might be interested in hosting your own Fellow in Dallas, watch for information in early 2019.

continued on next page



2017 Sandra Davenport Fellows, in glasses used for deaf-blind simulation. Front row left to right: Bree Kaufman, Hui Yao, Lauren Fogarty, Chathuri Illapperuma, Megan Connaughton, Pam Ryan. Back row left to right: Meg Hefner, Kareem Tawfik, Emily Fassi, Charlotte Reimer, Dieuwierke Dijk, Alex Donovan, Zachary Bird.

Davenport Fellows

What else did they do?

In addition to their Fellows meetings, time with their host families, volunteering in camp and attending sessions, many of the Fellows were actively involved in other parts of the weekend. Some had presentations at Professional Day or the International Conference, some had posters in Information Central and some were doing CHARGE research at conference!

So, how did it all go?

See the articles in this issue by Emily Fassi and Chathuri Illaperuma about their experiences and watch for more in future issues of CHARGE Accounts.

A brief update on the nine 2015 Davenport Fellows:

Five have had their CHARGE research published and three presented at the 2017 conference.

Emily Fassi

After attending my first CHARGE Syndrome Conference in 2013, I knew that I would be back. I feel fortunate to have had the opportunity to attend the 2017 conference as a Davenport Fellow because it made the whole experience so much richer.

PROFESSIONAL DAY

The conference started out with Professional Day. I appreciated the fact that presenters came from so many different places to share their research with us. One of my favorite parts of professional day was watching the sign language interpreters try to interpret the complex scientific presentations (especially when the presenter spoke at a fast pace). I do not envy them, for that is a very difficult job!

I also had the opportunity to present my own research at the poster session. This was actually my favorite part of Professional Day as I had the opportunity to meet, connect, and share my research with other professionals (and families). I made a connection with another researcher who may be interested in using our data to study milestones in more detail. I was also able to connect with a psychology graduate student who is interested in pursuing a career in genetic counseling, and hopefully I was able to give her at least some helpful information!

I had multiple families come up to me and offer insight into my research question which was extremely helpful. I will definitely take into account their comments when considering developmental milestones in CHARGE syndrome. For instance, one mother emphasized how the developmental



milestones in CHARGE syndrome do not always occur in the typical order that is usually the case for other children. This was something that was suggested in our data, but it was interesting to hear it from a parent. A comment from a different parent was the fact that a lot of times in children with CHARGE syndrome, they may gain a particular skill one day (such as being able to sit alone) and then that same skill may not show up until weeks or months later. This makes it difficult to say exactly at what age someone with CHARGE syndrome achieved a particular milestone - more difficult than in children without CHARGE syndrome.

FULL CONFERENCE

Having already attended a previous conference, I thought that the full conference would be less overwhelming than it was my first year; it was not. Well, maybe it was a bit less overwhelming but it was not any less exciting. Seeing all of the families with their children was really what I had been waiting for. One of my goals for this conference was to ask specific questions to families and connect more with

continued on page 10

Davenport Fellows

Chathuri Illapperuma

If I could express my thoughts and feelings about the conference in a song, I'd choose "What a Wonderful World" by Louis Armstrong. I hope this song plays at the back of your head as you read what I am about to tell you.

Picture a wonderful conference; a whole separate world you cannot imagine unless you have attended a previous CHARGE conference. It is a world with laughter, happy tears, precious memories, priceless moments, major achievements, and determination to survive, all made possible by our children with CHARGE and people who truly care for them. It is a place where the first step, the first swallow, the first smile, the first cry, first word, and even a first dance is celebrated and cheered! Let me tell you about this wonderful world that came to life for me for four days in Florida in the summer of 2017!

It felt like being a part of a bigger family although the presence of professionals partly added an official feel to it. Their work on Professional Day showcased results of years or months of work, educated other professionals, and helped translate research findings into practice. This day helped me find other professionals with similar interests and learn about each other to build future collaborations. Given the entire relaxed and cohesive atmosphere at the conference, none of the presenters appeared nervous. Compared to other professional conferences I have been too, at this conference I felt at home.

