

To Whom it May Concern:

On October 8th, 2016 our son Ezra was born a healthy and happy baby, weighing 6 lbs, 14 ounces of perfection. On October 26th, we received the devastating news that he had been diagnosed with Early Infantile Krabbe Disease as a result of newborn screening. After researching, we reached out to Hunter's Hope and they put us in touch with Dr. Joanne Kurtzberg at Duke University the same night. She explained the process, benefits and risks of transplant and we decided that it was the best option for our family, and most importantly for giving our son the best chance at life. The next evening, our family made the long drive from Missouri to North Carolina, so that Ezra could receive a stem cell transplant at Duke. There has never been one moment of time that have we ever regretted that decision. We spent five months in North Carolina where he received treatment and recovered. Gratefully, Ezra experienced no complications during transplant other than a small case of graft versus host disease, which was easily treated. The only medication he requires at this time is one to help with muscle tightness.

Today, Ezra is a 2-½ year old bright, social and active toddler. Due to his prolonged hospital stay, Ezra currently receives physical therapy services for some physical delays, as well as speech therapy to catch him up with his peers. However, that does not slow him down in any way. Ezra says many words and knows many sign language signs. He is walking assisted with a walker and is working on walking unassisted, which his therapists are confident is just around the corner. Ezra loves to sing, dance, build, laugh, swim, play with friends and anything that has to do with animals. He is very independent and enjoys learning to do things on his own, which most recently is eating his meals with a fork. In fact, many who do not know our story would not assume he has any delays at all.

For our family and friends, newborn screening changed our lives. Without it, our son wouldn't have been given a second chance at a fulfilling life. It truly saved his life. He is now a strong and determined child who is thriving despite his circumstances. He has added an immeasurable amount of joy to the lives of all around him and the progress that he continues to make daily is astonishing. The idea that there are children around the world who are not being given the same chance at life that Ezra was is both infuriating and heartbreaking. For someone to feel that our intelligent, playful and loving son's life is invaluable is unacceptable and should not be an option for the many babies being born around the world. We ask that you critically consider this life saving treatment and give other children and their loved ones the same opportunity at a fulfilling life.

If you have any questions, please do not hesitate to contact us.

Sincerely,
Ryan, Karlita & Ezra Blackwell
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