



## Jordy Family BBQ Fundraiser



The Friends and Family of the Jordys are gathering together on August 23<sup>rd</sup>, 2013 from 11am-2pm to raise money to help offset the cost of Kiersten's medical bills and associated expenses. The fundraiser will consist of BBQ sandwiches, chips, and drinks. We are accepting donations for items that will be needed. This will allow us to donate 100% of the proceeds. Any donations received will be graciously accepted and recognition given. Thank you from the bottom of our hearts!!

Kiersten, was diagnosed with Kabuki syndrome which is a pediatric congenital disorder of suspected genetic origin with multiple congenital anomalies and intellectual disabilities. It is quite rare, affecting roughly one in 32,000 births. Also Tuberous Sclerosis complex (TSC) which is a hereditary condition associated with changes in the skin, brain, kidney, and heart. Seizures are a frequent complication, and some people with TSC have learning disabilities. The Jordys have to make continuous trips back and forth to Houston for Kiersten's doctor's appointment, procedures, and any setbacks that come along the way. Here's a brief synopsis of what life has been like for the Jordys over that past year.

- ❖ Been sick since November 2012
- ❖ Admitted to Texas Children's May 3
- ❖ Moved to Memorial Hermann on May 10th
- ❖ 8 total admissions to date
- ❖ Diagnosed with Chiari malformation and Syrinx
- ❖ Had surgery May 13<sup>th</sup>
- ❖ Diagnosed a month later with Pseudo tumor cerebri
- ❖ Has had 6 lumbar punctures in 2 weeks
- ❖ Had a Lumbar-peritoneal shunt placed July 18<sup>th</sup>
- ❖ Having to wear a pressure wrap now to keep fluid from bulging around incision sights
- ❖ Will be placed on homebound school
- ❖ Will be receiving speech, occupational and physical therapies weekly

Despite all the Jordy family has endured over the past year, they continue to hold strong in their faith and know that God has blessed them in so many ways.