My particular CHARGE interest revolves around sexuality education and curriculum development. This is a topic that is unaddressed and overlooked. We presented a poster about this topic. One parent who stopped by our poster at Information Central poured her heart out to us for 30 minutes. Our topic was her family's current biggest concern for her child with CHARGE. Let me tell you, I learned more in these 30 minutes than I would have reading a text book. These situations are real.

The CHARGE Syndrome Foundation has come a long way since 1993! The positive impact it has had on the lives of individuals with CHARGE and their families is immense and mainly due to the tremendous collaborations of the stakeholders of



the organization. Some of those names that will always be in my head are Pam [Ryan], Meg [Hefner], Brownie [Shott], and Lisa [Weir]. These four ladies have worked day and night to bring this event to life! Oh, I must mention, they will also fill your inbox, and that's how you can tell they are getting super excited as the days to the convention gets closer. Another very kind lady, whose name is now engraved in my mind, is Dr. Sandra Davenport, the namesake of the Fellowship that made my first CHARGE conference possible. Being a Fellow made my first conference experience a unique and exceptional one! Apart from the financial assistance that accompanies the Fellowship, the learning experience was immeasurable. At one of our daily Fellow meetings, I was able to experience what it is like to have impaired vision and hearing, through the deafblind simulation activity. It was not the best feeling. At these meetings we also had the opportunity to each talk about how our day went, things we learned, and get mini lessons on aspects of CHARGE. We shared experiences about our host families: which child with CHARGE was being silly or who had a tantrum as well as their interests and strengths. Pam, Meg, and Dr. Davenport are great mentors and very humble people too!

Two other unique experiences we did were volunteering in Camp and pairing up with a family. Camp gives children opportunities to show off their skills, build friendships, and be entertained by magic shows and street dancing performances! Somewhere in Louis Armstrong's song, he mentions "They'll learn much more, than I'll never know" and this is very true! Their determination is beyond words!

continued on page 11

Emily Fassi

continued from page 8

families throughout the conference, and I definitely did this. I spoke to one parent about the pressure to be a successful mother and how difficult that can be when your child has so many medical/developmental needs. I spoke to another family about how their daughter was diagnosed with CHARGE syndrome and how the genetic counselor handled the “abortion discussion” during pregnancy - whether the mother wanted to continue the pregnancy or not. This was a good reminder to me to always first assess where your patient is coming from before trying to present them with particular options, otherwise what you say might come off in the wrong way. These are just a couple of the many enlightening discussions I had with families at the conference.

HOST FAMILY

I could not have picked a better family to be matched with than Cynthia and Brady! Brady is a 10-year-old boy who loves sports, especially soccer and baseball. He performs really well in school and has many friends. I asked him his favorite color and he denied having one (but his hearing aids and his outfit were all blue, so I suspect that might be at least one of his favorites). I accompanied Brady to camp, which was a bit overwhelming for him, but he was a good sport. I was also able to observe him participating in a research study. He impressed me throughout the conference with his mature attitude. Meeting Brady and his mother was definitely one of my favorite parts of the conference. One of the most intriguing parts was the fact that neither Brady nor his mother have a *CHD7* mutation identified, despite their clinical diagnosis of CHARGE syndrome. Obviously as a genetic counselor this is interesting to me and, given the fact that Brady has a somewhat atypical presentation, makes me wonder what the molecular cause of his condition is.

Although I could have developed a relationship with

them without the help of the Fellows program, having a structured program really helped me feel comfortable because I knew they were open to questions and willing to share information and experiences with me.

FELLOWS

Meeting and interacting with the other Fellows was one of the best parts of the conference. This was a critical piece to me and the conference experience/depth simply would not have been the same without the Fellows program. It automatically gave us a group of people that we knew and could connect with. I loved how everyone came from different perspectives and saw things in different ways. The Fellows meetings were a great opportunity for all of us to really think through our experiences at the conference and share them with others. Pam, Meg, and Sandy were all great mentors and brought different aspects to the leadership. Sandy has vast experience and knowledge of CHARGE syndrome from a developmental perspective. Pam really helped emphasize the educational piece and the importance of recognizing deafblindness. Meg's connection to so many families was inspiring and she was able to help us think of ways to put all of the pieces of the conference together, to make sure we were observing and noting things (such as child behavior, etc.), and to help us really fully embrace the conference for everything that it is.

