SPRING 2015

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.

OFFICERS
President: David Wolfe
Vice-President: Lisa Weir
Treasurer: Brownie Shott
Secretary: Neal Stanger

DIRECTORS
Eric Bluestone
Joanne Lent
Amrit Mehta
Pamela Ryan
Lori Swanson

SPECIAL ADVISORS
Meg Hefner

DIRECTOR OF OUTREACH
Sheri Stanger

DIRECTOR OF ADMINISTRATION
Jody Wolfe

In This Issue

President's Message

"The Sky's the Limit" in 2015. Whether used to describe our conference, research, webinars, fundraising, or the phenomenal people that make up our Foundation, I can't think of a better way to describe our group. There are truly no limits to what we can accomplish when we work together.

In just about two months, many of us will arrive in Chicago for the world's largest gathering of individuals with CHARGE, their families, and professionals. We expect around 1,100 people! We have a great mix of new speakers, important topics and fun evening activities. In addition, all of our original founders - Sandra Davenport, Meg Hefner, Marion Norbury and Jim Thelin - have agreed to gather together for perhaps the last time at a CHARGE conference. **Register now** and join your extended CHARGE family.

Our commitment to research remains strong. We received a record number of high quality Pilot Grant applications and will be announcing the recipients soon. We also have more research taking place at conference than during the past several conferences combined. We look forward to spending more on quality research in 2015 than in any prior year. We hope that a continued focus on research will lead to improvements in diagnosis and treatment.

We also will continue to deliver our free webinars and newsletters. Next month we will announce the first recipients of the Ethan Wolfe Recreational Assistance Program. We look forward to helping more individuals with CHARGE participate in recreational activities.

While "The Sky's the Limit," we all need to continue to work together to make sure that we can fund all these valuable programs. I hope you can all carve out a little time to help the Foundation raise funds this year. Whether Charge It for CHARGE, an event, putting together a basket for silent auction, soliciting sponsors, becoming a member or simply donating, we still have a long way to go to reach our goals.

Thank you to everyone that has helped us come so far, and thank you in advance to all of you who will help us go even further. The Sky's the Limit!

David

David Wolfe, President

Our New Address

The CHARGE Syndrome Foundation, Inc. • 318 Half Day Road, #305 • Buffalo Grove, Illinois 60089
info@chargesyndrome.org • 800.442.7604 • www.chargesyndrome.org

Conference Checklist

Now is the time to finalize your plans for the **12th International CHARGE Syndrome Conference, July 30th – August 2nd.** It’s just over two months until we get together at the Renaissance Schaumburg Hotel in suburban Chicago.

The Sky's the Limit!
12th International
CHARGE Syndrome
Conference
Chicago 2015

CONFERENCE SCHEDULE

PROFESSIONAL DAY
Thursday, July 30
Sessions 8:00 – 5:30

CONFERENCE
Thursday – Sunday
July 30–August 2

Thursday
A Time to Meet 2:00 – 5:00
Informal family gathering
Reception 6:30 – 9:00
Families & Professionals
Lots of Appetizers

Friday
Sessions 9:00 – 5:00
Camp Program (full day)
Exhibitor Fair
Poster Presentations
Interact at Info Central
Idol Extravaganza

Saturday
Sessions 9:00 – 5:00
Camp Program (full day)
CHARGE-A-Palooza
Silent Auction & Basket Raffle

Sunday
Presentations 9:00 – 12:00
Camp Program (half day)
Closing

Breakfast and lunch included on Professional Day.

Breakfast, lunch, dinner, and snacks included on Friday and Saturday. Breakfast included on Sunday.

Register for conference and **make your hotel reservations** as soon as possible to get the special conference rate of $149 per night.

Check out the Foundation’s **funding guide**, with recommendations to help you find organizations that might be able to assist with conference costs. The guide includes general tips, a sample request letter, and a cost breakdown template.

