

Grace Ann Dettra's Story



When others dreamed of being a doctor or a teacher my wife dreamed of being a mother. Gracie came into this world a healthy baby though it only took 2 months before my wife knew something wasn't right. Gracie started missing milestones. No tracking, no smiles, no interest in toys and when she was upset she would stiffen up and arch backward; we immediately called Early Intervention for an evaluation.

Therapies began at 4 months old and so did the visits to the specialists. Neurologist, Ophthalmologist and Neuro-Ophthalmologist and the search for answers would begin. The ordering of tests was overwhelming; before the tests were even done we had doctors telling us that Gracie was blind and possibly had this or that disorder. Between all the blood tests, the MRI and ERG we thought for sure some answers would surface but Gracie passed all the tests, and proved the doctors wrong about their assumptions.

At 18 months old we were asked by our now third Neurologist to get an EEG for Gracie. An EEG detects abnormalities in the brain waves or electrical activity of the brain. EEG tests are used most commonly to detect seizures. The results of this test revealed that Gracie does have abnormalities in the brain that have the potential for seizures. Our Neurologist went on to explain that this is most likely caused by abnormal growth of the grey matter in her brain. Grey matter is found in areas of the brain that involve muscle control and in the areas that control a person's perception, such as how things are seen or heard or the formation of memories. Speech and emotions are largely influenced by grey matter as well. The primary function of grey matter is to carry sensory information that comes from grey matter cells and sensory organs. This information is then passed to the areas of the brain that

process sensory information. Intelligence and skill are often attributed to this brain matter, largely because it covers so much of the brain.

The reason for the abnormal grey matter is unknown. We have been told that it is likely do to an abnormal genetic code within Gracie's DNA. Genetic testing is very expensive if not covered by health insurance. Our Neurologist also informed us that in 50% of cases like Gracie's we never find out the true cause of all this. He used the phrase "It's like chasing a ghost." He then finished with his honest opinion saying he doesn't believe Gracie will be able to walk by age 5.

Aside from all that Gracie is a wonderful daughter. Improvements are seen especially in her eyes. We are just now starting to see Gracie respond to seeing and hearing us. Words cannot describe this feeling. Gracie now smiles daily and gets very excited when she's happy. She has also become more interested in our faces and in toys. She is also very close to sitting on her own. Gracie is our little water bug she enjoys her bath time so much and we look forward to water therapy this summer.

Our current therapy team through Early Intervention has been extraordinary. Gracie works hard in therapy and sometimes has us speechless with the things she does. We are so proud of her and so grateful to our therapists.

What the future will be for Gracie is not predetermined and we do believe she will overcome any and all challenges. We are truly blessed to be joining the Shannon Daley Memorial Fund family. With their help our hope is with Early Intervention and other outside therapies Gracie will learn to walk and talk and prove all the doctors wrong. We greatly appreciate the support from the Shannon Daley Memorial Fund and from everyone around us. Thank you and God bless.

