



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

Leaving conference is always a bittersweet experience. I was filled with so many different emotions. How can one be so energized and excited for the future, yet so physically and emotionally exhausted at the same time? I was thrilled to see so many families and professionals learning, sharing and playing together. Yet, it is always hard to say good bye to my old and new friends. THANK YOU one last time to all our attendees, sponsors, advisors, interpreters, fundraisers, volunteers, donors, exhibitors, Board members and especially Lisa, Brownie, Neal and Jody for showing us that the "Sky's the Limit."

As we move forward this year and next, I hope all of you will adopt the "No Limits" philosophy that was so evident at conference. Together, we can accomplish so much. What can you do? Contact me about volunteering, join our [Eighth Annual Charge it For CHARGE campaign](#), become a member, host a fundraising event, participate in research projects and so much more. Please join me as we all strive to make the world a better place of all individuals with CHARGE.

Enjoy the newsletter.

David

David Wolfe
President



The CHARGE Syndrome Foundation, Inc.

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Conference is for families



A Weekend Oasis ... every two years

By Kevin Troupe

Where would you go to find kids randomly laying on the floor, suction machines and vents whirring in the distance, chewy tubes in all colors, feeding tubes and pumps, walkers, hearing aids, interpreters and every imaginable kind of wheelchair...a hospital? No, a weekend oasis where all of the above and more is the norm. Welcome to the 12th Bi-Annual International CHARGE Syndrome Conference. 1,200 people consisting of individuals with CHARGE, families, caregivers and professionals spending four days of fun, education and relaxation. A time to reconnect with old friends, finally meet face-to-face with "cyber" friends and a time to make new friends, all while learning more about this rare genetic disorder that has so profoundly impacted all of our lives.

The CHARGE Conference is not about professionals talking AT you...it is about professionals who care so deeply that many of them have devoted their entire careers to study, observe and wrap their entire lives around our kids, teens and grown-ups who have been impacted by CHARGE Syndrome. It is not uncommon to see these professionals rolling on the floor with our kids, eating meals and spending most, if not all of their free time at Conference with the families, collecting data for research from their hotel rooms and answering questions about "how-to's" and "what-to's" pertaining to our kids into the wee hours of the mornings.



Speaking as a parent, the time spent at Conference is a brief moment in our lives where we don't have to explain, make excuses or apologize on behalf of our kids. A kid having meltdown? No problem, we understand. Someone pooped in the pool? No problem, it could have been my kid...just wait for the "all clear." Waiting 15-20 minutes for an elevator because most of the people there cannot use the stairs or escalator? Again, not a problem...just more time to chat with other attendees. I recall sitting with another dad who was holding his daughter in the hot tub while she lapped up the saltwater as I was trying to keep Matthew from shedding his swimsuit. Our conversation never stopped nor broke stride. It was "normal" and it was okay. 20 blenders all lined up on a table in the dining hall? No, not a margarita party...many of our kids are on a blenderized diet and need a little help making their food easier to swallow or put through a feeding tube. A diaper flying through the air...that was Matthew...normal.

An oasis for sure. It has been six long years since we have been able to attend this life giving, refreshing event held every two years. The last one Isaac was a little to fragile to travel. The one before that...we just couldn't afford to go. In fact, many of those who come from around the globe can't afford to go...but they make it work. Many receive help to pay for their rooms, some get help with travel others get help to cover conference registration. We have a wonderful CHARGE Syndrome Foundation that is run completely by volunteers. Only one part time employee is a paid position and helps with the office stuff...but the rest of it is all done by people who have been impacted by CHARGE Syndrome. Some have even had to say goodbye for now to their CHARGE child and while they wait to see them again in heaven... they work tirelessly to make the research, the studies, and the grants to fund new doctors who are passionate to continue working to make the lives of those impacted by CHARGE Syndrome more understandable and meaningful. They work tirelessly to connect people with resources we need to raise these great kids who happen to have some unique needs.

Read Kevin's blog for more: <http://lessonsfrommatthew.com/2015/08/16/a-weekend-oasis-every-two-years/>



Read more from families on pages 11 & 12

Conference is for inspiration



From Gold Medal Moments to Challenging Your Limits!

The 12th International CHARGE Syndrome Conference started off with a bang – or more accurately, a beat. Drumming Around engaged and entertained kids and adults alike with a drum circle at Thursday night's reception. (Special thanks to the Texas Chargers for helping to make this possible.)

Some other conference highlights:

Marla Runyan (right), Olympic and Paralympic athlete, spoke about celebrating the gold medal moments in our lives and our kids' lives.

Camp was full of activities for your young attendees, including a petting zoo, magic show, Home Depot craft, a fire truck visit and an encore of Drumming Around.

CHARGE A Palooza – carnival games, dancing, basket raffle, face painting – fun for all!



Individuals with CHARGE of all ages and communication methods introduced speakers during breakout sessions

Our CHARGE Idol performers once again dazzled us with their talents

Our adult panel (below) – Dylan Lauger (front), Shannon Boelter, Meri Dwyer and Belinda Arnell – shared their experiences and provided insights into their lives. Read their speeches [here](#).