It’s not too late to **help the Foundation obtain new sponsors and advertisers - you can earn FREE conference registrations**. There's no limit to the number of registrations you can earn for your family and friends. Find out more about our incentive program.

Donate a basket for Saturday night’s CHARGE-A-Palooza.
The more prizes we have, the more fun for everyone, so be creative!
We need baskets for adults and for kids of all ages and abilities, with a value of at least $50 (date night, game night, spa day, chocolate lovers, sensory toys, etc.).
We are also accepting high-end items for the silent auction, including timeshares, fine jewelry, airline tickets, electronics, and sports memorabilia. Copies of our donation letter and form are available. Please contact Neal Stanger for more information.

Check out the program information and tentative agenda.
We have sessions planned for new families and veteran attendees, for young adults with CHARGE, for dads and grandparents.

Preorder Your Conference Attire!

New CHARGE Logo and Conference Merchandise are now available.
If you are attending conference, everything will be waiting for you when you arrive in Chicago. If you are not attending conference, and live in the US, we are happy to ship everything to you!

Not all of these items will be available at Conference and sizes will be limited. Click here to order now. Orders must be placed by June 30.

Visit the CHARGE Syndrome Awareness Store for additional products

Why do you come to conference?

To meet new friends and catch up with the old. To learn more about your child's health and education. To hear about the latest CHARGE research.

How does that research happen?

Because CHARGE is relatively rare, most professionals only see a few individuals in their local practices. Sending questionnaires to people is helpful, but there is nothing like coming to conference and seeing hundreds of children, meeting dozens of families. Conference provides a wonderful opportunity both for researchers and for families to participate in research.

We are planning to have about 10 investigators doing research AT CONFERENCE! We are hoping many of you will choose to participate in one or more of these projects. Some will take only a few minutes of time at conference. Others involve lengthy questionnaires or interviews which will need to be arranged prior to conference. All of the projects will include reading and signing consent forms. What sorts of projects are being planned? Here are brief descriptions and contacts if you want more information.

Projects that will only take a few minutes:

Growth study: with the goal of creating growth charts specifically for CHARGE, this group will perform weight, height and head circumference measurements, collect past growth data and collect information on growth hormone testing and treatment. charge@umcg.nl

Imaging: take 3D photos of individuals with CHARGE and their family members.

DNA study: Collect saliva samples on individuals with CHARGE and first degree relatives (parents, siblings) to look for other genes that may cause CHARGE and genes that may influence the variability of features.

Slightly more involved projects:

Sloping shoulders: examine individuals with CHARGE and see what differences there are between those who do and do not have sloping shoulders. Examination will include ultrasound of muscles and performing some simple tasks (~30 minutes). charge@umcg.nl

Balance: examine the cerebella (brain) contribution to balance issues. This will include videotaping individuals with CHARGE performing a series of tasks to assess balance and getting permission to review brain MRIs that have been done (~30 minutes). charge@umcg.nl

More extensive interviews/observations that would be best arranged before conference:

Overstuffing (eating): Parents of children who over-stuff their mouths while eating will complete a questionnaire and interview about these behaviors (45-60 minutes). alexandra.hudson@dal.ca

Prelinguistic communication: parents of children who have fewer than 22 words or fewer than 50 signs will complete a series of questionnaires and interview to better describe pre-linguistic communication behaviors (30-60 minutes). sbashinski@missouriwestern.edu

Autistic-like behaviors observed in children with CHARGE: parents of children over 2 years of age will complete a questionnaire and extensive interview about behavior characteristics of their children (45-60 minutes). kstratton@colled.msstate.edu

Play behavior: parents of children (ages ~3-10 years) will complete a series of questionnaires. Children will be observed and videotaped in Camp and in a structured setting (60-90 minutes, total). Schmi2m@cmich.edu

What can you do now? Enter data in CSCDP.

