Jack's Journey

Jack is our amazing, little star; the youngest of three boys. Jack was born full term and came into this world at 7lb 12 oz. I had a healthy pregnancy and there were no complications at birth. For all intents and purposes, everything was fine except we couldn't help but notice that Jack had a low bridge nose. Nothing was said and he was eating and sleeping just fine. Things changed a little the next day when the pediatrician came to look him over. The doctor had a list of things that weren't "normal" for newborn babies. Jack had a low bridge nose and lower set ears, he had the single palmar crease on one hand, his testicles were undescended, he had a heart murmur and he had a larger fontanelle. The doctor (not our regular pediatrician) quickly went over all of these abnormalities and set up chromosomal testing to rule out Down syndrome. He walked out and we were left speechless and unsure about the future of our baby. After talking to each other and our family members, Rich (my husband) and I found out that Jack had a little piece of everyone. Rich had the single palmar crease and did not have Down syndrome, one of my brothers had undescended testicles and Rich's older sister had VSD which is what the pediatric cardiologist determined Jack had. We realized we had to be patient, take it one day at a time and regardless of the outcome, Jack was our precious newborn baby.

We were due to be discharged from the hospital the following day. We would not have the test results from the chromosomal testing for a few days. Jack did however have to pass his hearing test in order to go home. Jack failed his hearing on one side but passed on the other. We were allowed to bring him home but had to follow up with another, more in depth hearing test in a month. We left the hospital both happy and anxious. We were so excited to be bringing Jack home to his two older brothers (five and two at the time) but had so many unanswered questions. We received a call a few days later that Jack's testing came back "normal". He did not have Down syndrome. Jack was jaundice so we had to take him for daily bloodwork for about two weeks until his bilirubin came down. We followed up with his hearing at St. Mary's School for the Deaf and he passed his hearing test with flying colors! We met with a pediatric genetics doctor at one month old as well who took note of all of Jack's "abnormalities" but could not give an answer as to what it could be. There weren't any specific syndromes or genetic disorders that completely fit him. Jack hated tummy time and was referred to Early Intervention by our pediatrician which resulted in him receiving physical therapy and occupational therapy services by the age of 5 months. We had to see a pediatric eye doctor around 7 months old because Jack's one eye was turning in. The doctor was able to determine that Jack was farsighted and he started wearing glasses at 8 months old and still wears them today. They have become his trademark! Jack also had clogged tear ducts and had surgery around his first birthday to clear the ducts and descend his testicles. Jack started receiving speech services as well around 18 months. He was somewhat picky with eating solid foods around this time also, so we took him to an ENT. Jack was tongue tied and his occupational therapist thought that this could be affecting his eating. We took him to a pediatric dentist in Albany who specializes in laser treatment. He performed a laser tongue release on Jack. If we

had this done locally, Jack would have had to go under and have an actual surgery with stiches. The laser treatment took all of two minutes, no stitches and he was eating solid food within days! Jack started wearing SMO's around this time as well. His feet were pronating in and these helped to stabilize him. Right before Jack's second birthday, he saw an endocrinologist because he was and still is on the lower side of the growth chart. It was also recommended because of the undescended testicles at birth. Jack was given three hormone shots over the course of three months. He has since been discharged from the endocrinologist, the cardiologist, and the urologist.

Through all of this, Jack was ALWAYS a smiling and happy baby! He nursed well and slept well, and was generally a healthy baby. He has had his fair share of hospitalizations due to bronchiolitis and RSV. We have added the pulmonologist to our list of doctors and it has been determined that Jack has asthma. We have it under control though, so no complaints! Jack is nothing short of a super star! He may be a little behind on his developmental milestones but he is still achieving them. It may be at a slower pace than the "norm" but that's okay! He continues to be a smiling and happy three year old who is full of energy, loves his brothers more than anything and loves all things hockey! He practices shooting pucks in the basement daily with his big brothers and just may make it to the NHL some day☺

Jack continues to see the genetics doctor once a year and she has run more in depth testing that has not resulted in anything. Jack is a puzzle to her but she is pleased with his progress! He was diagnosed with Childhood Apraxia of Speech this past summer. Several people asked us if we were okay with this diagnosis and I'm proud to say that we are! We have an answer to part of Jack's puzzle. Jack is such a hard worker and has shown so much progress! We are so proud of him! We have complete faith in Jack's future, regardless of the path we take to get there. He may be the most determined little boy I know! We love him for who he is and wouldn't change a thing. Jack has taught us to appreciate and celebrate the differences. He has also taught us that good things come to those who wait!