

## Reagan Reed's Story



After being told your chances of having a baby are less than 3%, our lives changed on that Monday afternoon in April 2013, when I called my husband to tell him he was going to be a Daddy. It was an awesome feeling to surprise our families and tell them that their prayers were being answered and we were expecting our baby in the second week of January 2014. To our dismay, when my water broke early and our daughter arrived on December 4, 2013, we were scared but happier than we ever thought we could be. Reagan, our little miracle entered the world with determination and love that was completely unexpected. She was in the Special Care Nursery at HMC for sixteen very long days. From a sepsis work-up to feeding tubes and endless chest x-rays due to the hole in her underdeveloped lungs, we thought this was going to be the hardest part. Reagan had to come home in a car bed because she didn't pass her car seat test and was diagnosed with laryngomalacia (which is tissue softness causing her airway to be partially blocked)

After three different newborn hearing screening tests, and Reagan now six months old, she was diagnosed with bilateral sensorineural hearing loss which is moderate to severe loss in both ears. After confirmation from an audiologist at CHOP, we ordered Reagan her first pair of pink, sparkly hearing aids to suit her joyful personality. After meeting with her ENT, he ordered an MRI, EKG, an eye exam, and genetic testing. What? This can't be happening, she could have a disease or many more medical conditions that we surely weren't prepared for. As parents you go through stages of grief wondering what you did to have this happen and it must be our fault, and how can we fix this?

Early intervention came to our house and brought more concerns to our attention, one of which our pediatrician would describe her as being floppy. Her

diagnosis, hypotonia which is low muscle tone. She wasn't sitting up or reaching the milestones that most children tend to do at certain ages. We quickly started physical therapy and speech therapy. Soon after, we added occupational therapy. Next appointment, neurologist. Is this ever going to end, we thought? No and what we soon learned as new parents was that we didn't need to "fix" her, what we needed to do was help her. She was given to us for so much more than we will ever understand. She is stronger than we will ever be. She has undergone endless tests, two strabismus surgeries (which is cross eyed), and continued doctor's appointments that we regularly go to at CHOP. Through all of this, Neurologists, Ophthalmologists, Orthopedic Surgeons, ENT's, Genetic Testing, we still have no answers.

When she was almost two and underweight, we then had to go for feeding studies. She pocketed her food like a chipmunk and we couldn't get her to eat in less than 90 minutes. This was another side effect of low muscle tone which is something that could get better with time and therapy. One of the most difficult things to deal with is that we don't know what our future holds.

So, here we are with a four-year-old who walks with her hot pink walker, who leaves a lasting impression on the people who enter her life. She currently receives ten therapies a week at school. We also take her for hippotherapy and aqua therapy once a week on our own. This is the highlight of her day because she feels like it is fun, not "therapy". We, as parents try to follow through with every recommendation given by medical professionals to help her get stronger but sometimes it becomes a financial overload. We are so honored to be chosen as a recipient of the Shannon Daley Memorial Fund. We feel like this is the beginning of a new start for Reagan and this will be able to give her endless opportunities to grow and achieve goals thanks to your help. We hope everyone embraces a little piece of Reagan's happiness, determination, and strong will to know life may be tough but it's only what you make of it.

