## **Patient Stories**

Web Content written for The Children's Institute



## "I am Not a Genetic Disorder" - Taylor's Story

Little Taylor Herman was only 9 months old when her foster family became her forever family. She was a beautiful, happy baby whose body had secrets yet to be revealed.

Her mother knew that Taylor had been born with Situs Inversus, a reversal of internal organs from one side of the body to the other, but the rare condition does not normally result in medical complications. What she did not know until after the adoption was that baby Taylor also had Charcot-Marie-Tooth disease (CMT), an incurable neurological disorder that causes the continued loss of muscle tissue and sensation throughout the body.

While not impacting Taylor greatly when she was an infant, as she learned to crawl and walk, the deficits caused by the disease became apparent. She was fitted with leg braces to help her walk, and suffered constant pain due to muscle spasms. She underwent multiple orthopedic surgeries to correct abnormalities in her legs and feet caused by the muscle atrophy. While her sister Makayla was running and skipping, Taylor was falling down and crying in pain.

When she was 5-years-old Taylor began therapy at The Children's Institute. In the months that she has been coming to The Children's Institute, she has learned techniques to manage her pain and cope with her genetic disorders. Taylor especially loves aquatic therapy, which to her, just seems like playing in the pool! Through outpatient therapy, Taylor learned how to manage her conditions so she can enjoy all the wonders of childhood.

## "I am Not Cerebral Palsy" - Dominic's Story

Born eight weeks early, Dominic Ruperto, even as a newborn, seemed to be telling the world he was ready to go, no matter what obstacles stood in his way.

After worrying about what seemed like a lack of normal development in her infant son, Michele Ruperto sought medical advice and 1-year-old Dominic was diagnosed with Little's Disease, a form of Cerebral Palsy affecting the lower extremities.

From the time he began to walk, Dominic received physical and occupational therapy. Although only a temporary solution, orthopedic surgery to release his leg muscles was done when he was 5-years-old, and will likely have to be done again as he grows. Following the surgery at Shriner's in Erie, Dominic came back home to Pittsburgh to receive inpatient rehabilitation at The Children's Institute. Dominic made huge strides during his time as a patient at The Children's Institute, and got involved with adapted sports through our Sports Clinic. Even so, Dominic uses a wheelchair to get around most of the time.

But that's not enough to hold down a remarkable boy like Dominic. He is musical – playing both the violin and trombone – and athletic, playing on multiple adaptive sports teams including sled hockey, basketball and rugby. He's popular too, making friends with schoolmates, teammates, firefighters, and veterans. At 11-years-old, Dominic's vivacity is contagious; it spreads in smiles on the faces of everyone he meets.