

Texas Chargers Seventh Annual Retreat and Conference

By Debika Ingham, Treasurer of Texas Chargers, Inc. and parent of 5-year-old with CHARGE

Texas Chargers, Inc. is a group of Texas families, friends and professionals dedicated to helping children and young adults living with CHARGE syndrome. Our two key goals are to provide an annual retreat to help families access the information and resources specific to the state of Texas and to support the CHARGE Syndrome Foundation in every way possible.

Texas Chargers held our 7th Annual retreat and conference in Navasota, Texas on the first weekend in November (aka opening weekend for deer hunting.) Early on, we had concerns about this and other conflicts families might face in attending this retreat especially since our lives only seem to get steadily more busy and complicated. Our concerns melted away when we had almost 50 families, 50 volunteers and many professionals and friends descend upon Camp Allen. Everybody was ready to share, learn and celebrate.

Not only did we marvel at how our attendance grew considerably from last year, we all marveled at the amount of change our group has undergone. At the group photo, we had individuals with CHARGE who had just been born to some who are entering their transition years and several beyond. Each individual's journey was marked with different challenges and successes. Whether the family was just entering this crazy yet often beautiful existence, or saying or signing the first few words, or moving out of a chair and into a walker, or moving out of a walker and taking their first steps, or eating a few bites on top of being gastric tube fed, or working towards an Acceptance, Review or Dismissal (ARD) meeting, or attending high school, or living independently....each family and each individual showed tremendous resolve to make the best life possible for themselves.



A group photo of all the individuals with CHARGE Syndrome in attendance.

Our weekend began with a group dinner and a casual meet and great with our guest speaker, David Brown. This was my first meeting him and the group had been buzzing about how amazing it was to have him in our presence, so I was a little uneasy about meeting such an expert on Deafblindness and CHARGE Syndrome. When I finally did watch him interact with the families, I was so impressed with how easy he is with both his conversation and with his intuitive observations of the people we were there to honor. He was either lost in conversation with the families or lost in the world of observation and interaction with the individual's with CHARGE.



David Brown, with his easy smile and with his dog.

As much as Texas Chargers pride ourselves on bringing in amazing experts and champions of those with CHARGE Syndrome as our keynote speakers, David was very quick to stress that he doesn't see himself as an "expert" but rather as "experienced" with CHARGE. He came to us from the California Deaf-Blind Project, and since the beginning of his career in education has been working with Deafblindness and CHARGE. He emphasized that CHARGE Syndrome has a few patterns or characteristics that bind, but the spectrum of behavior, capabilities, challenges, and considerations are dizzying. For example:

- The original set of six anomalies that were formerly used to define CHARGE Syndrome has now risen to almost 40 and there are possibly more
- CHARGE Syndrome is a true multi-sensory impairment (vision, hearing, taste, smell, balance, temperature, pain, pressure) effecting communication, learning, development and behavior
- These impairments are often coupled with pervasive issues with swallowing, breathing, eating, drinking and digestion and other fundamental body processes
- While individuals with CHARGE show an incredible resolve to face or overcome these obstacles, almost every action and decision is a battle filled with stress

David then shared some frameworks on how to approach and provide solutions to behavior, learning, communication and development from a multi-sensory point of view. During a question and answer session later in the day, these considerations were used to discuss several behavior and communications issues that families posed. He made it fun for the group by using the framework he shared about the hierarchy of arousal (from deep sleep to uncontrolled agitation) and observations of how we handled ourselves in the room as the talk progressed and our coping strategies....from wiggling in our chairs, to standing, to getting coffee. If this is how people deal with an hour long talk, imagine how those with multi-sensory impairment have to deal with just about everything in their lives!

While families enjoyed time with David Brown and with one another during various support groups and informational sessions, the children with CHARGE and their siblings were enjoying a variety of activities with the help of an army of generous and energized volunteers. Regardless of their age or ability, we kept



Camp Allen provided a scenic backdrop for play, exploration, and friendship

them busy with crafts, games, animals, movies, and time to socialize. One of the highlights of every conference is the social on Saturday night where families relax, visit, and dance. We also held another successful silent auction and raffle with many items being donated or made by the families themselves.

Providing support and resources is another important facet of our mission and we provide that during the retreat through a variety of support groups and special informational sessions. As always, the moms, dads, siblings, and grandparents of those with CHARGE met to share and connect. The presence of members from Texas School for the Blind and Visually Impaired (TSBVI), Texas School of the Deaf (TSD), the various Educational Service Centers (ESC) of Texas, the DARS (Department of Assistive and Rehabilitative Services) Division for Blind Services and the DARS Office for the Deaf and Hard of Hearing supporting us with outreach and information, financial assistance, and many of

them attend the retreat and conference, too! Their presence helps to keep a pulse on the families and help ensure the families are knowledgeable of not only what resources are available, but how to obtain them. A board member provided a session specifically geared towards transition and considerations of older individuals with CHARGE and how to provide a very person centered approach to growing their independence, decision making, and individuality. Financial and trust considerations were also discussed.

Each year, we celebrate a special Charger by awarding the “Star Charger” award to individuals with CHARGE. The Star Charger provides us with a presentation of his/her life with CHARGE and ways for us to view the world through his/her “eyes.” They encourage us with their communication styles (often multimedia and often working with friends and families to put it all together), self-advocacy, and an incredible spirit. This year, Robert Kocian signed, joked, and shared his way through an incredible presentation that left us all inspired. 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.

As a final gesture for the weekend, the board provided copies of Tim Hartshorne’s excellent text, *CHARGE Syndrome*, to all of the attendees. The book has been on almost everyone’s reading wishlist for a while, and we hope this definitive resource serves everyone well in learning more about various aspects of CHARGE Syndrome. This was a tremendous gift we were able to provide our attending members as we’ve had some great success building our organization over the last couple of years. The group has come a long way from its humble beginnings but knows there are always more opportunities and better ways to meet our mission and to support those with CHARGE Syndrome. We welcome you to our website to learn more, read presentations, and be in touch with board members and the member families. www.texaschargers.org

We are excited to announce that next year’s retreat will be held in Navasota, Texas at Camp Allen. Not only are the grounds, the rooms, the service and facilities all wonderful, we have all become acquainted with how to pull off a great weekend with the support staff as planned by our program committee. It also serves as a fairly central location the majority of the families within Texas who attend. The board has made a strong effort in the last year to look at longer term planning and ways to further assist families throughout Texas that have been and will be diagnosed with CHARGE Syndrome. The biannual International CHARGE Syndrome Conference will be held this year in Scottsdale, Arizona and the Deafblind Symposium is also coming early next year. We are very excited to continue learning and sharing within both the Deafblind and CHARGE communities. Into the New Year we go!

Thanks to all of you in the Deafblind community for providing support to our members. We at Texas Chargers hope you and yours enjoy the holidays

and remember to celebrate the best “present” of all – each and every day we have together in this journey called life.