Doing the deafblind simulation with the other Fellows was extremely helpful. This was honestly a game changer for me since I had never done this simulation before. It really helped me to recognize how difficult it is to communicate with others with dual sensory impairment.

CONCLUSIONS

What did I learn from this experience? More than anything, I learned how critical much they rely on this from other families. Therapists and support people (interveners,



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Emily Fassi

etc.) are making the day-to-day difference in these children's lives. However, I believe genetic counselors have an important role as well. From talking with families, one thing that kept coming up over and over again was how much of a shock it was to have the initial diagnosis of CHARGE syndrome after their baby was born (for those who received the diagnosis when their child was in infancy). For others, it was a long road to the diagnosis. Either way, families mentioned appreciating having someone there to help guide them through the process since it can be so overwhelming and hard to digest. Pediatric (and, increasingly, prenatal) genetic counselors have a role here to really be a support person through this process and identify themselves as such to families. Then, families may feel less overwhelmed or at least have someone to direct their questions and concerns to. My experience at the conference guided my discussion of deafblindness and its impact on sensory deficits at the National Society of Genetic Counselors annual conference. *[Ed note: see article at right.]*

I would like to thank the CHARGE Syndrome Foundation for the opportunity to be a Davenport Fellow.

Chathuri Illapperuma

continued from page 9

As this song comes to an end, I would like to thank each and every one at the CHARGE Syndrome Foundation, Meg, Pam, Dr. Davenport, and my advisor, Dr. Kasee Stratton for believing in me. This is only the beginning of my CHARGE journey and my intentions are global!

Deafblindness Workshop at the National Society of Genetic Counselors' (NSGC) Annual Conference

by Emily Fassi

I had the great pleasure of attending the CHARGE Syndrome Conference this past summer as a Davenport Fellow. After experiencing such a great conference, I was excited to head off to Columbus, Ohio in September to conduct a workshop on deafblindness and sensory deficits at the National Society of Genetic Counselors' (NSGC) Annual Conference.



In addition to myself, the team involved in creating and conducting this workshop were Meg Hefner (genetic counselor), Susan Wiley (developmental pediatrician at the CHARGE clinic at Cincinnati Children's), Leanne Parnell (educational specialist with the Ohio Center for Deafblind Education), and a couple of parents of children with CHARGE syndrome (Sally Strange and Jennifer Kile).

We focused on CHARGE syndrome during the workshop because it is such a great example of a genetic condition that can cause deafblindness (although there are many others!). Our audience consisted of about 50 to 100 genetic counselors who work in a variety of settings. Many of these genetic counselors work with children, but others work with adults, including pregnant women who may be at risk for having a child with sensory deficits.

During the workshop, we discussed CHARGE syndrome, deafblindness, the basis of various sensory deficits and how they can affect development, and how to refer children and families to state deafblind projects. Sally and Jennifer shared the stories of how their children were diagnosed with CHARGE syndrome and the types of services that have been most helpful to them. They also provided some suggestions as to how genetic counselors can help families after a diagnosis of CHARGE syndrome is made.

We also performed a deafblind simulation where participants were provided with smudged glasses and earplugs to simulate what it is like to have low vision and hearing. All of the participants walked around and tried to communicate and socialize with each other. One of the goals of the workshop was to try to help genetic counselors have a better understanding of deafblindness and the tools available to help encourage learning and success. However, we also tried to provide information in order to describe how, for someone with CHARGE syndrome, having issues with vision and/or hearing are just normal parts of life for many individuals, and not necessarily something to fear.

The workshop was very well received. Afterward, Meg and I heard from multiple genetic counselors about how helpful it was to have a session like this at the annual conference. Most genetic counselors do not get much education surrounding deafblindness or other sensory deficits. We are grateful to the families who participated in this workshop and helped educate genetic counselors about CHARGE syndrome!

Focus on Fundraising

9th Annual Joshua Kurby Charge for CHARGE 5K

We had a successful race this year, with about 60 walkers and runners. Our Kids Dash was two groups - a longer run for the bigger kids, and a shorter dash for the littler ones. It was great weather, a wonderful day and we raised over \$2,500 for the Foundation in memory of Joshua.



JACOB CAN FOR CHARGE



For the past two years, Jake has been soliciting donations through his Facebook Page, "Jacob Can for CHARGE." This is one of three jobs that Jacob has each week.

