

## **Angel's Story**

## Shellie Pearce, TxP2P Parent Volunteer

Hello to everyone, my name is Shellie. I have three amazing children named Benjamin, Alexus, and Angel. Benjamin and Alexus are eight year old twins and Angel is five going on six. Angel is the driving force that turned my life upside down; or more rightly, bottom side up. She was born in Indianapolis, Indiana at Wishard Hospital then transported down the street to Riley Children's Hospital. In utero we were not exactly sure what we were looking at; she had an enlarged heart and fluid on the brain. It somehow resolved itself through the pregnancy and she was born via caesarian. She was at a low birth weight at three pounds and ten ounces. She had to eat through a nasogastric tube and now has a MIC-KEY button. This is from her laryngomalacia. Angel has been diagnosed with epilepsy, hypotonia, laryngomalacia, and has several physical anomalies. She is displaying physical signs of puberty which is a recent development. Angel is non-mobile and non-verbal although she can kick and squirm, sing and get loud.



The syndrome Angel has been diagnosed with is called Diploid/Triploid Mixoploidy syndrome aka Mosaic Triploidy Syndrome and is not associated with Down syndrome. It happens when two sperm fertilize one egg. It is an extremely rare condition and has left doctors scratching their heads at times. There is no prognosis so we live one day at a time (not to sound too cliché).

Angel is a very happy child when she isn't fighting off seizures. That humongous smile she has could chase away any rain cloud. She loves to listen to her brother and sister run about the house and enjoys the sound of our dog barking. She likes to relax with grandma on the couch

and absolutely loves her music. Grandpa plays the guitar and she smiles and smiles when she hears it. She usually smiles at the sound of grandpa's voice (and that may be because she knows a snack is near).

I feel like I have literally been given an angel to take care of here on earth. How could this little blue-eyed, fair-skinned, collection of joy come into my life and change everything without saying a word? My little Angel...what a fitting name she has!

## **Texas Parent to Parent**