## **Bryan Rebimbas Story**



Bryan is a 12 year old, sweet, loving boy who has an infectious laugh. When Bryan was born on March 30, 2001, everything seemed perfect. Our 7lb 4oz baby boy seemed to be fine. We went to our scheduled well visits at the pediatricians where Bryan seemed to be progressing nicely. It wasn't until Bryan was a couple of months old that my husband Tony and I started noticing that he was reaching the milestones. He was not sitting up, rolling over, followed by not standing, nor babbling. I would mention my concerns to the doctor but I kept hearing "all children develop differently, don't compare him to other babies" I also heard "perhaps you are being a little too concerned being that you are a special education teacher"!

I finally had enough and asked for the phone number to early intervention so we can have him evaluated. Go figure...Bryan needed therapies in all areas-speech therapy, physical therapy and occupational therapy. Shortly after, Bryan was diagnosed with spastic dysplasia cerebral palsy followed by another diagnosis at the age of 3 of autism. He then began in a preschool handicapped class after much struggle trying to find a daycare for him.

Bryan has seen many doctors and specialists in both areas of CP and autism. Bryan has also been diagnosed now with ADHD. This past May of 2013, Bryan underwent 2 major surgeries on his legs at CHOP (Children's Hospital of Philadelphia). He had his hamstrings and Achilles lengthened, his knee caps lowered, his tibias broken and straightened and bone added to the outsides of his feet to prevent rolling. This is when we found out about Bryan's fragile bones. The surgeon came out to ask us if Bryan has ever had broken bones for no reason. We told him no and he said "well his bones are

crumbling in my hands"! Great, we said to ourselves...something else to worry about.

After recovering from these surgeries Bryan and I returned to CHOP for the summer for rehabilitation. The plan was to be there for approximately 8 weeks. Well on June 30,2013 I lost my job and as sad as I was we looked at this as a sign that we needed to do this for our son-how else would I be able to be with Bryan 24-7 if I had a job. Bryan is a trooper and is determined to walk with his walker or maybe nothing someday. He cries and gets frustrated often because all he wants to do is to play with his 2 sisters and walk his best friend Tyak (his service dog) but he is so weak and cannot stand.

Bryan has had several setbacks including a severe pressure wound on his heel followed by terrible in grown toe nails that required surgery this November 2013. At this time we were back at CHOP followed by another 4 weeks of rehabilitation. We continue to work with his therapists on strengthening his legs. Bryan receives PT at school (The Midland School) twice a week and we drive to CHOP in Philadelphia twice a week. Bryan still cannot stand and needs 100% assistance for everything. Our medical bills, losing my job and everything that Bryan needs to make his life more comfortable have put a tremendous amount of stress on our family while still trying to give our 2 little girls everything they need.

But the smiles and innocence of our 3 children give us our daily strength. Bryan needs constant supervision which makes the reality of finding a full time job again at this moment unreal. How will we manage the bills, the mortgage, etc...well, we keep hearing "everything happens for a reason" and "God has a plan". Perhaps connecting with The Shannon Daley family is a sign of better things ahead!!! Thank you so much for helping out our family