Most of these projects will be coordinating with the CHARGE Syndrome Clinical Database Project (CSCDP), which collects baseline information on individuals with CHARGE through a web-based set of surveys. You can see a demonstration of the database at conference. The CSCDP will provide baseline information directly to each research group. If your/your child's information is already entered in CSCDP, all you will need to do is complete a consent form for that information to be released to the other projects you are participating in. Information on CSCDP, including how to get started before conference, is here: http://chargesyndrome.org/CSCDP.asp

CHARGE Syndrome
Clinical Database Project
(CSCDP)

SAINT LOUIS UNIVERSITY

Watch for Foundation emails and postings on our Facebook page in June and July for more information.

Submitted by Meg Hefner

Kathy McNulty Retires from the CHARGE Syndrome Foundation and National Center on Deaf-Blindness (NCDB)

Interview by Lori Swanson

When did you first become interested in individuals with CHARGE? Coordinating national technical assistance activities for families has been one of my job responsibilities since I first entered the field. Very often this work would involve contact with individual families with children with CHARGE. However, my level of involvement with CHARGE radically changed after the first CHARGE conference I attended in Cleveland, Ohio in 2003. Then I became very involved with individuals who have CHARGE. Somewhere around 2007 Neal Stanger (former President) asked that I become involved as an advisor. Once you begin working with the Board you become immersed pretty quickly.

What attracts you most to children with CHARGE? The children themselves! They have great personalities, spirit, character, determination, and spunk. That became very clear to me during the first CHARGE conference I attended in 2003.

What has been your primary role with the Foundation? My position as Coordinator of Family TA and Outreach to the State Deaf-Blind Projects on the NCDB project gave me a unique view of and access to the national deaf-blind network. In the role of CHARGE advisor, I sought to bring network resources to the attention of the Board and conversely, help facilitate greater awareness among the state deaf-blind projects to the work of the Foundation.

What is the most significant thing you have seen change in the Foundation during your term as special advisor? I have seen an increase in professional strategic planning which has allowed for more predictability in the services that are going to be offered to members of the Foundation (e.g., conferences, research). Clear goals and outcomes have been identified by the Board with an increased focus on action planning and implementation. These good practices will enable the Foundation to continue to grow.

How has the Foundation changed the world for individuals with CHARGE? The Board has become increasingly successful in raising the awareness of CHARGE syndrome and providing easier access to the information families need. I think an excellent example of the Board's commitment to support families has been the creation of the position of Director of Outreach. It is so important for parents and family members to be able to speak with someone who is both knowledgeable and caring. Equally important has been the Foundation's unwavering support to conduct genetic research which will hopefully lead to long term, positive results for the field.

What would you say to individuals considering volunteering for the Foundation? It is fun, exciting, and provides lots of rewards, but it is also hard work.

What would you say to individuals considering a career in the world of deaf-blindness? I am probably biased, but I found the field of deaf-blindness to be a very special community, filled with many, many dedicated people. My advice to a newcomer would be to find those people who have the knowledge and experience in working with children who are deaf-blind. The National Center on Deaf-Blindness (NCDB) can help people do this. NCDB's website offers a wealth of resources to newcomers and seasoned professionals alike.

How did you become involved in the world of deaf-blindness? Twenty-seven years ago I was asked by the director of a federal grant on transition to conduct a national survey of 100 families who had a child with deaf-blindness. When I submitted my report, the director asked if I'd like to continue part-time. In 1-1/2 years, I was full-time. Parents were my initial trainers and mentors.

What advice would you give to a new parent of a baby with CHARGE or a parent of an adolescent? Absolutely go to the conference! For the new parents, attend the 101 session. Introduce yourself to Meg Hefner. Call Sheri Stanger who is Director of Outreach for the Foundation. Then call Pam Ryan (Board Member). They will then refer you to the appropriate individuals. These people never turn a parent away! They will always give a parent time. I would give the same advice to the parent of a young adult. Speak to Sheri Stanger who has lived it and is still living it. Speak to other parents of adolescents with CHARGE. Sheri will identify specific parents for you!

