

## Brayden's Story



We stood there looking around the NICU at St. Peters and thought that it was a bad dream.

It was a life changing moment, where there are no books or phone numbers to guide you through how to be parents of a sick child. Our lives, along with our 10 year old daughter's, were changing rapidly and would be changed forever.

Every situation is different in the NICU. Our son, Brayden, was born October 8, 2008 - 2 1/2 months early. For two + months NICU became our home. He needed many blood transfusions from lack of oxygen. He endured collapsed lungs, pneumonia, bilateral pneumothorax (caving in of the chest wall), prematurity respiratory distress, sepsis, hypocalcaemia and pulmonary hypertension. He also needed a pick line in his head because his veins were shot. An oscillator, ventilator, CPAP, feeding tube, sleep apnea, and heart machines helped him on his road to recovery.

Brayden almost beat all odds. We travel to CHOP to see many specialists including an Oncologist and a Neurologist for a tumor that is located in his head. He also has EE (protein allergy) and he is on a medical grade formula so he can thrive. He almost weighs 20 lbs. A feeding team and Gastroenterologist look out for his nasogastric tube which helps control his EE. This could be for life if no cure is found. He also sees an Urologist, a Pulmonologist for his chronic lung disease, an Ophthalmologist, an Audiologist physician from being on oxygen long term (delayed speech with the use of sign language) and he receives physical therapy for Torticollis.

We are able to go about life now and no one knows how rough he has it. He has almost no abnormalities that anyone can see, unless his nasogastric tube is in, which will make it difficult in the future for to eat most foods. If they only knew that he used to expel everything and beyond about 14-20 times a day .We're now down to 1-2 times a day. A lot of laundry!! He takes many medications, some of which are liquid and are only good for 14 days.

With all odds against him he has pulled through. Brayden is a very happy, curious little boy. His journey has not been smooth, but has been blessed from many prayers and the love that surrounds him.

