

## **Hannah McNutt Memorial – 4/7/12 – Written and Read by Sharon McDaniel, MD**

I first met Hannah in the hospital a few days before the epilepsy walk last June, and while Hannah slept, Allyson was busy making scarves for all the members of Hannah's Heroes team. When I showed up at the walk on Saturday, everywhere I looked, there was another person in a colorful fleece scarf. I was astounded that a 7 month old girl could already have such a huge loving fan club, such close family and friends that truly came together in support of her. Little did I know then that this club was going to just keep growing, and that I too would soon become a big fan of Hannah and her family.

By the time I became her neurologist last fall, a lot of very capable and experienced physicians had already been involved in Hannah's care, thinking in depth about her diagnostic testing and treatment options. In fact, I think everyone in our division had been involved with her at one time or another. Here I was, a brand new epileptologist, being asked to take over this little girl's very complicated case. All these years of medical school, residency, and fellowship... I was certain that this was really going to put my training to the test. Instead, caring for Hannah presented challenges that our medical education doesn't prepare us for. My training had taught me to diagnose and treat diseases, using evidence or research-based medicine. By this time, however, we were starting to suspect that Hannah had a disease that we can't yet put a name to and whose progress we don't yet have a way to halt. In this way, medical science failed Hannah. But Hannah and her family taught me to redefine failure and success. Allyson and Greg had the remarkable strength and courage to listen to Hannah and to each other, and we were all able to recalibrate. This was not something medical school or residency had taught me to do. Our shared goal shifted to giving Hannah a comfortable life at home with Allyson, Greg, and big brother Wes, a peaceful life that didn't involve frequent chaotic PICU stays and adrenaline-filled emergency room visits. When I saw Hannah at home during the holidays, embraced by the palpable love of the McNutts and Browns and extended family members I'd first met wearing the colorful scarves, I saw first-hand that this was the right path for her. When we all listened to her and let her be our guide, Hannah told us quietly but so clearly what she needed and when. The resulting time at home was a beautiful sunset to Hannah's life.

To be a part of this process is to be changed. For my colleagues and myself, caring for Hannah was a privilege that not only brought us close to an amazing family, but that also taught us valuable lessons to be carried on in our work and in our lives. I am reminded of these lessons every day when I walk into my office, and the offices of many of my colleagues, and am greeted by a card with a happy photograph of Allyson, Greg, Wes, and Hannah, and a single word: Joy.