What has been the single most rewarding thing you have done during your distinguished career? It has been the opportunity to work with parents for 27 years.

We thank Kathy for all she has done for the Foundation, and we welcome the future CHARGE syndrome professionals ...

Introducing the Sandra Davenport CHARGE Syndrome Fellows Program

Submitted by Pam Ryan and Meg Hefner

The CHARGE Syndrome Foundation came into being in 1993 along with the first International CHARGE Syndrome Conference. As the cohort of professionals who have been involved with CHARGE since then (and before) begins to retire, we recognize the need to encourage the next generation of professionals to become more engaged with the greater CHARGE community. We know that conferences provide a wonderful opportunity for professionals to learn more about CHARGE, to interact with one another, and get to know families. Meg Hefner, one of the CHARGE Syndrome Foundation founders, had an idea: Let's actively facilitate young professionals (including those still in training) coming to conference. Once we get them to conference, we know they will interact with the more seasoned professionals in medical, educational, and research fields and expand their overall knowledge of CHARGE syndrome. And of course there is no better way to engage the professionals than to have them meet all the wonderful individuals with CHARGE and their families while having the experience of a lifetime (because we are pretty great!).

Meg approached the Board of the CHARGE Syndrome Foundation and suggested funds be allocated specifically to support young professionals attending conference; the Board agreed and the Fellowship program was launched. We sent out a call to our current professionals, who suggested appropriate applicants. Applicants included graduate students studying in fields of medicine, psychology, genetics, and education. A fine group of people who we want to be part of our ever-growing community!

Describing these folks—these CHARGE Fellows—needed something more; a name that truly reflects what this opportunity represents: a chance to actively learn about CHARGE and become long-term members of a very dedicated CHARGE community. The name needs to do justice to the current professionals, many of whom have been active in the Foundation and been around for two or three decades.

Once again, Meg had a good idea: let's give these Fellows a name worthy of their selection from all the applicants; let's give them a name worthy of the special role we hope they will fill. Meg thought we should honor Dr. Sandra Davenport. Sandra was another of the CHARGE Syndrome Foundation founders. Sandra set the tone for conferences from the beginning – making sure medical and educational professionals interact with one another and that the conference is a family-friendly place. Her expertise in sensory deficits and deafblindness helped mentor a generation of CHARGE professionals. Sandra made sure that any question was answered; any person was welcomed in. Meg's idea? Name the Fellows and this new project for Sandra Davenport. Lisa Weir, Vice President of the CHARGE Syndrome Foundation, suggested The Sandra Davenport CHARGE Syndrome Fellows Program. This name honors our friend and founder and builds on her dream and vision for the Foundation: awareness, knowledge, collaboration, and a welcoming place for all.

At our upcoming conference, we will welcome the first Sandra Davenport CHARGE Syndrome Fellows. Some will have posters or presentations, and all will be participating in all aspects of Conference, including volunteering in Camp. Their experiences will be reported in later editions of *CHARGE Accounts*. Please welcome them to conference and to the greater CHARGE community.

2015 Sandra Davenport CHARGE Syndrome Fellows

Sara Espanet, Education student at Perkins School for the Blind
Caitlin Hale, Genetic counseling student from University of Michigan
Alexandra Hudson, Medical student at Dalhousie University
Ben Kennert, PhD student in educational psychology at Central Michigan University
Rachel Malta, Specialist in educational psychology student at Central Michigan University
Neeraja Reddy, Genetic counseling student at Brandeis University
Hailey Ripple, PhD student in Educational psychology at Mississippi State University
Lauren Siems, Genetic counseling student at Northwestern University
Ethan Sperry, MD/PhD candidate at University of Michigan

Parent Perspective

How state-funded services help my daughter with CHARGE syndrome

Perkins School for the Blind students, teachers and staff joined more than 100 members of the Massachusetts deafblind community at Deafblind Awareness Day, an annual advocacy event highlighting the importance of programs and services for children and adults with deafblindness This essay is adapted from a speech Nicole delivered at the State House on April 9.

