

# Christopher's Story

My name is Christopher Lesta.

I was born on August 26, 2002, was diagnosed with Hunter Syndrome on October 18, 2004 and joined the angels in Heaven on December 9, 2007.

I was five years old, but I left knowing that my life here was complete!

Hunter Syndrome (or MPS II - Mucopolysaccharidosis II) is a rare and untreatable genetic disorder caused by the body's inability to produce an enzyme called iduronate sulfatase. Due to this inability, cells do not perform properly and cause progressive damage throughout the body including the heart, bones, joints, respiratory system and central nervous system and a drastically shortened lifespan.

Since I was three months old, I had constant sinus infections. Each time I would have to take antibiotics and then I would feel better, but I would always get another sinus infection. This became a cycle. My parents insisted that something else was going on, so I had several blood tests and x-rays taken. But those all came back negative. Everyone was saying that it had to be my adenoids and tonsils. So we went to an ENT doctor. He said my adenoids looked larger than normal and in January 2004, I had them removed. I was better for a little while, but then the cycle started again. After several more months of sinus infections, my parents took me to a genetics doctor. I think the doctor knew instantly what I had, but he had to confirm it with a urine and blood test.

On October 18, 2004, my parents received the diagnosis of Hunter Syndrome. It was a very difficult time for them. But my parents wouldn't accept the fact that nothing could be done. They researched my disorder on the internet, spoke to other doctors, went for a second opinion, called other families and found out just about everything they could to help me. After one more surgery in January 2005 to remove my tonsils, my family and I headed South to Duke University Medical Center in North Carolina for further testing and information on an Umbilical Cord Blood Transplant - the closest thing to a cure at that time.

While at Duke, we found out that I had a slight hearing loss, but that I was also a good candidate for the Transplant. Before making any decisions on the Transplant though, the doctors wanted me to get hearing aids and then return about six months later to see if my hearing loss had any effect on my testing. In September 2005, we returned to Duke and although my hearing loss didn't show any effect on my testing, we were still told that developmentally I would begin to decline within one to two years. It was then that my parents made the decision to go forward with the Umbilical Cord Blood Transplant.

My family and I relocated to Durham, North Carolina in November 2005. I had an Umbilical Cord Blood Transplant on December 2, 2005. There were many ups and downs, but I was finally told that I could go home to New York in June 2006. I was doing well. We made our visits to Duke University Medical Center every six months for testing. In May 2007, I was told that I could attend Kindergarten, so in September 2007, I started in a special class at our local elementary school. Over the next few months, I was in and out of the hospital with fevers. In December, I picked up an infection (MRSA) through my mediport. The doctors couldn't save me and it was my time to go Home to God with my angels. It was December 9, 2007 in the early morning.

I am always around my family. I watch over them very closely. I love them very much. One day, we will all be together again. My parents hope that one day my story will be able to help another family who is dealing with this dreaded disease.