In Michigan, soda, water, and alcoholic beverages have a 10-cent deposit per container. When the containers are returned to the machines at the store, the money is returned to the purchaser. Many people find this need to return cans no more than an annoyance and will readily give them to fundraisers.

Every week of the year, Jake returns at least six full bags to the machine (3 times per week). He is nearly independent at doing this, from carrying the bags to placing each container into the machine; from taking the slip from the machine to walking to the self-checkout, from inserting the slip into the register to gathering the returned coins and cash.

In two years, Jake has collected, can by can, ten cents at a time, \$477.51 for the CHARGE Syndrome Foundation. The money is designated for new family scholarships to the conferences.



All You Have To Do Is Ask!

Deanna Steinhauser took to the podium during our Orlando conference to share how she raised \$12,000 in three days and to challenge us to raise \$12,000 in three minutes.

Thanks to the generosity of our conference attendees, we more than met the challenge, raising \$23,000 - which was later matched by several anonymous donors - for conferences, research and future Foundation activities.

Charity Walk

My wife and I have been Foundation members since our daughter Amanda was diagnosed with CHARGE in 2009. To cut to the chase, my employer sponsors a charity walk every May and two charities are selected based on the submission of employees. CHARGE was selected this year! Our team walked a total of 344 miles during the month of May and raised \$1,890.

—Steve Opelski

Focus on Fundraising

SPIKE for CHARGE

College student Josh Sirota hosted his second “Spike for CHARGE” fundraiser in August. Josh partnered with Spikeball, which sponsored and publicized the event and provided the equipment and prizes. Several nationally ranked teams in this relatively new sport - a combination of handball and volleyball - participated alongside friends and the Sirota family. Local businesses also supported the fundraiser, with Bea’s Cakes collecting \$400 in donations as well as donating treats for the event

Josh's primary motivation wasn't primarily financial - it was to raise awareness of CHARGE syndrome in order to make the world a better place for his brother David, who has CHARGE. He succeeded on both fronts: over 1,000 social media shares as well as over \$2,600 in donations.

Josh hopes that everyone will take the initiative and do something. The only people who can make a difference is us!



**Start your
Charge it for CHARGE
fundraiser today!**

Complete details are on our website

10th Annual
Charge It for CHARGE
Join Today!

Every dollar raised helps us provide support, information and scholarships to our families.

- Help a family attend our 2019 conference.
- Fund research into the treatment and causes of CHARGE syndrome.
- Provide resource material, information and support to families.
- Give an individual with CHARGE a chance to participate in recreational activities.

Our shared vision to make the world a better place for people with CHARGE syndrome can be achieved if we all work together!

The Importance of Movement for Individuals with CHARGE Syndrome

Enhancing Movement Opportunities In Your Home

By Dr. Beth Foster

Movement production emerges from a constant interaction of the individual, the environment, and the task. Movement also relies on the interconnectedness of perception, action, and cognition to initiate behavior change, which is impacted by the factors (i.e., constraints) related to the individual, the environment, and the task, that can either promote or delay movements.

In addition, the physical and social environment influences the development of new movement behaviors. All systems interact together for new movement patterns to emerge. New movement patterns only become preferred patterns under certain conditions. These preferred patterns of movements typically use the least amount of energy and, therefore, may lead to atypical or inefficient patterns at first. The emergence of movement patterns is developed by individual constraints based on the maturation of the central nervous system, development of posture, balance, muscular strength and endurance, and the ability to process sensory information. The arrangement of a movement pattern is then the result of the constraints provided at a specific moment in time, within a specific situation or environment.

How can we manipulate the task and environment to increase movement opportunities?