Finally, parents, professionals and a young lady with CHARGE syndrome closed the conference by sharing their passions, what keeps them and their families going despite the challenges of CHARGE syndrome.

Don't put limits on yourselves or on your kids. You never know what they will one day achieve ... Don't limit your challenges, challenge your limits.

—Belinda Arnell



Conference is for reflection



We welcomed the founders of the **CHARGE Syndrome** foundation to Chicago. Jim Thelin, Sandra Davenport, Marion Norbury, and Meg Hefner (front row, left to right) started it all with the first conference in St. Louis in 1993. Their vision and commitment to individuals with **CHARGE** syndrome set the tone for all the family-focused conferences that followed.

Look How We've Grown!

St. Louis (1993) - 200
Portland (1995) - 250
Boston (1997) - 400
Houston (1999) - 450
Indianapolis (2001) - 500
Cleveland (2003) - 492
Miami (2005) - 540
Costa Mesa (2007) - 625
Bloomingdale (2009) - 756
Orlando (2011) - 850
Scottsdale (2013) - 925
Schaumburg (2015) - 1213

There were 38 states and 11 countries represented, including:

567 First Time Attendees
233 with CHARGE syndrome
432 parents - 89 grandparents
223 professionals - 160 siblings



2017 Conference Orlando Florida

We're returning to the
Rosen Shingle Creek Hotel
for the
**13th International
CHARGE Syndrome Conference**
July 27-30, 2017.

Save the dates and start planning now!

More conference details, as well as online registration,
will be available at:

<http://chargesyndrome.org/conference-2017.asp>



Conference is for recognition

Every two years at conference, the Foundation recognizes those individuals, couples, groups, or organizations who have made significant contributions in any of the following areas:

- ♦ To the Foundation and its work with service or financial support
- ♦ To persons with **CHARGE** or their families or
- ♦ To the understanding, management, and treatment of **CHARGE** syndrome

The **Stars-in-CHARGE Award** is the Foundation's highest award, which is given for significant contributions over a period of time. The award is a crystal star with the Foundation logo and the name of the recipient. Stars were awarded to *Conny van Ravenswaaij-Arts* and *Joe and Kathy McNulty*.

The **CHARGE Recognition Award** is given by the Foundation for a very significant contribution in any of the three areas listed above. The award is a plaque with the Foundation logo and the name of the recipient(s) engraved on the plaque. These were awarded to: Donna Martin, Kasee Stratton Gadke (with David Wolfe and Lisa Weir) and Deanna Steinhauser (left to right, below).

Fundraising Recognition Awards were given to the families and groups that raised \$3,000 or more (right). A [list of fundraisers](#) can be found on the CHARGE Syndrome Foundation website.



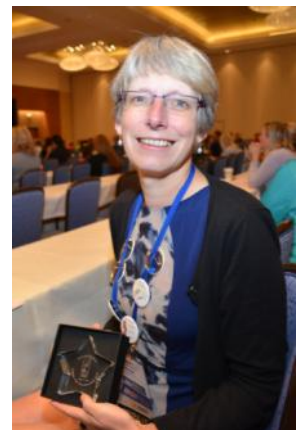
A Star in CHARGE:

Dr. Conny van Ravenswaaij-Arts

introduced by Meg Hefner

In the summer, of 2004, just as I was preparing to leave on vacation with my family, I received an email from someone in the Netherlands whom I did not know. The sender wrote, "We have found the CHARGE gene. We cannot tell you any details until it is published, but we wanted you and Marion [Norbury] to be the first to know." Little did I know that this would be the start of a both a wonderful friendship and a long-term relationship with the CHARGE Syndrome Foundation. The following summer, Conny came to the 2005 conference in Miami and told the families about her team's successful search for the CHARGE gene. Like so many others, once she came to conference, she was hooked. She has been coming to conference ever since, each time bringing more members of her growing team.

Conny's contributions to the world of CHARGE include identifying CHD7 as the CHARGE gene, establishing a web-based database of CHD7 mutations (which is openly available - www.chd7.org), coming to every conference since 2005 to present the very latest clinical and genetic information to both families and professionals in ways we can all understand, mentoring many young doctors in both clinical and research aspects of CHARGE, starting a multidisciplinary clinic for CHARGE syndrome which is recognized throughout Europe and where more than 100 children with CHARGE are now followed (<http://www.rug.nl/research/genetics/research/chargesyndrome/charge-clinic>). She is also really tall.



