

## Jonathan Mason's Story



Jonny was born on New Year's Day, 2012. Everything started out just right, Jonny was actually born on my due date, at Hunterdon Medical Center, our local hospital where I had worked for years. We had no idea that we were at the beginning of what would be a 2 month hospitalization full of tests, meetings with specialists and hard news. After birth Jonny was immediately taken to the Special Care Nursery where he was given oxygen to help him breathe and a nasogastric tube for feeding (a tube that was put through his nose and down his throat). No one knew why Jonny was having these problems so the doctor's decided to transfer him to Saint Peter's where he could be seen by specialists. He saw many doctors when he got there including a geneticist, cardiologist, nephrologist and neurologist. It really felt like every doctor in the hospital saw him, and then told us more about the challenges he would face. We learned that our precious son had a serious heart problem, an atrial septal defect as well as hydronephrosis. Jonny also developed seizures and had surgery to put in a feeding tube. When the genetic testing came back we learned that Jonny has Sotos Syndrome (characteristics include: a larger head, feeding difficulties, physical and verbal delays) as well as chromosomal deletions and duplications which make him truly unique.

After 2 months Jonny was finally able to come home, this however, was only the next step in our family's journey. Jonny immediately started Early Intervention, a team of speech, physical and occupational therapists came to our house every week to help Jonny learn how to move and communicate and they also taught our family all of the ways we could help

in him to develop, this was especially great as his older sisters, who love him endlessly, were able to take part in his care.

Since his discharge from Saint Peter's in 2012 Jonny has been hospitalized three times, including once when he was put on a ventilator due to RSV, you can't imagine what it is like to see your child in an ICU with all those tubes and wires.

Sotos syndrome is best described like a slow train, milestones are reached years late. Jonny is still nonverbal and this is one of the hardest parts of everything because we often have no way to know what he wants. He recently started walking with the help of a walker and leg braces - which he absolutely loves, he has even taken a few steps on his own.

We know that as Jonny grows we will face many more challenges, Jonny's cardiologist has told us that he will need heart surgery this summer or next to close his atrial septal defect, we are hopeful, that like all of the difficulties he has been through, he will come out of the surgery stronger than ever.

We are excited for the support from the Shannon Daley Memorial Fund and thank you for your generosity and support.

