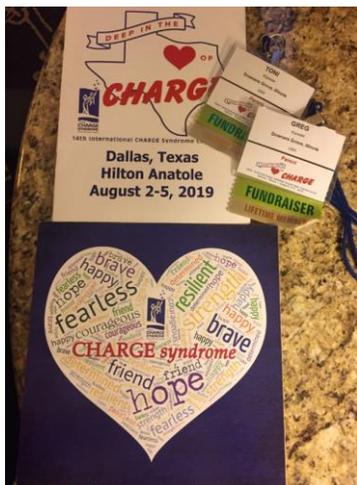




Karen Windy, Editor
Fall, 2019

From the Editor: I would like to *strongly* recommend you **CHARGE ON into this newsletter and see how the families and service providers of persons who are DeafBlind spent *their* summer. Project Reach was able to provide support in many ways!**

14TH INTERNATIONAL CHARGE CONFERENCE **By Antonina Kojowski, Parent**



Pictures provided by Antonina include to your left: their name tags, conference program and a picture of a heart with CHARGE syndrome in the middle and the CHARGE foundation picture with many words in many directions including hope, brave, fearless, friend, resilient, happy, strength, courageous, determined. The words are of multiple sizes and colors. Picture to your right is of Antonina and her husband in front of the CHARGE Syndrome Foundation poster.

The 14th International CHARGE conference was held in Dallas, TX in August 2019 with 1,235 attendees. Of those 1,235 attendees, 200 had CHARGE Syndrome. This was the biggest conference ever comparing it to the first conference in 1993 in St. Louis, MO with 250 attendees. Look how we have grown!

Our first conference, as new parents, was in 2005 in Miami, FL. Elizabeth was two years old. In the blink of an eye she turned 16! It was something that will stay with us forever. We felt tearful, scared, and overwhelmed. It was an emotional roller coaster. At the end we came back armed with new information, support system, and resources. We have been fortunate to be able to attend each conference since then.

Sometimes as a whole family; sometimes just parents; sometimes just me, but each conference was so uplifting and brought strength to CHARGE ON!

This conference (in Dallas) was also amazing. It was a big CHARGE family reunion with the wonderful CHARGE community. Where families spend magical time embracing each other laughing and hugging. Lifting each other up from the dark times and sadness. Where families learn from the professionals and each other how to overcome the challenges that are lined up on our CHARGE journey.

It reminded us how important we are in our children's life. To believe in their potentials despite all the challenges that are ahead of them. It reminds us how special the siblings are. How important it is to stay involved with our CHARGE syndrome organization. Fundraising for research to make a better and easier life for our kids

CHARGE foundation now has liaison programs in 18 states, Illinois is one of them. Thank you Gallimore family! Each session touched every aspect of the CHARGE journey from medical, communication, behavior adolescence and adulthood. All the professionals did an amazing job.

My favorite as always is David Brown the extraordinary DeafBlind educator. He finishes the conference with his *Deep Thoughts* session. It is so uplifting and motivating that you are ready to battle anything that will come your way.

Tim Hartshore, psychology professor, is a wealth of information on behavior. It's so easy to listen and talk to him because he is also a parent of CHARGE adult.

On behalf of our family we would like to thank the Project Reach for making it possible for us to attend this conference. I will always be grateful. As for each conference is a life changing experience.

Editor's note: A few changes were made to this article to accentuate comments or clarify for the reader.

NOTE: If you were unable to attend the CHARGE conference, Project Reach may be able to access most of the reading material that was made available during the conference. Please reach out to your DeafBlind Specialist if you are interested in a topic related to CHARGE or want to know more about CHARGE in general!



These two pictures were provided by another family who attended the CHARGE conference. The picture to the left is Angelina Roeters and her father, Dan Roeters walking “all the way from the grand ballroom to her room in her walker!” (Dan notes she may have complained a bit). The picture to your right includes Standing, left to right: Dan Roeters, Stacey Litke, Victoria Litke. Seated: Angelina Roeters. They are in front of the 14th International CHARGE Syndrome Conference Poster.



In the next newsletter we will share pictures and stories from the CHARGE Foundation Liaisons and about the 2019 GLOBAL FOUNDATION For PEROXIMAL DISORDERS FAMILY & SCIENTIFIC CONFERENCE!