Stars in CHARGE:

Joe and Kathy McNulty

introduced by Sheri Stanger

Kathy and Joe McNulty—the dynamic duo in the field of deaf-blindness. They have devoted a majority of their careers in deaf-blindness to advocacy and developing, supporting, training and nurturing family organizations and leaders. Joe, as the Director of the Helen Keller National Center (HKNC), offered the CHARGE Syndrome Foundation shelter about 7 years ago when we were looking for new office space. Kathy became an advisor to the board in 2007 after attending CHARGE conferences and facilitating a few board meetings. As an advisor she attended board meetings and helped on numerous projects, offering her unique organizational skills to action planning. Without Joe and Kathy's support, I don't think the Foundation would be where it is today. They helped to nurture the connection of the CHARGE Foundation with the

greater deaf-blind community opening doors for future collaboration and educational research. Joe was a staunch advocate for deaf-blind children and adult services that directly impact our population and was a well known voice on the "hill" in Washington DC. Kathy, in her role as Coordinator of Family Technical Assistance and Outreach for NCDB (National Center on Deaf-Blindness) had access to the national deaf-blind network and brought network resources to the attention of the board and made the network aware of what the CHARGE community had to offer. Both Kathy and Joe believed in partnering with family leaders to affect change and listened carefully to our needs and took action. I can't think of two more devoted professionals in this field and believe them to be deserving of this prestigious award.

Unfortunately, they could not be in Chicago to accept this award in person, but I know that they would be honored to receive it from the Foundation. And if you know Kathy and Joe, they would be very humble about it too.



Everyone Deserves a Chance to Play

Congratulations to the 8 recipients of the 1st Annual Ethan Wolfe Recreational Assistance Program (EWRAP)

EWRAP was created and funded through generous gifts from The Wolfe family and friends in memory of Ethan Wolfe. The program provides families funding in order to participate in recreational programs or purchase recreational equipment. This year's recipients are:

Cody, Samuel, Antonio, and Jon - adaptive bikes
Hannah - gymnastic classes
Landon - swimming lessons
Mark - summer camp
Ryder - hippotherapy

*Applications will be available for the 2nd Annual EWRAP toward the end of 2015/beginning of 2016.
Stay tuned for email announcements.*



Conference is for shining stars



★ ★ 4TH ANNUAL CHARGE IDOL ★ ★



S
T
A
R
S



★ TOP: Stephanie Petock ★ Kimberly Swanson ★ Heather Ritchie ★ Alivia and Alaina Roth ★
★ LEFT: Felix Andersen ★ RIGHT: Aman, Anmol and Rynah Meta ★ BOTTOM: Kristen Ogan ★
★ Megan Stanger ★ Meredith Dwyer ★ Mackenzie Colp ★



Congratulations Magician Felix, grand prize winner, stage performers!



More Idol SUPERSTARS

LEFT

- ★ Destiny Chinnichi ★
- ★ Garland Goodwin ★
- ★ Melanie Reed ★
- ★ Aubrey Williams ★
- ★ Lavina Sergi ★

CENTER

- ★ Aubrie Westmaas ★
- ★ Amrita Srinivasan ★

RIGHT

- ★ Penina Simon ★
- ★ Kylie and Dominic Steinauser ★
- ★ Brandon Reid-Marshall ★
- ★ Samsun and Jonah Van Spronsen ★