By Nicole Feeney

Our daughter Shelby has CHARGE syndrome, a rare genetic disorder that causes congenital defects, health complications and varying degrees of deafblindness. Shelby was born in 2013 and spent her first 5-1/2 months of life at Boston Children's Hospital. I could talk for hours about all the things Shelby is to us, how far she has come and what we wish for her, but I'll simply say that Shelby is a very happy 18-month-old. She loves her "Mumma," her "Papa" and her sisters, repeats "I love you" and has the cutest smile.

When Shelby was born, we had no idea what was in store for us. And I mean that about everything: Shelby herself, her health, our lives, how this would affect our 2-1/2-year-old twin girls. I started the early intervention paperwork before Shelby was discharged from Children's Hospital so that when she came home she could get plugged in right away.

Shelby is now blessed with a huge team that loves her and that she loves too. That team includes an early intervention generalist, occupational therapist, physical therapist, teacher for the deaf, speech therapist, sign language teacher and visiting nurse, who come once a week. Her teacher for the visually impaired (TVI) comes twice a month and a child life specialist, music therapist and massage therapist come once a month. On Thursdays, we drive to Perkins School for the Blind in Watertown for the Infant/Toddler Program's play group. Shelby has been home for a little over a year now and with all the early intervention she has grown by leaps and bounds... Read the rest of Nicole's story **here**.

Minnie's View from South Carolina

Robert Frost wrote of the road less traveled but what if you found yourself at a point where there was no road? What are these new words that these doctors are telling me? What is "CHARGE Syndrome"? Every time I say it I get the same feeling; there comes THAT look. Heck I felt this same feeling when I first heard it myself. We are almost done with our 11th year of this journey and through education, connections, seeking and learning I have come to realize that this road that we are on is not that bad. It does have some major issues now and then but between the multiple doctor visits, therapy appointments, specialty appointments, school meetings, research time and connecting with others, I have come to the great conclusion that WE are not alone.

It all started back in 2008, Andrew was 5 years old at the time, I had come to my very last straw; hours of sitting in front of a computer, hours of crying and feeling that I had no clue what I was supposed to do or where I was supposed to turn next. School issues had overcome me and no one seemed to understand, they just didn't want to deal with him and treated him like a terror, one teacher had even labeled him as "a threat to her AND her students." I sat in front of the glowing screen of my laptop and I prayed. I said Lord there has to be someone out there that can help me. Someone HAS to understand. I went back to the site that I had visited so much before. The website of the CHARGE Syndrome Foundation, thinking to myself, there is no way these

continued on next page

Parent Perspective

people sitting in their desks at a "Foundation" in NY understand what it is that I am going through here in SC. But I continued to read and read a little more. I looked a little deeper. There was a little girl named Kennedy that kept popping up. Wait, her mom is the VP of the Foundation. She does know. I searched for her mom's blog and I read her story. It sounded a lot like mine.

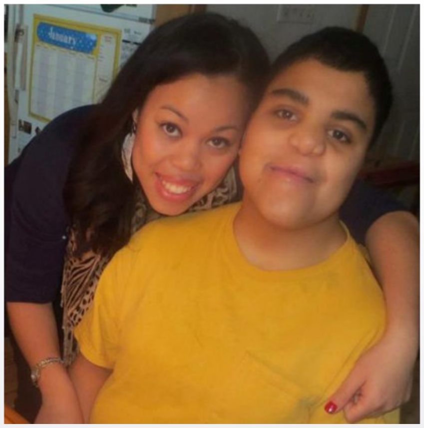
Minnie's story continues on page 7 of the SC School for the Deaf and the Blind newsletter.

