Hunter at One and Two

Hunter was born on his daddy's birthday, Valentines Day, February 14, 1997. Hunter passed all the newborn tests with flying colors, weighing in at 7 pounds 14 ounces, and measuring 21 inches. Our dream had come true. God had given us a beautiful healthy son. We were ecstatic.

The first month, Hunter appeared to be a normal healthy baby showing some signs of colic. The second month, he became more irritable and, by the end of the third month, he spent most of his waking hours screaming. Our pediatrician continued to say that Hunter had colic, while we tried practically every formula and nipple on the market. When he became even more irritable, started stiffening his arms and legs, and was unable to achieve any developmental milestones, our pediatricians said he was showing signs of Cerebral Palsy (CP). We were devastated, but determined to do everything we could, with God's help, to give Hunter the best life possible.

In Hunter's fourth month, his body became stiffer, he was having trouble swallowing, and he was experiencing mild seizures. Because Hunter's health continued to decline, our pediatrician suggested he go to a child neurologist. Hunter's neurologist decided to test his blood for leukodystrophies. Our worst nightmare came true. On June 23, 1997, Hunter was diagnosed with Krabbe disease. Now we are praying for a miracle. At the time of his diagnosis we were informed that no treatments or transplants were available and that we should just make him as comfortable as possible. The first year of Hunter's life was quite a battle. Our primary goal was to make him comfortable, therefore, various medications were the only options for controlling his irritability, stiffness and seizures. Due to his inability to swallow, Hunter began losing weight and started aspirating his formula. On July 3, 1997 a feeding tube was placed in his stomach and he now weighs 20 lbs. To date, Hunter has been treated for pneumonia over a dozen times and hospitalized four times for severe pneumonia attacks. In January 1998, he had RSV (respiratory system virus) and spent two weeks in the ICU, nine days of which he survived on a respirator. As tough as he is, our little guy struggled through it all. Following Hunter's 1st birthday celebration (we had a huge party for him - of course!) we realized that we needed to make a few major changes. We decided to become more aggressive and proactive in our approach to caring for him. From the Ketogenetic diet and natural food supplements, to air purifiers and respiratory therapy, we tried it all. Hunter's physical and occupational therapy sessions went from being pretty relaxed and uneventful to very active, upbeat and fun for all of us.

Our philosophy was to "get him moving", - be AGGRESSIVE !! Today, Hunter receives PT and OT 5 days a week and is showing signs of improvement in his motor skills. He loves lying on his belly, relaxing in the Jacuzzi and cruising around the house in his KidKart. Although Hunter still hasn't smiled since he was four months old, he now opens his big, beautiful eyes for us wider and longer (we think he smiles with his eyebrows). Because Hunter's lungs have been through a lot over the past year and a half they are very damaged. We visited a respiratory specialist in June of 1998, did lots of tests, scans and x-rays and discovered that both of the lower lobes of Hunters lungs had collapsed, and the majority of his upper lobes were severely scarred. The only solution we felt comfortable with was to provide him with more aggressive respiratory treatments and 24 hour oxygen maintenance. Today, Hunter receives chest therapy six times a day and believe it or not he loves it. Now when Hunter gets pneumonia he recovers much quicker and we stay out of the hospital.

On February 14, 1999, Hunter Boy celebrated his 2nd birthday "WOW!" The 2nd Annual Hunter's Day of Hope for Children was again a huge success. Unfortunately however, a week prior to the celebration Hunter came down with a severe cold and was unable to attend. On his birthday, Hunter was once again admitted to Children's Hospital for pneumonia. Luckily our little soldier avoided the respirator and was back home in 5 days. When Hunter was diagnosed with Krabbe disease, we were told that his health would decline rapidly and he would probably not live past fourteen months. Hunter is now over two years old and with our continued love and aggressive support, he will celebrate his third birthday. You never know, with his courageous spirit, that "never give up" attitude and prayers from so many hearts all over the world, he just may surprise us all and beat the odds for this dreadful disease.