*Funny and
heart warming.*

-Comment from conference evaluation

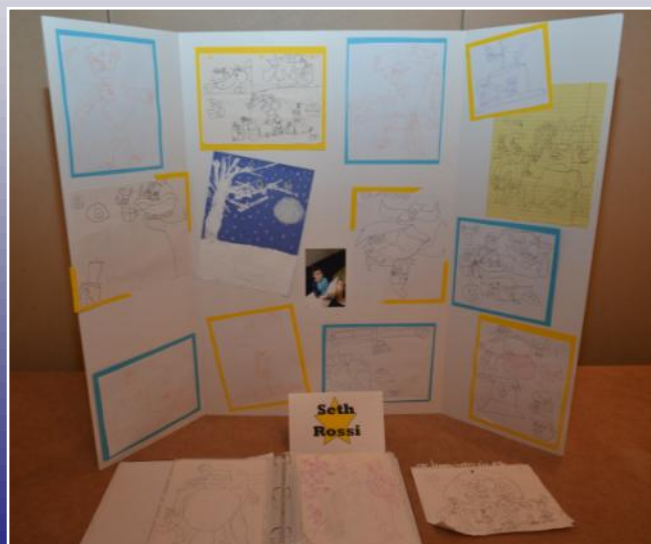


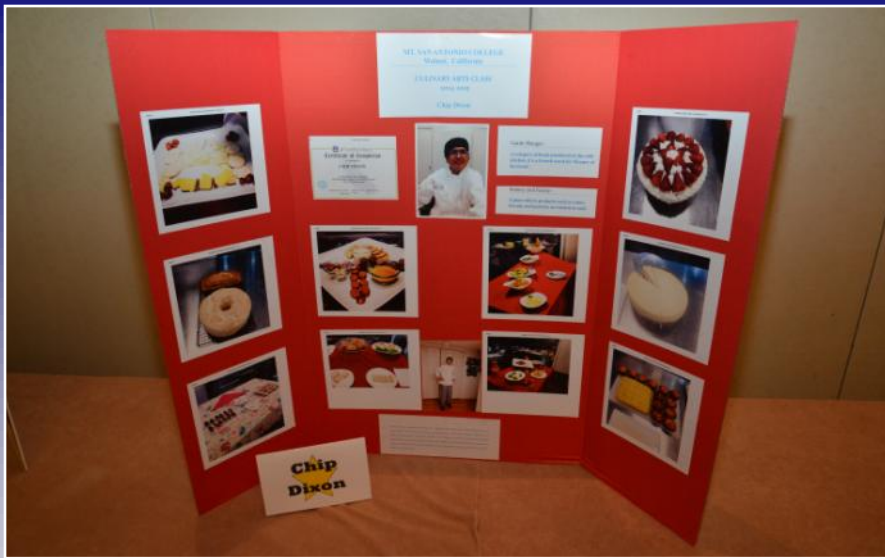


IDOL STAGE STARS ★ Shannon Boelter ★ Ysabel Cluver ★ Rachel Allen ★ Jennifer Siewicki ★
OFF-STAGE TALENTS ★ Jason Jones ★ Anna Lobaugh ★ Seth Rossi ★ Win Edwards ★
 ★ Chip Dixon (next page) ★



Congratulations, Anna!
Off-stage winner for the film "Dolce & Eric in Love"





Special Thanks to
Surprised Performers Jeremy Kirk and Sheri Stanger
Emcees Kennedy and Lisa Weir
Talent Coordinator Sally Roth
and
Judges Sharon Stelzer, Ben Kennert
and Sally Thelin



Working with CHARGE Idol, I had the opportunity to work with, meet and make friends with many individuals with CHARGE and their families, a true blessing in my life!

—Sally Roth



Conference is for families

The CHARGE Syndrome Foundation was pleased to provide scholarships to several families, allowing them to attend conference. Some of their comments follow.

Claudia Junghans

We want to thank you for the opportunity to join the CHARGE Conference in Chicago. Without the scholarship we would not have been able to come all the way from Germany. It was impressive to see so many CHARGE affected people. I was particularly impressed by the adults



with CHARGE Syndrome. The adult panel was so fantastic. To listen to their thoughts, their feelings and their attitudes - great. It was also a great opportunity to meet all the professionals at the same time. We already met a few of them in Germany but never had enough time to talk. That really gave us chance to have a longer conversation than only 5 minutes.

So, thank you again for giving us the Scholarship. Best regards from Germany,

Kaylee Schlafman

Chicago was one of the most amazing experiences for us as a family. Ryder loved spending time with the other kids. She also really enjoyed all of the activities that they did during camp. I personally thought one of the best activities was when they brought in a petting zoo for the kids. I learned a lot more of the details that are involved in CHARGE Syndrome. When your child is born with CHARGE they always seem to prepare you for the worst, and overload you with information. Having this experience at the CHARGE conference shows you how much these individuals can do. They are all so happy and determined to overcome all of their challenges. A very good example is when you watch all of the kids in their talent show. They were so proud to show what they could do, and they really did do a great job. At first the conference was a bit overwhelming. There were a lot more people than I was expecting, and so much information was available.

Something that I would like to share to others who were not able to attend is that it really is beneficial to go. There are so many resources available to you. Also the people you meet understand what you are going through, and they may even be able to give you some advice based on their own experiences. Plus you are able to spend time one on one with professionals who work with CHARGE everyday. I also wanted to say thank you for helping us go to Chicago. We really did learn a lot and seeing all of those wonderful people in one place was super reassuring as parents of an individual with CHARGE. It helps to show you that everything does work out and these kids are going to go places in their lives. I can't wait for the next conference. Thanks again,

Amanda, Robert and Jack Howard

Thank you all so much for allowing us to take part in this wonderful experience. Our son Jack is 17 and we are from Ireland. We have a recently formed CHARGE group with approximately 12 families. Jack to date seems to be the oldest so we wanted to go to the Conference so that he might meet other young people with CHARGE who are living fulfilled lives.

We left Ireland on 28th July not knowing what to expect. After a great flight we arrived safely in Chicago airport. We then took a cab to the Renaissance and we couldn't get over the size of the hotel. We checked into our room and then came down to register at the conference.

The organization of the Conference was unbelievable, 1200 people and we were told 232 of those had CHARGE, we had never felt so at home. Everyone around us had gone through or were going through what we had been through with Jack.

I have to say we still didn't know what to expect over the next few days, we met strangers who became friends. We shared our stories with many others and they in turn shared theirs. We went to several break out sessions not knowing what they would entail but WOW did we learn so much. Our doctors told us Jack's balance was affected because he was blind

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(coloboma) in his right eye and profoundly deaf in his left ear, at the conference we learned about semi circular canals :) Makes much more sense.

Jack even went to a session by himself about relationships and friendships.

The professionals we met were wonderful, kind, interested in our story and they amount of research being done into CHARGE was fantastic to see.

We even managed to meet some other Irish people, a wonderful Cork lady living in New York who has a daughter with CHARGE and a grandmother from Carlow whose granddaughter has CHARGE. Life long contacts.

