

(Taylor's Story)

Taylor was born on March 5, 2004 after a normal, uncomplicated pregnancy and delivery. It was one of the happiest days of our lives. She is our first-born and has forever changed our lives in so many ways. She is a big sister to Addyson and Finn. Taylor loves music, going to school, swimming, and blowing bubbles. She is the happiest and friendliest child you'll ever meet. Everywhere we go, someone knows and recognizes Taylor!

We first noticed that something wasn't quite right when Taylor was about 4-6 months old and wasn't hitting her developmental milestones. Looking back, there were many red flags, like feeding issues, but as first time parents, we didn't think anything of it. Her pediatrician group wasn't concerned and told us it was probably just a mild delay. When Taylor was one year of age, she still could not sit up, crawl, walk, pull to stand, etc. We began the early intervention process, which led us down many paths as far as testing, specialists, doctor appointments, MRIs, and genetic testing. Her neurologist told us at the beginning that there was a less than 1% chance we'd ever have a clear, precise diagnosis. All of her tests came back, "normal". Taylor was diagnosed and classified as Globally Developmentally Delayed with Hypotonia and Ataxia. While we were relieved that all of these test results were normal, we were frustrated, confused, and exhausted. For the most part, Taylor was a healthy and happy child. We were concerned, and wondered if this would happen again if we had another child. It was a puzzle.

Taylor began preschool at the IU20 where we met Ann and Lauren. Taylor and Lauren were classmates. We struck up a friendship at pick up time and have been involved with Lauren's Hope in some way ever since it began. Taylor's favorite event is Breakfast with Santa. She loves meeting Santa and enjoying everyone's company. We've also been fortunate enough to take part in the Mother's Day massage events, and the 5k walk.

One of the biggest struggles through the years has been trying to help Taylor find her "voice". Taylor is non-verbal but makes many sounds and noises that sometimes sound like familiar phrases. We would always know what she wanted by simply looking at the clock. Usually, she was hungry, tired, or needing to be changed. As she grew, it became increasingly harder to understand her needs. Taylor would throw food, cups, toys, and lash out her frustration by hitting or pinching. Speech therapy helped teach her some basic "baby" sign language, which she still relies on today. Taylor will now point to what she wants or guide your hand toward it. She has been using a GoTalk communication board for almost a year now, but it has been a long road in finding what worked best for her.

The physical struggles are challenging. Her gait is unsteady and she requires assistance to ascend and descend stairs. Taylor wears specially molded inserts in

her sneakers to help correct her gait and tremulousness. She is heavy and is not yet toilet trained. Taylor requires total hygiene care and the house still has to be "child-proofed". We are a very active family and are always on the go. Everywhere we go, Taylor goes. This can prove difficult while on vacation, long car rides, public restrooms, and even simply running an errand. But, this is our life. We don't know any other way.

Fast-forward through years of therapies, appointments, and IEP meetings and Taylor is now a teenager. Our hope for Taylor is that she continues to progress, becomes more independent, and that she can enjoy life to the fullest!

Although we have many struggles, which are forever changing and increasing, and that she requires constant care and attention, she is always making progress and is always moving forward. She is our sunshine after a long, hard day at work. Her unconditional love, smile, and personality are what keep us going. We are a stronger family because of her. We are lucky enough to have a large supportive system of family and friends to help guide us through the ups and downs. Overall, we are blessed to be her parents.