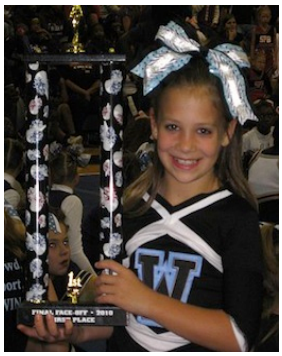
Aiden Rae Gabel- PEDIATRIC FMD



"All kids have high blood pressure when they are sick", is what my husband was told by the nurse during a 'sick' visit to my then 5 1/2 year old daughter's pediatrician. Aiden had a cold, nasty cough, headache and a slight fever. Her BP was 180/105.

Luckily, my husband caught it and he asked the nurse to take it again, and again, and then had the Pediatrician take it. All four times, it had been around the same, 180/105. We were told to go home and come back in one week. No one seemed concerned about her blood pressure.

I took her back for her follow up and her BP was still around 180/105. I asked the nurse to take it again, it was still high. She brought me to the exam room and looked up her past blood pressures. She said "Well, looks like her blood pressure has always been high so that's normal for her", and turned the computer screen so I could look at it. My first horrifying thought was: "how as parents could my husband and I never have noticed this?". My 2nd thought was: "how could her Doctor not be concerned when her BP had been high for years?".

We were sent home that day having been told she had hypertension and a referral for blood work and an echo at Scottish Rite. We were told no physical activity for her. No PE at school. No running around. No gymnastics or softball (she was playing softball and was on a training team for competitive gymnastics). We were told that would make her headaches go away.

Over the course of almost 4 months, including wait time for test results, Aiden had tons of blood work, echos with normal results, renal ultrasounds with abnormal results and an MRI.

Aiden had the MRI and the doctor at Scottish Rite told us she had FMD in her renal arteries, primarily the right one and he showed us the 'strand of beads'. "She has what???", my husband and I both said.

He referred us to an AMAZING pediatric nephrologist, Dr. Jernigan, (who, I recently learned, also treats another local child that has FMD) here in Atlanta who we saw right away and immediately put her on Enalipril. While Aiden still had to keep the physical activity to a minimum, she no longer complained about headaches. Dr. Jernigan gave us a little info on FMD but her regular pediatrician had little to no info.

That's when I found the FMDSA website and e-mailed Pam and both were my savior. Pam put me in touch with local Surgeons and we had consults about what to do next. It was decided by Dr. Jernigan and the Surgeons that since the Enalipril was keeping her BP close to normal, and given the size of her arteries, angioplasty was not needed at that time and we were to revisit this when she was 10.

We have had renal ultrasounds every 6 months, and MRI once a year to make sure all is ok. Both of her kidneys are growing fine, and her BP has stayed great on the pills. Last year she was upgraded to seeing Dr. Jernigan once a year and we are to schedule for that appointment in April 2011. We also take her blood pressure at home.

I do not have FMD and as far as I know, no one in my family has it. However, my mother had diabetes and had high BP. She did end up having a kidney transplant due to failure and eventually

had a stroke and passed away (before Aiden was diagnosed with FMD). All of those were a result of her diabetes but we wonder if she did have FMD as well.

In reading these stories, I know 100% that we have been very fortunate with Aiden and FMD. Yes, she has been poked and prodded, spent nights in the hospital and couldn't run around for 6 months but there has been nothing major that we have had to worry about thus far. (Knock on wood!)

It has now been 5 years and Aiden is a normal 10 year old that takes Enalipril twice a day. She no longer plays softball or gymnastics but is in competition cheerleading and tumbling classes twice a week. You would never know she has any condition. I know that her future will be full of challenges, hospital visits and many tests but I thank God every day for her and that we find a cure for FMD someday!!!!

Shawn and Kristie Gabel - Atlanta, GA
Aiden's Proud Parents