

Sebastian Washuta's Story



Sebastian and his twin sister Abigail were born 9 weeks premature. They were in the NICU for almost 3 weeks then transferred to the special care nursery. After almost 3 weeks in special care our babies could come home! We had 4 days of endless feedings, changings and no sleep but we were as happy as can be.

Then on the 4th night Sebastian did not want to take his feeds. We went to the pediatrician first thing in the morning who told us to immediately take him to the ER, his breathing and heart rate did not sound good. In the ER they told us he tested positive for RSV virus and begin giving him oxygen. However, hours later HMC realized he needed more care than what they could provide and transported him to St. Peter's Pediatric Intensive Care Unit. We followed the ambulance and by the time we were able to see him he was in an induced coma and on a ventilator. We were just shocked and horrified that things had gone so completely wrong so fast. Later we received a call that Sebastian was having seizures and they needed permission for an MRI. When we go to the hospital we heard the words no parent ever wants to hear "brain damage". At this point they didn't know what this meant for his quality of life or honestly if he was going to pull through.

Seb spent 2 weeks in the coma then another 3 weeks in the PICU. He was then transferred to the Pediatric floor for an additional 3 weeks. Finally after 8 weeks, his seizures were controlled with medication and he had gained enough weight to maintain body temperature. He was just about 3 months old when he came home again to his twin sister.

Seb was immediately evaluated and began Early Intervention. He started with physical therapy and developmental intervention. After a few months we added occupational therapy and speech & feeding therapy. We soon realized that his vision may have been affected because he was not tracking objects or people. Along with Cerebral Palsy he was diagnosed with cortical blindness and began receiving services through the commission for the blind. At around a year and a half old Seb began to stop gaining weight. Within a few months he was considered failure to thrive. We went to multiple feeding clinics and all gave us the same conclusion, it was time for a feeding tube. Last May Sebastian had his G-tube surgery. Within months of his surgeries Seb was gaining weight, happy, more alert and active. He has doubled his weight in a year and has grown 8 inches. He is now tipping the growth charts in the opposite direction.

Sebastian is fully dependent on adaptive equipment and will most likely be for the rest of his life. He cannot sit or hold his head up for long periods of time. He will be dependent on his feeding tube for nutrition for an unforeseeable amount of time. He is routinely seen by many specialists other than the pediatrician. Sebastian takes daily medication for seizure control. This past September he started preschool at the Lakeview School (NJ institute for Disabilities). He is making progress with communication by using voice recorded switches to make choices. All his difficulties aside, Sebastian is a happy boy who will easily give you smiles and kisses. He loves playing with his sister, listening music, being outside, and going to school.

Sebastian and our family will continue to face many challenges as he gets older and we could not be more thankful and appreciative to now be a part of the wonderful Shannon Daley Memorial Family.

