

The hot Texas wind made a strong cooling shift to the north welcoming participants to the 3rd Annual CHARGE Retreat held at the Merritt Bois D' Arch Buffalo Ranch in Denton, Texas. Anticipation was high, as those who had waited all year for the event originally scheduled on the same weekend as Hurricane Ike's arrival had to be postponed until November 16th, 2008. The wait was well worth it.

Over 30 families made the journey with approximately 150 total attendees. The Texas CHARGE board, as well as many others behind the scenes had worked diligently to make the rescheduled event happen and to make it the retreat everyone had looked forward to.

The activities began on Saturday morning during registration when family members received their CHARGE designated shirts and thus began the reunion of friends old and new. Volunteers designated by white shirts waited anxiously inside the door to meet their little CHARGErs. The day had been well planned with lots of emphasis on fun for the kids that included arts, crafts, games, scavenger hunt, hayride and many fun events.

While the kids were being entertained the parents, grandparents, and siblings were offered educational information from agencies from the State of Texas in the form of a speaker's panel. Agencies attending included TSBVI, DARS, Helen Keller National Center, and an Education Service Center Specialist from Region 13. They discussed the challenges of deaf/blindness. It was a poignant reminder to everyone that there is help out there.

The lead speaker, Amy Parker a PhD. student from Texas Tech working with the National Coalition on Deaf blindness, explained her goal to help gain assistance from the federal government for children with sensory impairments. She indicated that the funding for deaf-blind children has stayed generally the same amount, 12.8 million dollars, for the last 20 years. She assured the audience she was working to get that number increased and asked for assistance from participants in the form of support for the increase.

Always emotional and thought provoking, the parents panel gave unique perspectives of those parents dealing with CHARGE. The panel comprised of five parents of children with Charge Syndrome ranging in age from 6 to 26, participated. The parents shared their struggles and their achievements parenting children with CHARGE. One parent noted that raising a child with CHARGE is similar to swimming up a waterfall. One should stop and take a look back because the view from a waterfall is beautiful. The profoundness of the statement struck a deep chord with all.

Also included in the day's activities were the varied forums. Participants could attend the forum that was most appropriate including different forums for fathers, mothers, and grandparents. The fathers sat in a large circle downstairs and shared their experience with challenges of parenting a child with CHARGE. Also discussed were the differences in dealing with charge as fathers compared to mothers. Each father praised their

wife/girlfriend for all support and additional responsibilities that the role of mother entails.

The mothers met upstairs in the loft meeting room and discussed how important it is to take time for themselves, as well as how to be the best moms possible for their CHARGE kids. They shared their ideas and shared stories of how their CHARGE child has made them smile/laugh. It was a great bonding time for all the mothers. Also discussed were the frustrations, and emotional challenges of being the primary care giver to a child with special needs. The grandparents networked and discussed the many facets of being grandparents to a CHARGE child, including concerns about their children, the parents of CHARGE children. Each forum provided an excellent and unique opportunity for openness and honesty and to share ideas and mindsets.

After serious discussions it was time for a little fun. Everyone was lined up to immortalize this 3rd retreat in a group picture and then it was time for some good eats. Not only was the meal great so was the 2008 Star Charger, Kayla Ortegón. Kayla shared her life challenges with CHARGE. Everyone was delighted when she declared, "I have CHARGE Syndrome but I like to think of it as I am in charge and can do a lot about it." Kayla's goal included helping other people in life and thanked her family for all their support. She stated she considered herself just like any other young woman.

Following dinner, a genuine Texas CHARGER Hoedown, was celebrated with a bonfire and smore's, music, popcorn and cotton candy. Everyone danced and played with one another bringing to end another educational, emotional, and life changing retreat for families and children with CHARGE.

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