Movement Task



- Provide opportunities for practice
- Utilize assistive equipment (i.e., sofa, chair, walker, push cart, gait trainer)
- Teach your child, when they fall, to fall correctly by protecting their body
- Make sure your child feels comfortable and safe
- Increase their confidence with positive reinforcers (i.e., use a preferred task or object like an iPad as a reward for performing a new task)
- Utilize any residual vision or hearing by placing motivating objects within the area to encourage your child to move to that object
- Increase muscle tone by performing the task for a longer

period of time (i.e., if your child can stand for 7 seconds, try to increase standing for 9 seconds) or increase more repetitions within the same time frame (i.e., stand for 10 secs, four times a day; then the following week try for five times a day)

Environment

- Use open flat surfaces to increase movement success when trying new skills
- Provide cushion mats or pillows to assist in falling safely
- Move furniture for your child to use as assistance when walking or transitioning from sitting/ kneeling to standing
- Support your child's hips to assist with balance during movements
- Once a child can stand, move all preferred objects (i.e., toys, balls, iPads) to tables and couches to promote an upright stance

continued on page 15

Enhancing Movement Opportunities In Your Home



If a child does not have the stability to walk independently (i.e., balance, muscular strength), the body will self-organize to a movement pattern with a more stable attractor state (e.g., scooting). Attractors are preferred states of stability and confidence within movement patterns. When a change in constraints is imposed on an individual, its stability is endangered and a new form is established. The attractor states occur in a similar pattern to basins; where deep attractor basins are much more stable and are difficult to change, compared to shallow attractor basins, which are

more susceptible to change. Therefore, motor development delay can occur when a child is not able to shift into a new movement pattern and maintain stability in a desirable attractor state. Providing opportunities at home to practice movement patterns will increase your child's motor confidence and competence. With practice and positive feedback a new motor pattern may emerge, gaining stability and development into a deep attractor basin. So, LET'S GET MOVING!!

Dr. Beth Foster, CAPE is an Assistant Professor in Adapted Physical Education, Department of Kinesiology and Health Promotion at California State Polytechnic University, Pomona.

[Click here to read this article with academic references.](#)

Spanish-speaking Conference Calls for Families

Servicios de Sordociegos de California estará re-anudando sus llamadas mensuales, dirigidas a familias de habla Hispana que tengan hijos con sordoceguera.

Únase para estas teleconferencias de 90 minutos, con el motivo de ayudar a proveer información y apoyo a las familias, se llevarán a cabo cada **3er Martes de el mes a las 6PM tiempo del Pacifico / 9PM Tiempo del Este** (excepto cuando se indique diferente).

Marque su calendario con las siguientes fechas:

- Noviembre 21, 2017: IEP (Programa Educativo Individualizado)
- Diciembre 19, 2017: Actividades en la Casa (Invitado especial)
- Enero 23, 2018: Comunicación y comportamiento
- Febrero 20, 2018: Duelo y como lidiar con el
- Marzo 20, 2018: Autoayuda

Para registrarse para las llamadas y obtener la información para acceder la llamada, porfavor de comunicarse con La Coordinadora de Familias de los Servicios de Sordociegos de California: Myrna Medina por email o por teléfono a:
myrnam@sfsu.edu / tel 323-363-7499

WE NEED YOUR CONTRIBUTIONS
FOR THE NEXT ISSUE OF

CHARGE Accounts

Share your knowledge

Share your events

Share your successes

**Contact joanne@chargesyndrome.org
for deadlines and additional information**

Show Your Support!

If you share our vision of a better world
for people with CHARGE syndrome,
join or renew your membership today.



Your membership is a vote in
support of our vision!

\$30 per year

Lifetime memberships also available

Research Update

by Meg Hefner



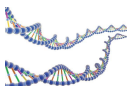



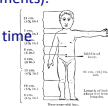












The biennial International CHARGE Syndrome Conference is the largest gathering of CHARGE professionals, individuals with CHARGE and families in the world. This provides a unique opportunity for both those doing research and potential research participants. We do our best to facilitate CHARGE research at conference – by encouraging researchers to come to conference, notifying conference registrants about what projects will be enrolling at conference and encouraging lots and lots of participation. We have been very pleased with participation at both the Researcher and Family levels.

In 2017, there were nine research projects enrolling participants during the conference, as you can see on the poster. There were a wide range of studies – everything from long interviews about social skills and short questionnaires about gut issues or x-rays, to photos to use for measuring growth or for better understanding the facial features of CHARGE, to running an obstacle course to evaluate motor skills or spitting in a tube for DNA analysis. A total of over 220 people participated in the nine studies! Thank you all very much – and watch for data from these studies at future conferences

Update from 2015: There were 11 projects which enrolled about more than 300 total participants at conference. Data or information from six of those projects was presented at the 2017 conference. Five of the projects have published their findings and several more are preparing to publish or use information collected in other professional venues.