We are now back in Ireland, Jack and I are going to Dublin on 3rd October to talk to all the other Irish families about our Conference experience. I am hoping to persuade as many of them as possible to come to Conference in Orlando in 2017. We might even outsize the Canadians. Thanks so much and see you all in Orlando!



International attendees in Chicago

Anna's Team CHARGE's to the CHARGE Conference!

by Ingrid Lobaugh

Having attended every conference since Cleveland (2003), I had often wished that we could take more of that knowledge home with us for our daughter Anna's benefit. We don't receive any financial assistance from our state, our school or our Deaf-Blind Project. About six weeks prior to this summer's Chicago conference, I thought, "Why not try?" I started talking to Linda Ford, Anna's homebound teacher, about a garage sale. I shared with her that I had a t-shirt design idea, and would be willing to host as many online parties as it would take if she would be willing to attend. Willing??? Sign her up! Besides being a lifelong learner, Mrs. Ford is Queen of the Garage Sales! We picked a close date. I made one innocuous Facebook post asking for some garage sale donations, and that's when things got a little crazy

While attending the 12th International CHARGE Syndrome Conference, I enjoyed hearing personal stories from individuals and families with CHARGE Syndrome. What I brought back home with me was the importance of an Intervener.

—Barbara Knutson, paraprofessional

Within 24 hours, Mrs. Ford's trip was funded through private donations! We proceeded with the garage sale, which took many man-hours but was a great team effort. I chose an online Tupperware fundraiser because the consultant was very active, and we sold 115 SuperCHARGE shirts. I also set up a GoFundMe account, which raised the bulk of our \$4000.

I was amazed at what I learned from CHARGE adults. In our field of education, we have to be so careful not to box ourselves in. It's important to understand that limits and barriers are consistently broken in this community. I was also impressed by the easy access to interpreters at the conference. We are currently planning a roundtable in October for area DeafBlind educators so we can share what we learned."

—Erin Hoefer, middle school teacher for Deaf/HH students

As a first timer to a CHARGE conference, may I compliment the planning committee, presenters and parents for an inspiring experience. I especially enjoyed the emphasis, involvement and amazing personalities of the individuals with CHARGE.

A highlight was the interaction of Kim Lauger and Dylan. Their wonderful example of creative and effective communication demonstrated flexibility, respect and a willingness to go beyond routine methodology.

David Brown summed it up best: "Don't be a prisoner to your training." As an educator, may I add "Don't be a prisoner to your lack of training." Thank you for a great training ground.

—Linda Ford, Special Education Teacher
Deaf/Hard of Hearing/Multiple Disabilities

By the time the conference rolled around, we were able to fund Mrs. Ford, Mrs. Erin Hoefer (Anna's 7th grade teacher), and Mrs. Barbara Knutson (Anna's paraprofessional). They were blown away! By the people with CHARGE, the speakers, the families, the professionals a CHARGE conference has to be experienced to be understood. I am so excited about this school year! I can't wait to see how their attendance will make a difference in Anna's education. I encourage other families, whether you are raising money to attend yourselves, or you are raising funds for your child's professionals to come to with you to conference, to CHARGE on!

SuperCHARGE Supporters!

Left to right, Front row: Eddie Lent and Christian Roberts; Second row: Barbara Knutson, Anna Lobaugh, Christian Lobaugh; Third row: Erin Hoefer, Ingrid Lobaugh, Rachel Lobaugh, Andrew Delaney; Back Row: Brandon Marshall, Linda Ford, Minnie Lambert





**Eighth Annual
Charge It for
CHARGE**



GOAL: \$150,000

Help us reach our goal! \$150,000

Our eighth annual Charge It for CHARGE is now underway!

With the end of the year giving season rapidly approaching, what a great way to use the power of email and Facebook to raise money for the Foundation. This year we hope to raise more than \$150,000 for support, outreach, awareness, and research. With about an hour of your time and the e-mail addresses of friends, family, and colleagues, you can help us reach our goal.

Go to <http://CSFeighthAnnualCIFC.kintera.org/> to begin your campaign or to make a donation to another participant. You will be amazed at the support you receive from your friends, family and colleagues.

If you are hosting an event or party, or participating in a run, walk, or bike trip to benefit the Foundation, we can help you create your own web page to collect donations and track your progress. For any questions about fundraising, contact our president and fundraising chair, David Wolfe, at david@chargesyndrome.org.

IT CAN BE DONE!



Become A Member

We depend heavily on the commitment of our members to help create a better, more understanding and educated world for all individuals with CHARGE.

