



Texas School for the Blind & Visually Impaired

Outreach Programs

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## Texas Chargers: Our family's journey finding a community of support

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*Abstract: The author shares her family's experience finding resources and connections through the Texas Chargers family organization.*

### What is CHARGE Syndrome?

"CHARGE syndrome is a recognizable (genetic) pattern of birth defects which occurs in about one in every 9-10,000 births worldwide. It is an extremely complex syndrome, involving extensive medical and physical difficulties that differ from child to child. The vast majority of the time, there is no history of CHARGE syndrome or any other similar conditions in the family. Babies with CHARGE syndrome are often born with life-threatening birth defects, including complex heart defects and breathing problems. They spend many months in the hospital and undergo many surgeries and other treatments. Swallowing and breathing problems make life difficult even when they come home. Most have hearing loss, vision loss, and balance problems which delay their development and communication. All are likely to require medical and educational intervention for many years." (National Charge Syndrome Foundation website 2012)

My daughter, Elise, was diagnosed with Charge Syndrome in 2013, and we found ourselves immersed in a whole new world with endless questions. We knew nothing about the DeafBlind world or how to deal with the growing amount of medical diagnoses that were stacking up or where to start getting her the help and support we need. We left the doctor's office with more questions than answers and were completely overwhelmed.

We were fortunate that we found the Texas Chargers organization soon after my daughter was diagnosed. Through Texas Chargers we were able to attend our first family conference a few months later and able to connect to local resources with other local families, which has helped us navigate this new world and make the most informed choices possible.



*Figure 1 Elise on the beach holding her hand up in the "I love you" sign*

### Annual Conference

We attended our first Texas Chargers conference in 2013 when Elise was 9 months old. The annual conferences that Texas Chargers hosts take a lot of work from everyone involved, but the time spent has been invaluable to our family and is hard to put into words how much we have appreciated these conferences.



Figure 2 Photo of a group of children and youth in red t-shirts at the Texas Chargers conference

The conferences bring in world experts on Charge Syndrome who can answer questions that are at the top of my mind. Getting to spend time talking to these top researchers about our daughter has been invaluable. Some of the topics we have benefited from were information on how to approach and provide solutions to behavior, learning, communication and development from a multisensory point of view.

Every year as she grows the various experts have all contributed to us making informed decisions as parents.

Providing support and resources is another important facet of the Texas Charger's mission. During the retreat this support is provided through a variety of support groups and special informational sessions. During this time, the moms, dads, siblings, and grandparents of those with CHARGE meet to share and connect. The retreat is supported with resources from the Texas School for the Blind and Visually Impaired (TSBVI), Texas School of the Deaf (TSD), the various Educational Service Centers (ESC's) of Texas, the Health and Human Services Blind Children's Program and Office for the Deaf and Hard and Hearing. These partners support with outreach and information, financial assistance, and many of them attend the retreat and conference, too! Their presence helps ensure families are knowledgeable of not only what resources are available, but how to obtain them.



Figure 3 The author and her family at the International CHARGE Syndrome Conference in 2015

Each year at the conference we celebrate a special Charger by awarding the "Star Charger" award to an individual with CHARGE. The Star Charger provides us with a presentation of life with CHARGE and ways for us to view the world through the "eyes" of a person with CHARGE. We are encouraged by their communication styles (often multimedia presentations with friends and families to put it all together), self-advocacy, and an incredible spirit. Every year these incredible presentations inspire us all. It's the highlight of many of our weekends because it's the very essence of why we get together: to share and celebrate the unique life of someone living with CHARGE.

While parents attend sessions, Chargers and their brothers and sisters get to attend camp and have fun in a safe environment. Regardless of age or ability, they are kept busy with crafts, games, animals, movies, and time to socialize. Some of the kids' favorite characters usually visit, they take train rides, try horseback riding, and sensory activities are available. Then, one of the highlights of every conference is the social on Saturday night where families relax, visit, and dance.

We look forward to the conference every year and also make it a priority to attend the national conferences, where a lot of the research on CHARGE Syndrome is being funded and presented. Texas Chargers supports the National Charge Foundation and encourages families

to get involved. However, we find support in both groups, as Texas Chargers is able to dive deep into Texas issues and resources facing families.

## Connecting our family to local resources



Figure 4 Photo of Elise and Ivuk at Texas Chargers

As Elise grows, our family's needs for support evolve and different questions become top of our minds, the continuing support we get from Texas Chargers has had a huge impact on finding the right medical, education, and community support that we need.

When your child has a rare disorder, it is uncommon to know other families with the same syndrome. Thanks to the website and the Texas Chargers Facebook group, we have been able to connect and form friendships with a whole community of other families who are in the same phases and working on the same goals at the same times. We sometimes have local playdates with other moms, where the kids get together and play.

Through other families we have learned about specialists, educational options, camps, and received a lot of advice in real time as challenges come up. We are very fortunate to have this larger community of families who are willing to help.

## Conclusion

If you don't have a support system as a parent, I encourage you to find one. If it doesn't exist I encourage you to create one. Starting small with a Facebook group and having small get-togethers is one way to do this. TSBVI also has some great programs and training to help parents looking for support to connect or learn about how to start a group.

As life became a bit more normal for us and less medical concerns came up daily, I joined the board of the Texas Chargers two and a half years ago and serve as Secretary. There are nine people on the board, in addition to lots of other parents who help volunteer. Our goal is that everyone has a shared amount of responsibility making sure the conferences and other events and activities come together as planned.

If you have a child with Charge Syndrome, I encourage you to get involved with Texas Chargers, join our Facebook group, and if possible attend our 2017 Texas Chargers Retreat on November 3 – 5, 2017 in Camp Allen Texas. To learn more visit the Texas Chargers website at <http://www.texaschargers.org/>.



Figure 5 Elise with her mother and father



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