

Hannah McNutt Memorial – 4/7/12 – Written and Read by Jonna Clark, MD

Many of us, as parents, dream that one day our children will impact and touch the lives of many, making the world a better place. Hannah, in just a short 16 months, did just that. Since her passing, so many of those who have been touched by her life wear a different pair of eyeglasses.

I first met Hannah and her family when she was six weeks old. She was recovering from an illness that was nearly fatal, that had required numerous invasive life sustaining interventions to support her, an illness that to this day we do not fully understand. And yet, while we were there together in the cold and sterile environment of the Intensive Care Unit with loud alarms, noisy machines and flashing lights, there was Hannah, sleeping comfortably in her mother's arms, feeling the love of her family. I was drawn to Hannah and her mother, who shared with me stories of Wes, her brother, who loved to play with Legos. At that time, as a critical care physician in training, I did not realize the impact that Hannah and her family would ultimately have on me.

The following months were extremely rough for Hannah and her family, for she required numerous physician visits and hospitalizations, some of them prolonged, requiring invasive and painful procedures. With each hospitalization, more tests were drawn, more subspecialists consulted, and yet, there were no answers. The cause for her intractable seizures, global developmental delay, and progressive neurological decline remained a puzzle. Hannah, as a unique and special person, did not like to follow the rules. She challenged each and every physician who cared for her, pushing our current state of knowledge to the extreme limits. Each time I interacted with Allyson and Greg, I would ask them hopefully, "Any answers from the smart doctors (referring to the neurologists and metabolic physicians)?" Based on the look on their faces, I usually knew the answer before they replied, "No."

Along this journey, Allyson and Greg became too familiar with the healthcare system. Having relocated to Seattle for Hannah, they knew how to navigate EMS, the emergency department, the turnover of medical staff and nurses, the trainees. They spent endless hours advocating for Hannah, for they knew how special she was and wanted her to receive the best medical care possible. They remained hopeful that someday the seizures that engulfed Hannah's body would resolve, and Hannah would one day be free to live the life that every child deserves.

While holding onto the threads of hope, amidst the challenges of the medical system and the extreme uncertainty in prognosis, Allyson and Greg recognized that Hannah deserved to live a high quality of life filled with dignity. They knew that Hannah, who was born on a warm, sunny day in November, did not want to live her life trapped in a cold and sterile hospital, attached to machines and tubes, with numerous nurses and doctors prodding her. They, along with her neurologists and other care providers, reached above and beyond the boundaries of the hospital walls to provide Hannah with the best medical care, in an environment where Hannah could be a child, close to those who loved her the most, in her own home. As her incurable disease continued to progress, Allyson and Greg, as two of the most loving and caring parents, gave Hannah the opportunity to enjoy her short life in the comfort of her own home.

The night that Hannah passed away, listening to beautiful singing, held by her mother's arms in her own home, I was working in the intensive care unit. Through one of the patient's windows, I caught glimpse of the beautiful glowing sunset. Amidst the chaos of the ICU, I felt a sense of peace. A few hours later, one of the neurologists informed me that Hannah had passed away. I took pause, shed some tears, and reflected on Hannah and her family's journey over the past year and a half. Beyond the advances in science and medicine, beyond the bells and whistles of our life sustaining technology, there is so much more that we have to learn. Acknowledging the reality that many times we do not have answers, we need to think outside the artificial box of medicine that we have created. Through listening to the wishes and hopes of the children and their families, we can make the greatest difference in the care that we provide. Hannah and her family helped all of us gain a new perspective, a new set of eyeglasses, a gift that has taught all of us to remember what is important in life.

Thank you, Hannah. May your legacy live on forever.