

(Joey's Story)

I want to share my story with you about my son, Joey. My pregnancy was watched very closely. Joey's older brother Anthony was 11 years old at the time and disabled when I got pregnant. At 24 weeks during an ultra sound the doctors found that the ventricles in Joey's head were enlarged. The dr.'s tried 3 series of steroid shots to help develop his lungs and get them stronger. That helped us take Joey out earlier. Finally, at 34 weeks I had a C-section. Joey was born weighting 4 pounds. It was at this time we found out that my boys had MASA Syndrome. This is a rare inherited disorder. MASA stands for mental retardation, aphasia, shuffling walk and adducted thumbs. Those with MASA syndrome also have increased fluid in the center of the brain. Joey spent 4 weeks in the NICU. A shunt was placed in his head at 2 days old. At 4 months, Joey's shunt got infected. The dr.'s had to externalize the tube that meant one end of the tube is pulled threw a small cut in the skin then the tube is connected to a drainage bag. It took 3 week for the infection to clear. During that time we could only reposition him, we were unable to pick him up due to not moving his head. A new shunt was placed, but on the opposite side of his head. As a result of the infection Joey became blind. Joey was enrolled into the early intervention program through the County. That's where Joey got started making friends and learning. When he transitioned into preschool he enjoyed being around the other kids. That's where we met Lauren. They were classmates. On July 4th of 2007, Joey got his shunt replaced again but this time it was malfunctioning. In September 2007, the first day of kindergarten, Joey had his first seizure. He was hospitalized for 3 days until they could get them under control. 2 days later, Doctors discovered that the shunts broke in his brother Anthony's head. Anthony had a stroke and passed away 5 days later. 2007 was a real ruff year for our family with both boys having so many medical problems. Through the years, Joey has had 12 different surgeries. He has ongoing problems with his ears. He has never passed a hearing test. Joey is wheel chair bound and non-verbal. We are very cautious with his head. If he bangs it, the shunt can break and that would mean brain surgery again. And he has started scoliosis in his back. In 2012 and 2013 Joey got pneumonia 3 times. A swallow study was performed and we learned Joey's muscles were getting so weak he forgot how to swallow which caused him to aspirate his food and drink and led to the pneumonia. Everything he ate or drank was running

down his vocal cords rite into his lungs. On October 1st 2013 Joe got a G-tube. That is a small tube in Joey's stomach. That is how Joey gets nourishment and his vitamins. All of Joey's medicines also go threw the tubing. We stayed in the hospital 10 days till he tolerated the feedings and I was taught how to change and care for the tube and do the feedings. We've been doing a lot of mouth exercises, but last month we did another follow up swallow study and there wasn't any improvement. Joey is a very outgoing 7th Grader. He is in an MDS (multi disability support) class, but does go to art and music with the other 7th grade peers. Joey really enjoys going on his tricycle and swing. This winter has been long winter and he hates to be inside. Joey enjoys music and playing on the iPad. He likes to plays sports with his friends. He plays baseball, he swims and is on a bowling league with other special needs kids. Joey does know some colors and numbers. He likes sorting things out and listening to stories. Joey wears MOFO braces on his legs and feet. He goes in a stander 30 minutes every day. But he needs a lot of encouragement for physical therapy. He gets physical therapy, Occupational therapy, and speech during the school day and gets private physical therapy 3 times a week and occupational therapy and speech with mouth strengthening exercises. We see 10 specialists every 3 months. When we get close to Lehigh Valley Hospital's Cedar Crest campus Joey starts saying home. He is so used to being there. It's his second home. Joey does have fun practicing learning his brothers electric wheel chair. He thinks it's funny to run into people. So it's going to take some time.

We got involved with Lauren's Hope Foundation from the beginning. We are so very thankful for everything Ann and the organization does for each family. She takes time for each family to get to know them. And is always a call away if anyone needs help or just needs to talk.

Unfortunately, Anthony didn't get an opportunity to enjoy these fun events, but I am so grateful we are involved. We made many friends and enjoy getting together during the Christmas party. Joey always enjoys the picture with Santa and they even send a frame to put the picture in. Each child gets presents that are picked especially for them from their wish list. In May, for Mother's Day the foundation makes every mom feel very special with a body massage and manicure while the kids are being entertained and making crafts. Every year each child gets to put in a request for something they need. The first year Joey got a lightweight adapted stroller. It helped so much. It was much lighter then the wheel chair to get in and out of the car. The past 2 years has

been our biggest excitement. The Lauren's Hope Foundation helped fund part of Joey's hippo therapy. Those horses are Joey's favorite thing. His horse's name is Mr. Magoo. This past Monday was his first week back since the fall session. When we pulled up Joe started talking and yelling and he didn't stop until we got half way home. He remembers everything from tapping the horse to saying "ride on" which alerts the horse to start walking. Joey helped put on his own helmet and sat up big and tall for the entire 45-minute session. Usually the first week back is hard and he falls over, but not this year. We are so grateful for everything the Lauren's Hope Foundation has done for Joey and our family. I can't ever thank them enough. To see the smile on my son's face and the giggles and laughter.....It's the best moments. My life is hard, but I wouldn't trade it for anything.