Siblings Speak Up

The View from the Next Bedroom: Siblings of Children with CHARGE

By Hayley Hoesch, Tim Hartshorne, Lalaina Rabary

Guilt comes naturally to parents of children with CHARGE. There is no way that a parent can provide all of the care and nurturing that these children need and deserve. Another source of guilt is the sure knowledge that the other children in the family are not receiving the same level of attention, care, or nurturing. So how are these siblings doing? There is very little research on the topic. The CHARGE Syndrome Research Lab has conducted a study that we will present at the 12th International CHARGE Syndrome Conference. As part of this study, we asked siblings what advice they had for others who had a sibling with CHARGE. Some of their responses are on the next page. But first, from her blog, Lalaina Rabari writes about the experience of growing up with her brother Jon.



DO NOT FEEL SORRY FOR ME. As a sister to a 23 year old brother with CHARGE syndrome, I have not led a "normal life." My family and I have gone through quite a lot, emotionally, physically and spiritually throughout the years and with each year more challenges are added. Our lives have been filled with early mornings, late nights, hospital visits, doctor's appointments, caseworker calls, insurance statements, social engagements cut short, and stressful vacations.

We have always had a one-income household. Because of my brother's significant needs, my mother has had to stay home and my father has worked. On top of all this, we are immigrants and all our relatives live in Madagascar. Needless to say, life hasn't always been the easiest. We have had a lot of ups and downs and this year has been filled with transitions; more specifically, moving from one state to another and having to find the right placement for him. Let me tell you, transitions are tough for people without mental challenges, but for young adults with various conditions and mental challenges, they are 1,000 times more difficult.

I am NOT trying to complain. I'd be lying to you if I told you I didn't have moments of complaining, but right now I am not complaining. Instead, I am trying to paint reality for you. My reality. And I am going to stop you right now.

DO NOT FEEL SORRY FOR ME. I know when my brother screams at the top of his lungs in Sam's Club or while we are walking or for no apparent reason, people feel sorry for us. Or when we are eating dinner at a restaurant and all of a sudden he throws forks and his food, people feel sorry for us. The stare is recognizable. I can't blame them. From the outside looking in, I would probably feel sorry for someone too. But from the inside out, I am telling you.

DO NOT FEEL SORRY FOR ME. DO NOT FEEL SORRY FOR MY FAMILY. We do not need your pity. The more you feel sorry for us, the sorrier we feel. When we are weak, we need your strength. We don't need your sorrys.

Read more of Lalaina's blog post here

Siblings Speak Up

Advice from siblings to other siblings

The relationship between siblings is likely the longest lasting one in life. Lalaina and the other siblings may not represent all siblings of children with CHARGE, but it is clear that they value their siblings and their relationships, and for many, the experience has taught them something and they value it. They value their siblings. Life can be full of challenges, but learning to grow from your experience is important. Embrace the journey.

Help out as much as you can and take responsibility

Accept who they are, not what they're not. The more you understand them, the more you grow to love them.

Don't be afraid to bring your friends around. In most cases, they are interested more than scared. If you act at ease, so will those around you.

Be patient, understanding, and put yourself in their shoes

Go with the flow and work with their schedules. Don't force them to do anything

Learn sign language

Try to find something you can do together, like video games or rock climbing.

CHARGE doesn't define them. It's just a part of their life.

They are people too!

Take it day by day. Remember they are still a wonderful, smart, and energetic part of the family

Visit Info Central at conference for more sibling insight.

The Power of Families as Communication Partners

Submitted by Amy T. Parker, Ed.D. & COMS, CEC's DVIDB Deafblind Committee Chair

The longing that families have to understand and connect with their members who have complex communication needs is profound. For families of people with CHARGE syndrome, focusing on communication supports for individuals is often interrupted by the pressures of providing care to persons with intensive health care needs. The strength and resiliency of individuals with CHARGE syndrome and their families cannot be overemphasized, as so many families find ways to promote connections and shared understanding even within busy and challenging schedules.

