

## Jonathan Thomas (“JT”) Schoppe’s Story



JT was born in April of 2009. He lives at home with his mom and dad, and his excellent big sister, Ella. He is 7 years old now and is a sweet, happy boy with an amazing smile! JT was an identical twin. At 17 weeks into the pregnancy, we were diagnosed with TTTS (Twin to Twin Transfusion Syndrome) and underwent fetal surgery at UMMC in Baltimore. The surgery was a success. But, unfortunately 3 weeks later, JT’s brother passed away at 20 weeks gestation. Due to the TTTS and the passing of his brother in the womb, the pregnancy only lasted 26 weeks and JT was born. At 1 pound, 7 ounces, and 11 inches long, he was a peanut. His skin was translucent. He was so tiny we could not hold him for two weeks. His whole foot was half the size of a thumb. His dad’s wedding ring fit up to his shoulder. He wore half of a surgeon’s facial mask for a diaper. He was a miracle! He spent 2 months in the NICU in New Jersey at Saint Peter’s Hospital and another 2 months in the NICU at Philadelphia’s Jefferson Hospital.

Along the way JT has been diagnosed with: Cerebral Palsy, Periventricular Leukomalacia, hearing issues, Partial Agenesis of the Corpus Callosum, glaucoma, Retinopathy of Prematurity, Peter’s Anomaly (a rare genetic eye disorder causing cloudy corneas), strabismus, cataracts, Bronchopulmonary Dysplasia, failure to thrive, GI reflux, hypertension, a heart murmur caused by a hole in the heart, a hernia, elevated liver enzymes and an enlarged liver, brachycaphaly (a mis-shaped head), severe speech delays, short-stature, unexplained body jerks, sensitivities to light and noise, as well as oral sensitivity, teeth grinding, near-sightedness, aphakia (removal of the lens in his right eye) and a partial duplication of chromosome 13.

JT has had the following procedures: 2 laser eye surgeries, right eye cornea transplant, strabismus surgery, right eye cataract lens removed, inguinal hernia repair, G-tube insertion into stomach, liver biopsy, brain MRIs, nerve and muscle function studies, Botox injections to various parts of his body (30+ needles) to treat CP (every 6 months under full sedation – JT has had 10 of these procedures since birth), 22 eye evaluations under anesthesia to monitor his eye conditions, 3 EEGs (to detect seizure activity), hip surgery due to hip dis-location, barium swallows, x-rays and ultrasounds.

JT takes 6 drugs orally (12 doses daily) and has 7 eye drops (22 doses daily). We connect his G-tube to a pump every night to “feed” 12 ounces of special formula to him, which is about half of his day’s nutrition. JT has 12 different pieces of equipment and bracing that he needs to use on a daily basis. JT requires one on one care and assistance with all daily living activities. Due to the Cerebral Palsy, JT cannot walk, stand or sit on his own. He can roll back and forth. JT’s speech is very limited.

Besides frequent trips to CHOP and Wills Eye Institute in Philadelphia, JT enjoys swimming at the local YWCA, Hippotherapy (horse therapy) at Special Strides in Monroe, listening to stories and music (he’s a HUGE Barney fan!!!) But, most of all, he enjoys listening to his big sister Ella play the flute for him! In addition, he attends a special school suited for his needs five days a week. There he receives nine sessions of therapy (speech, OT & PT) weekly. Since the beginning, the odds have never been in his favor. However, JT handles the daily rituals and stressors with smiles, giggles and an easy going personality. He has come a long way and is an incredible fighter. We are grateful to the Shannon Daley Memorial fund for this opportunity.

