

Thomas' Journey

On November 13, 2008 at Saint Barnabas Medical Center, Patrick and Thomas were born prematurely at 30 weeks. Shortly after their births one of the twins, Thomas, was noted to have significant abnormality of his skull and face. The neonatologist at SBMC consulted Dr. F. Desposito, the Pediatric Geneticist and member of the NJ Institute for Craniofacial Surgery at Saint Barnabas. Dr. Desposito diagnosed Thomas with Crouzon's Syndrome and referred him for an evaluation by the entire team. Crouzon's Syndrome is a genetic disorder first described in 1912 by Dr. Octave Crouzon, a French Surgeon. It is characterized by Craniosynostosis and Midface Hypoplasia (a restriction of growth in the bones of the forehead, eyes, cheeks and upper jaw). These growth restrictions lead to a characteristic facial deformity and may lead to increased pressure surrounding the brain, exophthalmous (bulging eyes), difficulty breathing, developmental delay and significant jaw and dental issues. We met with the team from NJ Institute for Craniofacial Surgery only three days after the twins were born. The first surgery for Thomas was performed to correct the Craniosynostosis by removing the skull bones and repositioning them in order to provide more room for the brain to grow. Dr. Arno Fried, Dr. Frank Ciminello, and Dr. John Amato performed this surgery for Thomas in September 2009 and Thomas recovered remarkably well. Thomas will undergo several more surgeries by the team. We met with the whole team, who were very reassuring with my husband and I, as well as Thomas.