TOUCH SIGNALS for INDIVIDUALS WHO ARE DEAFBLIND CONFERENCE
By Constance Riley, Special Education Teacher
SPEED 802 EARLY LEARNING PROGRAM

I was extremely privileged to attend the Touch Signals for Individuals who are Deaf-Blind conference with Ryan Odlong this summer. My name is Constance Riley and I am a Kindergarten Special Education teacher for Speed 802 in Chicago Heights. I happened to find Project Reach: Illinois Deaf blind Services on-line when I was struggling to help a student who had CHARGE Syndrome. Through this group I was able to tailor a learning system that helps all my significant students learn and by attending the Haptic training it increased my ability to reach all my students

Haptic was a word that I was not familiar with, but I found out the origin of the word is Greek for “I touch”. Since many of my students are non-verbal, touch is a very important way to communicate. Haptics allows my students to understand who is around them, how people show emotion with facial expressions and teaching concepts like colors and numbers. I started using Haptics this week in the classroom and I feel it is helping me develop a trust with my students. **I never knew how to convey color to my blind students, but Haptics gave me a way of showing my student the world around them.** Thank you again for the opportunity and knowledge I received from the conference. I am looking forward to making a positive difference in my students learning.

Editor's note: A few changes were made to this article to accentuate comments or clarify for the reader.



To your left: Two Illinois participants, Rose Halpin (L) and Susan Hamlink (R) work together as a Haptics provider.
To your right: Constance Riley practices giving Haptic Signals with a partner. She is referring to the text used for the workshop, "Haptic Communication." Copies are available for loan from the Project Reach library.

PROJECT REACH *FIRST AREA* ACTIVITY DAY WILLOWBROOK WILDLIFE CENTER By Michelle Clyne, DeafBlind Specialist

On lovely Saturday in September, five families met at the Willowbrook Wildlife Center for the first-ever Project Reach Area Activity Day! Activity Days opportunities for Project Reach families to meet during fun family learning events, planned with a wide range of ages and interests in mind. They are not "conferences," but have an active learning component for all.

During this activity, DuPage County Forest Ranger Stephanie planned a **hands-on exploration of "touchable biofacts: fur and skulls, feathers, wings, beaks and feet, snake skins and turtle shells.** Stephanie and a volunteer were on hand to explain about the items and how they help the animals and are unique to them.



Picture to your left: Austin Savickas tries on some type of animal eyes to see how they might work. He's not afraid to try anything!

Our group had about an hour to explore and ask questions. In addition, there were visual exhibits, and an outdoor trail where injured animals are rehabilitated and live. There was even a deaf fox!

After the exploration, we shared a potluck lunch and resources from the “Guide by Your Side, Illinois Advocates for the DeafBlind, National Center on Deaf-Blindness and the National Family Association for the DeafBlind.” While the parents chatted and the children played, most of the brownies were finished. Project Reach hopes to have more Area Activity Days, and hope you find one you want to come to!



Picture 1 credit: Bridget Withrow



Pictures 2 & 3 credit: Eva Savickas



1st Picture to your left: David Withrow and Donna Stanton, Sign Language Interpreter. Donna shows David the sign for turtle as David gestures towards a turtle in a water-filled tank. Middle Picture: Zachary Savickas listens intently to what the guide is telling him. Picture to your right: David Withrow, Evangelia and Zoe Diehl. Seated: Nina and Tammy Diehl. The group touches a long, winding dried snakeskin.

UPCOMING ACTIVITIES/EVENTS/OPPORTUNITIES

February 13 & 14, 2020 – Illinois AER Conference, Naperville

This is a great conference for Teachers of the Visually Impaired and other who work with the visually impaired. They have wonderful sessions and provide the opportunity to see the new and upcoming technology out there for the Visually Impaired and DeafBlind!

April 3, 4, & 5 – IADB Family Weekend, Peoria

Project Reach and Illinois Advocates for the DeafBlind will host a weekend for parents of children and youth who are DeafBlind. **PLEASE put this on your calendar now!** Start arranging childcare if you need to. All families who have attended in the past say that the best part of this weekend meeting and collaborating with others who know what it is like to have a family member who is DeafBlind.

The [National Deaf Center on Postsecondary Outcomes](https://www.nationaldeafcenter.org/topics/deaf-101) (NDC) launches **Deaf 101** today. **Deaf 101** is a free online short course designed to provide basic knowledge and tools necessary to communicate effectively with deaf individuals, especially in educational and professional settings. Check It out here: <https://www.nationaldeafcenter.org/topics/deaf-101>

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Thank you!

A publication of the Project Reach, 818 DuPage Blvd., Glen Ellyn, IL 60137 – Voice: (630)790-2474, Fax: (630)790-4893, TTY: (800)771-1158, www.philiprockcenter.org/project-reach; email: mclyne@philiprockcenter.org

***Project Reach
Philip J. Rock Center and School
818 DuPage Blvd.
Glen Ellyn, IL 60137***