

**Hannah McNutt Memorial – 4/7/12 – Written by Alexa Craig, MD and Read by Lyn Kratz, MSW**

I was in my last 6 months of child neurology training when I got to know Hannah and her family. Knowing I have a tendency to develop close bonds with patients and their families, and knowing I was leaving Seattle soon, I consciously thought that in this case I should not let this happen. Maybe it was the 10th or 11th time I stood in the ER with Allyson and Greg as we poured anti-seizure drugs into precious Hannah, or maybe it was when I realized Greg and Allyson were violating resident duty hours by spending more time at the hospital than me, but the inevitable happened and despite my best efforts the bond developed. Their presence as a couple was captivating. We so often see families pulling apart, arguing, blaming and there they were, Greg holding Allyson's hand and Allyson holding Hannah's hand. Team McNutt, we all wanted to be part of it.

The next thing I knew I was spending hours convincing other providers that Hannah needed the ketogenic diet and "oh by the way, I admitted her last night and I had mom read the book already, so can we start today?". When that did not seem to be working as I had hoped, we proceeded with the placement of a central line, me secretly hoping that with Allyson and Greg's skills of seizure management and the tremendous support of Medic One that one day home iv phenobarbital would be possible and save some of those countless ER visits. I think it was then that I began the early transition in my thinking from how can we cure these seizures, to how can we help Team McNutt live with these seizures.

I left Seattle in June feeling gutted as I hugged Allyson goodbye on Train 2 knowing that I had not accomplished my goal of stopping the seizures. While that felt at the time like a failure (even though I recognized it was probably an unrealistic goal), what I have learned from Hannah is that it was not. Hannah has taught us all that we focus too much on the name and symptom list of known diseases and that in the face of the unknown we crumple. The McNutts taught us to be better providers by refocusing the family centered approach to the goal of living graciously with the symptoms of disease, rather than on the conquering of disease. I know this lesson has profoundly affected each and every provider who had the privilege to know Hannah and her family. It is astonishing to me that one little girl with that much phenobarbital in her system could teach us all so much.