13th International CHARGE Syndrome Conference Research at Conference

Introduction	Social Skills in CHARGE	DNA Studies
<p>The International Conference is the largest gathering in the world of families and individuals with CHARGE syndrome and of CHARGE professionals. This creates a unique opportunity for CHARGE research. Check out all these CHARGE research projects and participate in as many as you can.</p> <p>Unless otherwise noted, Research will be</p> <p>Panzacola F1/F2 (Information Central) on Friday</p> <p>Hall tables near the dining area on Saturday.</p> <p>More detailed information is at the Research Table (near Registration/Sales). You can also contact the researchers.</p> <p>Watch for Buttons about their projects on many researchers</p>	<p>Who: children 8-18 and their parents (& teachers if available)</p> <p>What: questionnaires to fill out (answer questions on a rating scale) about social skills and situations</p> <p>How Long: about 20 minutes</p> <p>Appointments needed</p> <p>To set up a time, call/text Researcher:</p> <p>Lori Swanson 715-441-4897</p> 	<p>Who: anyone with features of CHARGE, their parents & siblings are invited to participate</p> <p>What: answer some questions and provide saliva samples for DNA extraction to look for other causes of CHARGE and genes that influence features</p> <p>How Long: 20-30 minutes – <i>walk ups welcome</i></p> <p>Researchers:</p> <p>Stephanie Bielas 858-525-1757</p> <p>Amanda Moccia 248-470-1634</p> <p>Donna Martin 734-645-3564</p>   
<p>Growth Proportions in CHARGE</p> <p>Who: Any child with CHARGE who can stand upright</p> <p>What: Have two photographs taken (in undergarments).</p> <p>Sign up for a time slot at Research Table</p> <p>Where: Hospitality Suite 1602 at your scheduled time</p> <p>How Long: walk across Lobby to Suite then 15 minutes</p> <p>Researchers:</p> <p>Dieuwierke Dijk</p> <p>Conny van Ravenswaaij</p>   	<p>What imaging has been done</p> <p>Who: parents of individual with CHARGE up to 30 years old</p> <p>What: questionnaire about what imaging studies (X-ray/CT/MRI) have been done through your child's life</p> <p>How long: about 20 minutes – <i>walk ups welcome</i></p> <p>Researchers:</p> <p>Lauren Fogarty 902-229-6267</p> <p>Kim Blake 902-488-0128</p>   	<p>GI and Feeding Issues –what do you do?</p> <p>Who: parents of individuals with CHARGE (any age)</p> <p>What: questionnaire covering GI/feeding issues and treatments tried (meds, surgery, behavior) – what worked, what didn't</p> <p>How long: 10 minutes – <i>walk ups welcome</i></p> <p>Researchers:</p> <p>Alex Hudson 902-877-8727</p> <p>Kim Blake 902-488-0128</p>   
<p>Motor Skills & Balance in CHARGE</p> <p>Who: children 6-14 who can walk (with or without aids)</p> <p>What: questionnaire for parent, child will be observed performing motor tasks (run, jump, etc)</p> <p>Where: Info Central area (Friday), TBA Sat & Sun</p> <p>When: Fri/Sat/Sun mornings</p> <p>Appointments (some walk up may be possible)</p> <p>How Long: 30 minutes</p> <p>For appointments, contact researcher by phone/text</p> <p>Pam Haibach 814-883-4439</p> <p>Lauren Lieberman 585-943-2829</p>   	<p>3D photo taken</p> <p>Who: anyone with CHARGE (even if you did this at the last conference –updates welcome)</p> <p>What: answer a few questions, then have a 3D photo taken</p> <p>Where: Research area – <i>walk ups welcome</i></p> <p>How long: 10-15 minutes</p> <p>Find our table or call/text</p> <p>Researchers:</p> <p>Pedro Sanchez</p> <p>Annie Pham 470-236-2911</p>   	<p>CHARGE Family Demographics</p> <p>Who: parent/guardian</p> <p>What: questionnaire about demographics, family composition</p> <p>How long: 15-20 minutes – <i>walk ups welcome</i></p> <p>Researcher:</p> <p>Madison Sully 704-516-2640</p> 