

(Makenna's Story)

February 14, 2011, Valentine's Day, we had our first ultra sound and learned we were having TWINS! We were educated about Twin-to-Twin Transfusion Syndrome (TTTS) and since we were carrying identical twins, this was something that we needed to be monitored. TTTS is when identical twins share a placenta and depending on the size and sharing of blood vessels, blood can be transfused disproportionately from one twin (the donor – Makenna) to the other twin (the recipient – Lilli). This transfusion causes the donor twin to have decreased blood volume which leads to slower than normal growth than the recipient twin and poor urinary output causing little to no amniotic fluid. Our ultra sounds were looking great; we had our 20-week appointment and learned we were having girls. I went alone for our next appointment, thinking all was well and the girls were doing great. At this appointment the doctor told us the girls had TTTS and we would need to see what our next option would be by traveling to Children's Hospital of Philadelphia. After the longest weekend of our lives, we had surgery that Tuesday at 23 weeks to correct the TTTS. At 31 weeks and 5 days, the girls decided they were ready to enter the world! Makenna was born weighing 2lb, 13.5oz and Lilli 3lbs, 2 oz. They were small, but doing well. After a week in the NICU, they received head ultra sounds. This was the day Makenna was diagnosed with Periventricular Leukomalacia (PVL) and we were told that she would most likely have Cerebral Palsy. I lost it. I sat there hysterically bawling, thinking of children I have worked with that have Cerebral Palsy, I was heartbroken and in shock. Because they were able to detect the PVL at such a short time after birth, it was concluded that the TTTS was the cause of the PVL. The girls both left the NICU after 27 days. Shortly after their arrival home, we had Makenna's early intervention evaluation and had physical therapy started immediately – even though at that time she did not qualify and presented as a typical premature infant. Makenna was diagnosed with spastic quadriplegic Cerebral Palsy at 15 months. We have continued with early intervention and outpatient PT, OT, Speech, pool therapy, as well as Craniosacral Facial Treatments and the Anat Baniel Method and she has had one surgery called Selective Percutaneous Myofascial Lengthening; a minimally invasive procedure to help reduce spasticity

paired with phenol alcohol blocks and she also attends Mercy School for Special Learning's inclusion preschool with her sister. Makenna wears glasses to address her strabismus, DAFOs on both legs for strength and stability, hand splints to help to stimulate her hands to open and her thumb to not tuck under and a full body Dynamic Movement Orthotic (DMO). We heard about hippotherapy through a cerebral palsy support group, so I started looking to see if we had any places that offered it in the Lehigh Valley. This is when I found Lauren's Hope Foundation! I read through the information and applied to have Makenna receive a grant for hippotherapy and we received the grant! The first five lessons, she was not happy. She fussed the entire time and I thought I was going to need to take her out of the program, but knew how blessed we were to have the grant so gave it another try. By the sixth lesson, she was loving it and we have continued full force since then! She knows when her lesson is about to end and will vocalize to those working with her, "I don't want to go!" Hippotherapy has helped Makenna gain core stability. You can see in the pictures the difference between last year and this year, how much stronger she is. She rides the horse sitting up like shown, laying on her back, her belly, side saddled and all kinds of different directions to work on various skills. They also work to strengthen her hips and provide flexibility. She is finding a love for a beautiful animal and the movement of the horse regulates her with vestibular stimulation in movement that relaxes her and gives a different control of her body that she cannot have in any other environment. Her horse's name is Snickers and he is the most tolerable horse! Makenna can be loud at times, but he takes it all in and works great with her. Makenna is a happy 3 ½ year old girl that loves to smile, play, laugh and dance to music. She is learning to sit, stand and walk independently, but is getting stronger every day. Lauren's Hope Foundation gave us the opportunity to try such an amazing therapy and we are forever grateful. I'm not sure if we would have jumped right into the idea if it would not have been for reading Lauren's story on the website and seeing what a positive effect hippotherapy had on Lauren.



2015



2016