Family – \$25
Professional – \$40
Lifetime Silver – \$250
Lifetime Gold– \$1,000
Lifetime Platinum– \$5,000
Lifetime Diamond– \$10,000

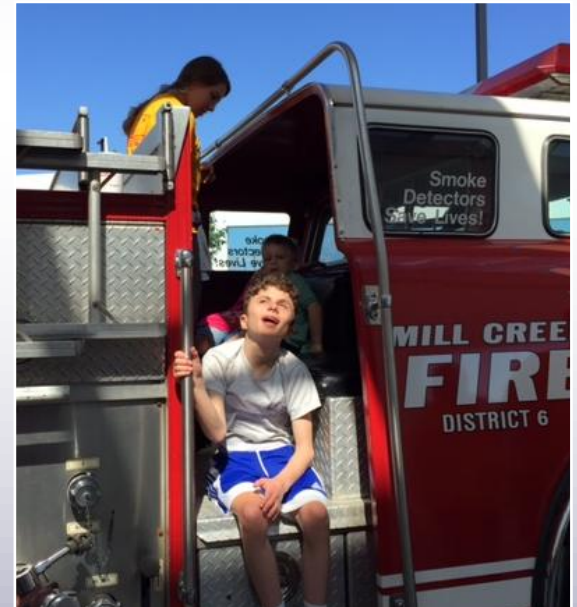
Members receive 10% off conference merchandise
Lifetime members receive a 10% discount off
conference registration

Click here.

Email: info@chargesyndrome.org

Visit us on the web: <http://www.chargesyndrome.org>

Conference is for kids



Conference is for kids



Conference is for research



A lot of research happened at conference

by Meg Hefner

Study at 2015 Conference	# of participants	Still need more?
CHARGE database	73 signed up	Yes
DNA Collection	58 families gave saliva	No
3D imaging	52 individuals imaged	No
Prelinguistic Communication	28 parents interviewed	No
Autistic-like behaviors	14 parents interviewed, 15 signed up for phone	Yes
Food pocketing and overstuffing	20 parents interviewed	No
Management Checklist	40 people gave direct input; more by email	No
Growth Chart	49 children measured	Yes
Sloping Shoulders	16 individuals evaluated	No
Balance	12 individuals evaluated	No
Research Survey	220 surveys returned	No

As we all know, there are many, many unanswered questions when it comes to CHARGE. And each question that IS answered appears to pose two or three more. Results of research are presented at conference. But research also happens as part of conference. After all, what better place to do CHARGE research than CHARGE Conferences? In Chicago this summer, there were more than 1200 people at conference, including more than 200 with CHARGE. Below is a recap of the research that occurred during the conference weekend. A few of these studies are ongoing, so there is still a chance to participate. When data from these projects are published, we will let you know. Watch for more information in later editions of the newsletter and as presentations at future conferences.

CHARGE Syndrome Clinical Database Project Meg Hefner, CHARGE Syndrome Foundation and Saint Louis University

This is my database and registry for people with CHARGE. It is web-based; the parent (or adult with CHARGE) enters information – starting with prenatal! The purpose of the database is to collect baseline information on as many people with CHARGE as possible. We can share that information with other approved studies so they don't have to ask those questions over again. All of these studies need to know: (1) is it definite CHARGE? and (2) which features does the child have? More than 70 new participants signed up at conference, but only about half have entered data. [If you signed up, please enter the data.](#) All the other projects are counting on data from CSCDP as part of their project. If you would like to sign up, go here for more information: <http://chargesyndrome.org/CSCDP.asp>



CHARGE Syndrome
Clinical Database Project
(CSCDP)



DNA collection Donna Martin and Stephanie Bielas, University of Michigan.

Not all cases of CHARGE syndrome are caused by mutations in the CHD7 gene. This team is interested in finding new genetic causes of CHARGE and CHARGE-like syndromes. They were particularly interested in collecting samples on people who had negative CHD7 testing or have not had CHD7 testing. Saliva samples were collected from 58 families – DNA from those samples will be sequenced and examined for other possible CHARGE genes. Information from the DNA samples may also eventually give clues about why the features of CHARGE vary so much from one child to another. They will know which features each individual has if they are entered in CSCDP.

Prelinguistic communication

Susan Bashinski and Barbara Braddock, Missouri Western State University and Saint Louis University

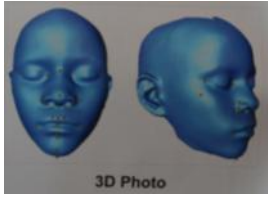
Children with CHARGE typically take a long time to master language (verbal or sign). Before that, they are communicating, but how? What different forms of pre-linguistic communication are children using? Twenty eight parents participated in long

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Conference is for research

(Continued from page 16)

interviews (about 90 minutes each) to help gather that information. We hope that this information will help us understand more about communication in these children – what steps happen before they are able to communicate using language.



3D imaging: FaceBase Sheri Riccardi, University of Colorado, Denver

Anyone who has seen several people with CHARGE can appreciate that there are similarities in facial structure. FaceBase is an international study aiming to better identify and categorize genetic syndromes that include facial abnormalities, including CHARGE syndrome. The aim is to eventually develop a system to help physicians diagnose the disorders. Sheri collected medical information and took three-dimensional (3D) facial photographs of 52 people at conference. Most had CHARGE, but a few had other known syndromes. These photos will be used to precisely measure and define the specific facial abnormalities associated with each syndrome. The 3D photographs and medical data will be entered into the National Institutes of Health FaceBase database (<https://www.facebase.org/>) so it can also be used by other scientists.

