

## Texas Chargers Sixth Annual Retreat and Conference

By Debika Ingham, Treasurer of Texas Chargers, Inc. and parent of 4-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. This article serves to share our 2011 progress and some of our 2012 plans towards fulfilling that mission.

Texas Chargers held our 6<sup>th</sup> Annual retreat and conference in Navasota, Texas in early November. We chose Camp Allen in Navasota for its relatively central location (Texas is a mighty big state so central is a big area in itself!), wonderful amenities and our now familiarity with holding a retreat of this size at this facility. This year, November gave us our first real respite from the heat, but temperatures climbed quickly during the weekend. This month also gives families who attend National some time to gear up for another family reunion – since most of the families of Texas Chargers (and many at the National level) consider one another extended family.

Approximately 30 families and 22 individuals with CHARGE gathered to share our trials and tribulations, to pose our questions, to provide a shoulder to lean on and, most importantly, to celebrate each and every one of our roles in supporting families and individuals with CHARGE. With over 150 people in attendance and 60 volunteers to help with childcare, activities, and other logistics, the 6<sup>th</sup> Annual Retreat was packed with great moments and lots of new approaches to our traditional events.



Sally Prouty spoke to parents and professionals while kids participated in a variety of activities at the 2011 Retreat and Conference

The traditional parent panel kickoff for the weekend changed into a CHARGE focus panel which included parents of children with CHARGE but also teen and adult individuals with CHARGE. The viewpoints offered by our younger panelists helped shape a broader and richer discussion about what parents and children go through over the years. With the benefit of hindsight, they also gave advice to parents on how to respect them as individuals first and to view CHARGE as one of many attributes that make them unique. We concluded the evening with a tough discussion about legislative updates. Texas, like many other states has gone through a brutal legislative session where budget cuts threaten to impact the services and support our families receive. We received updates on what changes have been made, what changes are looming, and ways to continue to influence the decision with our lawmakers in Austin. The importance of finding and keeping important resources on hand is something our keynote, Sally Prouty, is well aware!

Sally Prouty shared the story of her 30 year quest to ensure her son with CHARGE syndrome had access to quality medical, educational, and social services. She (and at the ripe age of 4, her son) has been instrumental in defining, developing, and coordinating services for the Deafblind including intervener services. After paving the road herself in many cases, she offered a presentation on “How to Get What Your Child Needs by Being Respectfully Demanding.” She stressed the importance of understanding and building relationships with the other stakeholders in your family’s success. The key is how to go about demanding what you and your child need without alienating those people that hold the resources in their hands.



Sally Prouty highlights Minnesota, the last of many stops along the way to find and often create the right environment for her son’s education and wellbeing.

One of the great things about Texas Chargers is how vested the agencies themselves are in our mutual success. We have many individuals from the Texas School for the Blind and Visually Impaired (TSBVI), Texas School for 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 and Hearing supporting us with outreach and information, financial assistance, interpretive assistance, and many of them attend the 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 few other changes and additions to highlight were mostly geared towards thinking about the individuals with CHARGE and their needs, perspective and talents. We added a sensory room to allow those with CHARGE who were overwhelmed by the bustle of the conference a chance to have a peaceful place for respite. We added a visual simulation station so people could “see” for themselves what vision loss and impairment is like. We had a Cochlear representative on site to answer questions about hearing loss, devices and eligibility, and to demonstrate various conductive devices. One teen liked an upgrade to her BAHA so much she signed, “I’m happy now” and ran off with the demonstration device down the hallway! We celebrated the art of living in a world with CHARGE by asking those with CHARGE to enter an art contest. The mom’s support group turned its focus from the moms themselves and instead worked with a fabulous array of donated scrapbooking material to put together a portfolio for their children with CHARGE to share with educators, family, medical and other communities. The culmination of our focus on the individuals themselves comes in a special presentation every retreat we call “Star Charger.” This year’s Star Charger, Rachel Gibson, gave a wonderful multimedia presentation which her mother voiced and she signed along. She shared her family, her school, her likes and dislikes, and snapshot of the world according to Rachel. That evening, we all celebrated living with CHARGE in a wonderful family social filled with dancing to a DJ, balloons, face painting, and a chance to smile. Last year’s Star Charger, Rachel Allen, gave an encore performance that won her the best of the “Stage” category at National.



Lexi at work creating her first place art for the Texas Chargers Art Show

For those families that could not attend National in Florida this year, Brownie Shott, a foundation board member, gave an overview of this year's conference, logistics for 2013's conference and a highlight of the key goals and plans for the CHARGE Syndrome Foundation.

### **Outcomes of 2011**

As the families packed and made for home, The Texas Chargers board met on Sunday to review business but to also review the feedback from the members. While much of the feedback was positive, we took to heart the constructive criticism and have earmarked time to discuss how to further improve the conference. One of the most exciting decisions was ways to further our mission to support the CHARGE Syndrome foundation. We've decided to provide all families who attended our conference with family memberships to the National Foundation. We are certain this will provide our families with valuable information provided by the Foundation, help foster increased dialogue with our group on how best to serve the Foundations goals, and will provide better "numbers" at a National level which helps draw attention to the need for research and additional financial support.

### **Plans for 2012**

With the conference barely behind us, we are happy to announce the date for our 7<sup>th</sup> Annual Retreat: November 2-4, 2012. While planning details for the next retreat are a few months away, we have focused on several areas to help support growth. We have increased our focus on our outbound communication by encouraging our families to stay connected all year with Facebook and working on ways to update our website more frequently. We have a board member who is driving fundraising efforts beyond our traditional means to help grow the resources with which we can deliver a retreat, support our families, and support the CHARGE Syndrome Foundation. We are working with our growing population of teens and young adults to focus discussion on transition and

transition planning. We are encouraging families to stay connected with the Deafblind community including other Texas organizations like DBMAT, events, workshops, and ways to develop additional communication access. The Texas Deafblind Census has identified approximately 80 individual students with CHARGE Syndrome from birth to completion of public school in Texas alone. We know this doesn't count adults who are no longer counted on the census and the untold many who are either undiagnosed or who have not come forward for support. We are working with social workers, professionals and educators across Texas to share information on CHARGE Syndrome. Our goal is that no family in Texas with CHARGE is traveling that road alone.

From the first day we heard of the syndrome (the day our younger son was born), we heard great things about Texas Chargers and the wonderful support Cathy Springer, President, has created for Texas families with CHARGE. My first phone call with her put me on the path to great doctors, resources, and an open invitation to call anytime for support. My first retreat had me in a puddle of tears – overwhelmed by the fellowship, the stories, and renewed hope for the future. The following year, I watched as my husband experienced the same roller coaster of emotions. This last year, I've tried to give back by joining the board and helping to put together another wonderful retreat. For more information on this incredible organization, visit our website, [www.texaschargers.org](http://www.texaschargers.org), or join our ongoing discussions and updates on Facebook under the group "Texas Chargers." Our contact information is also on the CHARGE Syndrome website under the "RESOURCES" tab. Feel free to contact myself, Debika Ingham [debikaingham@yahoo.com](mailto:debikaingham@yahoo.com) with comments, questions, or family referrals or to contact any of the other board members listed on our website.