For the past few decades, Dr. Charity Rowland, a researcher and speech language pathologist at Oregon Health & Science University, has partnered with professionals and families to develop ways to recognize and promote communication development for individuals with complex communication challenges. Some of Dr. Rowland's work has included parents and professionals within the CHARGE Syndrome Foundation community (See Home Talk, a free tool specifically designed to support families: https://www.designtolearn.com/uploaded/pdf/HomeTalk.pdf).

Recently, Dr. Rowland was awarded a grant to develop a virtual community of practice- a free online space where family members, professionals and researchers can contribute ideas and collaborate to support people with complex communication needs. Because parents of individuals with CHARGE syndrome are educators- teaching their own children, other family members, and often, the professionals that serve their loved ones, there is a need for families to have access to reputable, reliable and just-in-time information to educate themselves and others. The virtual community of practice is meant to address that need and to advance our knowledge of communication development and intervention through collaboration.

Consistently, intervention researchers report that the individuals with communication challenges make the most progress when they have access to responsive communication partners throughout the day - those who recognize their subtle communication cues and help them have access to communication supports. Parents and family members of individuals with CHARGE syndrome are some of the biggest contributors to developing successful communication skills. The tools and resources offered within the virtual community of practice also provide a way for families to share language and ideas with professionals, using the same language to document progress. For example, families might use the Communication Matrix Assessment to orient new teachers or providers to the ways that a child refuses, makes requests, shares comments or asks for information. By participating in the virtual community, parents may gain some ideas for using video samples or adapting home routines to provide more opportunities for communication each day.

If you have a family member with complex communication needs or know others who do, I encourage you to explore and share this wonderful resource: https://community.communicationmatrix.org/

More information will be shared at the conference In Chicago this summer! See you there!

State Parent Liaison Project

By Sheri Stanger, Director of Outreach

The CHARGE Syndrome Foundation's State Parent Liaison pilot project is well under way and I'd like to remind our constituents of the program, its purpose as well as introduce you to our wonderful state parent liaison volunteers.

We are in our first year and currently have 11 parent volunteers. The purpose of the project is to enhance our collaborations with the State Deaf-Blind Projects to improve on our outreach efforts for identification of families, family networking and the sharing of information and resources. The liaisons and I meet quarterly and their primary function is to share the latest CHARGE resources with the state projects and the families; assist in helping both the Foundation and the state project in identifying families; update the Foundation on available state resources; promote connectivity among the CHARGE families in their state. I'm happy to report that our project is successfully moving forward and as we end our first year we will be looking to add more state parent liaisons to our list. It is my hope to eventually have a liaison for each State Deaf-Blind Project. The success of this project stems from the dedication of our current liaisons as well as the support of the State Projects involved.

I'd like to introduce you to our current state parent liaisons. They are:Allie Strang-Jones from AL, Ana Saruski from FL, Maureen Schultze from IL, Karin Dagley from MA, Michelle Case from MI, Laurie Suter from NH, Mary Cox McDonald from NY, Minnie Lambert from SC, Kathi Barksdale from TX, Amy McKinley from WA and Corki Hobson Roth from WI. It is a pleasure to work with these wonderful parents and I know that all of our efforts will help us to better inform and serve our families. If you have any questions about this pilot project, please contact Sheri Stanger, Director of Outreach at 1-855-5CHARGE or at sheri@chargesyndrome.org.

CHARGE Syndrome Foundation Partners with CEC's Division on Visual Impairment and Deafblindness (DVIDB)

Submitted by Amy T. Parker, Ed.D. & COMS, CEC's DVIDB Deafblind Committee Chair

At this year's Council for Exceptional Children (CEC) international convention in San Diego, our division wore its new name for the first time. In many ways, one could view DVIDB as a child with a low incidence disability, like deafblindness or visual impairment, showing up at her local school. She is just one child with a unique story and some of her access needs are different from students represented in the vast school, teaming with other children. Within the larger CEC structure, DVIDB is a smaller group. For example, out of the 800 sessions across the 3-1/2 day convention, our division hosted 15 sessions, 1 general business meeting, 1 social event, and a Deafblind Community Forum meeting. One might look at that small presence and think, "Whoa, is it even worth it to be a part of that organization?" As I reflected on the experience of being a low incidence division within the largest special education organization, I've come to think about the value of participating with a different set of glasses- not based on viewing the numbers alone.