Autistic-like behaviors Kasee Stratton, Mississippi State University

We know behavior is a big issue in the CHARGE world. Behaviors get all sorts of labels: OCD, deafblind, autism. Some children with CHARGE appear to have autism, or at least autistic-like behaviors. This study hopes to add to the understanding the relationship of CHARGE syndrome and autism spectrum disorders. This study involved both a questionnaire and a long (90 minute) interview with parents about their child's behavior. Fourteen parents of children with CHARGE (children over the age of 2) participated at conference and 15 more signed up to do so by mail and telephone. More parents are encouraged to participate (your child does not need to have specific autistic-like behaviors). If you are interested, please contact Kasee Stratton: kstratton@colled.msstate.edu

Food pocketing and overstuffing Alexandra Hudson and Kim Blake, Dalhousie University

There are many feeding issues in CHARGE. Even when children are able to eat by mouth, there may be issues. Food pocketing (in cheeks or palate) and overstuffing are some of the behaviors often seen, even in adults with CHARGE. These behaviors may have consequences like choking or aspiration, which can be very serious. Alex interviewed parents to ask about feeding behaviors and structural anomalies, motor impairment, and/or oral sensory impairment. To better describe the mouth overstuffing during eating, its associated consequences, and any potential solutions to reduce this eating issue. Results of this study are already being prepared for publication.

Management checklist Carrie-Lee Trider, Queens University

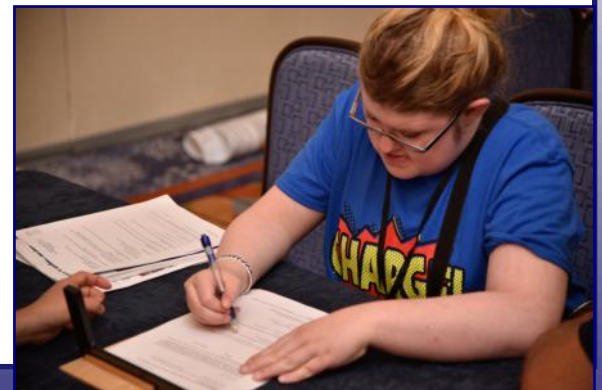
There is a wide spectrum of medical, physical and psychological issues individuals with CHARGE syndrome. There are guidelines for evaluating a newborn who may have CHARGE. But guidelines are needed to help direct screening and management of clinical problems issues over time. The aim of this project is to develop a comprehensive checklist for CHARGE syndrome across the lifespan: from head to toe. A draft of a one page checklist was developed and brought to conference for feedback from families and health care professionals. Carrie interviewed 40 people at conference and contacted many more by email following conference. The completed checklist will be made available to the CHARGE community.

Conny van Ravenswaaij and the Dutch team had lots of things going on: growth, shoulders, balance, and a questionnaire:

Growth Chart for CHARGE Monica Wong and Conny van Ravenswaaij, University of Groningen, Netherlands.

Don't you wish your doctor had a growth chart just for CHARGE so you could know if your child was in range compared to other children with CHARGE? Of course, it is important to know not only height, weight and head circumference, but also growth hormone (GH) status – was GH tested? Was there GH treatment? It is possible to create a CHARGE growth chart, but it requires information on lots and lots of kids. At conference, Monica took the height, weight and head circumference of 49 children with CHARGE.

(Continued on page 18)



Conference is for research



(Continued from page 17)

You can still participate. She needs more growth information on as many individuals as possible. Contact Monica for more information and the consent form. CSCDP information (Section 9, Milestones and Growth) will be shared with this project. Monica Wong: charge@umcg.nl

Sloping shoulders in CHARGE *Christa de Geus and Conny van Ravenswaaij, University of Groningen, Netherlands*

Have you noticed that many (but not all) individuals with CHARGE have sloping shoulders? Did you ever wonder why? This team wanted to look more closely at the anatomy of the shoulders – muscles and bones – to see if there is a difference between those whose shoulders slope and those who do not. They brought ultrasound equipment all the way from the Netherlands (TSA and customs had lots of fun with that!) to do this study. They did shoulder ultrasounds on 16 individuals with CHARGE during the weekend. They can add that to those they have examined at their CHARGE Syndrome Clinic in the Netherlands. They have collected lots of information and are now in the process of analyzing it. Stay tuned!

Balance/ataxia *Christa de Geus and Conny van Ravenswaaij, University of Groningen, Netherlands*

We know that most individuals with CHARGE have small or absent semi-circular canals. Those are sort of the internal levels that make up part of the balance system. But balance also involves input from vision, proprioception (the feeling you get from your muscles that tells you where you are in space) and the brain – especially the cerebellum. This study has two parts. One part, done at conference, was to videotape individuals doing a series of balance tasks. The second part involves reviewing brain MRIs to see if there are any changes in the brain (especially the cerebellum) that seem to go along with specific balance skills or deficits. They will add the information from the 12 individuals evaluated at conference to those seen at their CHARGE Syndrome Clinic in the Netherlands. This will help add to the understanding of brain differences in individuals with CHARGE.

