Dianna Greene

My name is Dianna Greene. I have been married to the love of my life, Jeff for 21 years. We are a blended family with Jeff having two daughters from a previous marriage and me having 5 children from previous marriage plus we have a daughter together. I am Mom to Jodi, Anthony, Joshua, Ashley, Dakota and Dalton and stepmom to Selina and Nicole.

In 1988 my first son, Anthony who was born completely healthy, at least that is what I thought. At three months old Anthony started having trouble with his formula and became extremely irritable. By four months old, he was getting worse and had started crying more like he was in pain. I took him to several doctor's appointments and the ER a couple times with nothing more than a colic diagnosis. I was a young mom with two children, but I knew in my heart something was wrong. Anthony was in clear pain and was getting worse with each passing day. I was told during one ER visit that he will eat when he is hungry and to take him home but to bring him back if he doesn't start eating better in one week. I told that doctor I was not going to let my son go a week without eating. I left that hospital and took Anthony to a neighboring hospital ER where he was immediately diagnosed as dehydrated. He got IV fluids and was referred back to his PCP for a follow-up. Of course, that follow-up visit we got the same diagnosis as usual..."He has colic. He will get better as he gets older." I was treated like a young mom who didn't have a clue about children. The frustration was taking a toll on me and his father. We were tired, we were ill, and our son was still getting worse. We looked for another pediatrician only to be told no one was accepting new patients. Finally, when Anthony was five and a half months old, I was able to get a local pediatrician to just see him for a consultation. In a matter of five minutes, she told us that she could tell just from Anthony's composure and his arching of his back with the fisting of his hands that he had a neurological condition. She didn't want to confirm it without further test, but she thought Anthony had Cerebral Palsy. I thought my world was crushed that day...little did I know what the upcoming test would confirm.

After a short hospital stay, a spinal tap and a small piece of his skin taken for further testing, we were finally getting the doctors to hear us and believe that Anthony was sick. They told us during this hospital stay that they thought Anthony had a lipid storage disease called Krabbe Disease. They gave us a little bit of information, scheduled an appointment with a genetics doctor and released Anthony from the hospital. We left feeling quite confused but found comfort in knowing we were getting a diagnosis (still not knowing exactly what that would mean for Anthony). We also had pain management for Anthony, and he was even able to eat better with some formula adjustments.

I went home and found a medical journal of my mom's. There was a very brief description of Krabbe Disease. That is the day I found out that my precious baby boy had a terminal disease and was probably going to die before his second birthday. Now my heart was crushed!!!

We went to the geneticist a couple weeks later and were given more detailed information on Anthony's possible diagnosis. We spent a long time telling our family history and hearing genetics. We were even asked if there was any possibility that we were related (I was highly offended, but I understand that question a little more now). We were told we should have a confirmation within a few more weeks but the geneticist truly felt like Krabbe Disease was Anthony's diagnosis. I prayed she was wrong but on August 5, 1988, I received the telephone call that no parent would ever want to receive, "I'm sorry but Anthony has Krabbe Disease. We will help you keep him comfortable and provide you with resources. He is not expected to live past two years, and it is our belief that he may not live to his first birthday." I will never forget that phone call...NEVER!
For the next six and a half months we loved on Anthony. I had to learn medical interventions that would assist Anthony such as suctioning, ng tube feedings, medication, and oxygen. He was placed in hospice care but remained at home with his family. The wonderful pediatrician who saw him for a consultation became his new PCP and she learned all she could about Krabbe. We were told there were about 11 confirmed diagnoses of Krabbe Disease in the United States so we would probably never meet another family with this diagnosis.

January 22, 1989, we celebrated Anthony's first birthday. It was a beautiful day with family celebrating this day that we never knew for sure would come. My Heavenly Father gave us that day and I am so thankful.

Just a couple weeks after Anthony's birthday he developed his third bout of pneumonia. I never knew for sure, but I felt like Anthony was mostly blind. His tiny body was so weak. On February 21, 1989, Anthony was released into Heaven with our Heavenly Father. Our family spent several hours afterwards holding Anthony, crying, and loving him; each one saying their own goodbyes. I was forever changed but I tried to hide my grief because I had my daughter, Jodi who needed me to be her mom and take care of her.

As the next few years came and we had to learn to live life without Anthony, the sadness remained but joy also came. I somehow managed to live with both emotions. Soon came Joshua and then five years later came Ashley...neither of them having Krabbe Disease. In 1996 I found out I was pregnant again. Shortly afterwards I learned that I would be having twins. Wow...I was nervous and excited. Ashley was only six months old and in seven months I was going to have twins. How in the world was I going to do this? Now I had two more babies that would be tested

for Krabbe Disease. I reached out to our geneticist for any updates on treatment for Krabbe Disease to be told there was no beneficial treatments for infantile Krabbe Disease. I made the decision to test the twins when they were born and to just enjoy what I knew would be my last pregnancy. So that is what I did.

On October 3, 1996, I had an uncomplicated labor and delivery just five days before my due date. I gave birth to my daughter first. When we saw she was a girl we were in total shock. The ultrasound showed baby A was a boy at one visit and baby B was a boy at another visit. We were prepared for two boys, but God had other plans. Eighteen minutes after Dakota was born, Dalton came. He started crying immediately and I felt complete joy.