Our presence as a division within the larger CEC structure is important because of the representation that we provide at meetings on developing legislation, national and international educational policies, and trends within the larger special education community. We actively remind such groups about the needs of students with deafblindness and with visual impairments. Members of DVIDB bring up the ongoing challenges our students face in having access to prepared teachers and interveners, and of even being recognized at all in local school systems. The CEC plays an important role in developing and maintaining professional and paraprofessional standards, which universities and school systems look to for designing coursework and professional development opportunities. It is significant that DVIDB has developed and will maintain (update regularly) the knowledge and skills standards that teachers of the deafblind and interveners should have to provide appropriate instruction and support. It is also important to know that the Office of Special Education Programs (OSEP) looks to the CEC and its divisions to help define standards for research and best practice.

Council for Exceptional Children
The voice and vision of special education

Aside from the division's role in representing the practices and needs of students who are deafblind and those with visual impairment, participation in the larger CEC structure also offers our members a chance to learn about the larger world of special education. The conversation and trends within universe, helps DVIDB members become better communicators about how our students fit into educational systems. While we, at times, like our students who are deafblind, would prefer to stay in our own worlds and focus on our immediate interests, it is important to strategically join in this larger community so that representatives in our field can effectively navigate, communicate with administrators, and incorporate innovative or useful ideas that will benefit our students.

This year, we continued our efforts to partner with parent organizations by inviting Lisa Weir, the CHARGE Syndrome Foundation Vice President, to share input at our DB Community Forum. In our action planning session, we developed plans for more community education opportunities regarding the roles of teachers of the deafblind, and interveners through upcoming PSA videos, free webinars, and updates on legislation that promotes the educational services for students who are deafblind. Stay tuned for more opportunities to share our common efforts to improve the lives of students and families with CHARGE syndrome. For more information about news and events from the CEC convention, please see this link: http://community.cec.sped.org/dvi/dbportal/dbnews

In conclusion, if we personify our small division within the CEC as a young girl headed to school in a large district, we consider her ability to share her voice, her ideas within this community and to learn from what it has to offer as well. She, like our students with deafblindness, has a purpose in participating and with the right structures and supports in place, her contributions make the community a more welcoming place for other students who are deafblind.

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. **Click here.**

THE CHARGE SYNDROME FOUNDATION

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
Email: info@chargesyndrome.org
Visit us on the web: http://www.chargesyndrome.org

Watch Our Webinars

Your membership dollars also support our webinar series, all available for viewing on our website

- Strategies for Success that Work: At Home and In the Community
- Why Does My Child Do That? Compulsive Behaviors and OCD in CHARGE Syndrome
- CHD7 and CHARGE Syndrome Research: Unveiling the Mysteries
- A Conversation on Intellectual Assessment: What Parents Need to Know
- The Forgotten Senses
- Pain Issues in CHARGE
- CHARGing Into the Teens
- Techniques to Improve Feeding Skills and Speech Clarity
- Top Ten Strategies for Promoting Positive Behavior
- Physical Education for Children who are Deafblind

SEVENTH ANNUAL CHARGE IT FOR CHARGE

is under way and we're close to last year's record of $101,000 raised!

We can make 7 our lucky number with your help

Join the Team
Donate or
Become a Fundraiser

Do you have a story you'd like to share?

An upcoming event to promote?

Please tell us about it.

Submissions for the Fall 2015 edition of CHARGE Accounts are due by September 15th. Submit articles to Joanne Lent.

CHARGE Accounts Submission Guidelines