Research survey *Conny van Ravenswaaij, University of Groningen, Netherlands*

Funding for research has become more and more difficult for everyone, around the world. Conny is a member of a European group looking at priorities for research. They developed a questionnaire that asked about (1) what features of CHARGE should be top priority for development of treatments and (2) what sorts of risks are reasonable to have in research studies. Having feedback from large numbers parents and professionals is a powerful tool in convincing powers that be that CHARGE research is an important area to fund. We were delighted that 220 people completed and turned in surveys at conference.

Conference is for professionals



167 Professionals attended the 4th Annual Professional Day

Prior to the official start of conference, professionals had the opportunity to learn from each other. For the first time, Professional Day featured three break out sessions: **Medical/Clinical Approaches, Genetics/Research, and Education.** Most professionals also presented during the conference and shared their expertise with families.

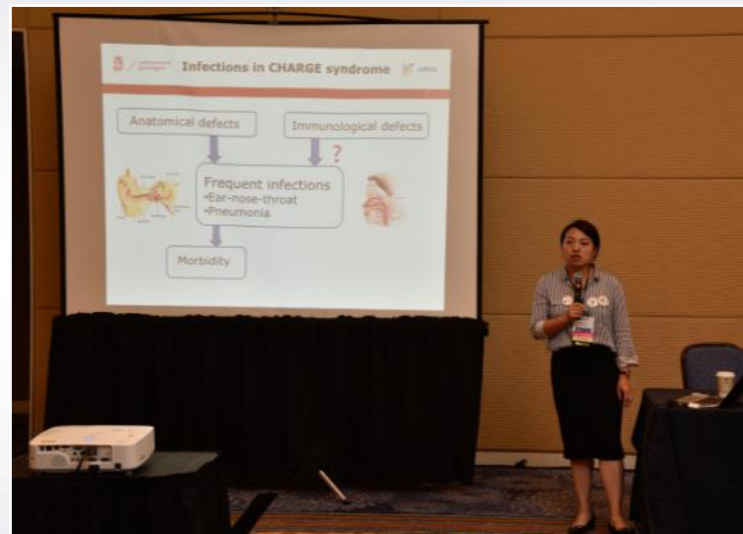


Conference is for learning



*The conference was awesome.
Every workshop I went to I learned
something new!*

-Comment from conference evaluation



Conference handouts are available here:
<http://chargesyndrome.org/conference-2015.asp#handouts>

Conference is for playing



Conference is for friendships

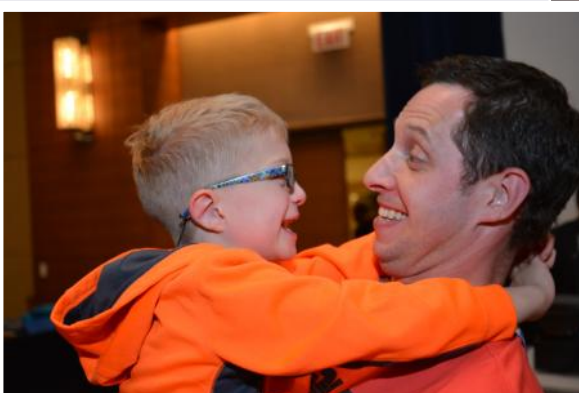


*Seeing so many young adults with CHARGE is one of my favorite things about conference.
We have so much to learn from them !*

-Comment from conference evaluation



Conference is for togetherness



The chance to meet and talk with other parents and families and visit with some of the children with Charge was invaluable. It was an exceptional experience.

-Comment from conference evaluation



To our professionals for their dedication
To the amazing volunteers



To the incredible interpreter team
To Sandy & Janet Buller for the conference photos

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Hear now And always



WE WANT TO HEAR FROM YOU!

Share your story in the Winter 2015
edition of **CHARGE Accounts**.
Submit articles by November 15th to
[Joanne Lent](mailto:joanne.lent@umcg.nl).

[CHARGE Accounts Submission Guidelines](#)

Visit the **CHARGE** Syndrome Awareness Store

COMING SOON ...
We will have new
merchandise for
holiday gifts.

Stay tuned for
our email blast
in November.



Developing Growth Charts for Children with **CHARGE** syndrome

What do we want to do and why?

We want to create specific growth charts for children with CHARGE syndrome. These growth charts can be used to evaluate whether a child is growing sufficiently compared to what can be expected in a child with CHARGE syndrome.

Why do we need your help? In order to make reliable growth charts, we need growth data of as many CHARGE individuals as possible.

How can you help us? If you are interested in helping us, please let us know by e-mail (see below). We will then send you an e-mail with more information on this project and how you can provide us the information we need. This can be done in two ways: filling out a short questionnaire and/or giving us permission to use your data that already is in the CSCDP database.

For participation or more information,
please contact us via e-mail
charge@umcg.nl

Monica Wong, PhD student, and
Prof. Conny van Ravenswaaij, clinical geneticist,
UMC Groningen, Netherlands