As most mothers know, after giving birth there is the chaos of weighing and checking vitals, washing the babies, and just getting everyone ready for bonding time. That time came and I was holding my two precious babies. After having a child with Krabbe, I always watched my other children, just looking for that sign, any sign, of Krabbe. It is still something I always do now. I find I do that to all babies. Dakota looked so healthy and pretty content. As I looked closely at Dalton and watched every single move he made, my heart knew, my brain knew...I knew. Dalton had Krabbe Disease. We had made the decision to test them at around two weeks so we could just have some time with them and enjoy our healthy babies.

We followed up with our geneticist at two weeks and waited two more weeks for the test results. On October 31, 1996, we got that call again, you know, the one no parent would ever want to get. She said Dakota does not have Krabbe, but she is a carrier. Then she said Dalton has been confirmed to have Krabbe Disease. Again, we were told there was no new treatment, and they would help us to keep Dalton comfortable as he progresses in his disease. To say we were devasted is an understatement. I was so sad. I kept asking God why he would send our family these two precious babies only to take one away. I was sad for Dakota because she would never know her twin brother. And I was sad for our other children because they were going to experience a great sadness that they could not possibly understand.

The World Wide Web was a new platform for information for some families via personal computers and was also available for public use in the library. We had many of our family and friends doing the latest research. Within a week, they found research information about bone marrow transplants being done as a treatment for Krabbe Disease. Studies showed there could be a benefit from a bone marrow transplant from a nonaffected person to an affected person which would allow the recipient to start producing the missing enzyme and stop the progression of Krabbe Disease. There was no documented case of a successful transplant in the infantile onset form of Krabbe Disease.

I found the website for The United Leukodystrophy Foundation (ULF) and called them to ask for more information on this treatment. I was given the name and phone number to Dr. William Krivit in Minneapolis, Minnesota. I called Dr. Krivit's office and told the lady who answered the phone why I was calling. She let me speak directly to Dr. Krivit. He expressed the urgency in getting Dalton to him for an evaluation so we quickly decided we would go immediately to Minnesota. I hung up the phone and began making arrangements for the care of my other four

children because I would be flying over 1,100 miles away. Then I called to check on emergency flights leaving the next day.

I called Dr. Krivit back to tell him we were set to leave the following day. He explained that he would not be in the office upon our arrival, but he told me who we would be meeting and that we would see him the following day. Then he started asking more detailed information about Anthony's life and his history with Krabbe Disease, then asked about Dalton's signs, if any, of Krabbe. I told him the only real thing I noticed in Dalton was a twitching in his eyes on occasion. He immediately said, "It's too late." I asked why and he said infantile onset progressed so quickly that even if he did the transplant, Dalton would most likely have irreversible neurological damage. He told me we could still come, and he would evaluate Dalton, but he could not say that he would do the transplant. I told him I knew Dalton's outcome without a transplant or any other treatment so I would be willing to take the chance. I told him I needed to talk with our geneticist, and I would be back in touch with him soon.

The next day I called our geneticist and asked her why no one ever told us about the possibility of a bone marrow transplant. She explained that no child with early infantile onset of Krabbe Disease has had a successful transplant and that is really was not a recommended treatment. I told her that I felt that was something the parent should at least be informed about as a possible option. She advised me that she would contact a doctor at UNC Chapel Hill Hospital to schedule an appointment for Dalton to be evaluated.

In less than a week, Dalton was seen at UNC Chapel Hill Hospital by the bone marrow transplant team. At that appointment, they also did bloodwork on our family to test for a possible bone marrow match. We went home from the appointment feeling anxious and hopeful. Just a week later we received a phone call from the transplant team coordinator with an update on our insurance policy requirements and with the great news that Dakota was a perfect six out of six match for being a bone marrow donor for Dalton. Our insurance stated that UNC Chapel Hill Hospital was out of network for the bone marrow transplant that Dalton would need but stated the hospital just 10 miles away was in network. So, we were referred to Dr. Joanne Kurtzberg at Duke University Medical Center. Within another week, another evaluation was done by the transplant team at Duke University Medical Center and Dalton was soon admitted to the hospital to start the process of receiving his bone marrow transplant from his twin sister, Dakota.

On December 4, 1996, at just two months and one day old, Dalton received a bone marrow transplant at Duke University Medical Center by Dr. Joanne Kurtzberg. Dalton was her first

patient with Krabbe Disease, but she had just given a transplant to a young man with ALD, so she was familiar with leukodystrophies.

Dalton had a successful treatment and through many years of research and studies, Dalton was with our family for twenty-one years, eight months and twenty-two days. Dalton was a very happy young man. He loved WWE and going to church. He especially loved his visits to New York where he got to see his extended leukodystrophy family. He loved his family so much and you could see that in everything he did. His father and I divorced in 2000 when Dalton was almost 4 years old. He loved his visits with his dad so much. He had a special friend, Scotty, that he enjoyed spending time with. He even had a "girlfriend", Britni that he said he was going to marry someday. Dalton attended regular public school and graduated high school with honors in June 2015. He was crowned Homecoming King his senior year by his peers. Dalton made a difference in everyone's life he came into. You would always find him smiling.

On June 25, 2018, after 10 days in ICU due to a severe respiratory infection, Dalton passed away peacefully with his entire family by his side. Our family has been completed changed as Dalton had such a wonderful impact in our lives. He taught us all so many things but mostly how to enjoy life to the fullest. We take it day by day (actually minute by minute) but we are moving forward and looking forward to the day we are all reunited as a complete family with Anthony and Dalton.