

Hi! I'm Max.



Me

I was born July 7, 2016. I'm the little brother of Gabriel and Wesley. I was born with spina bifida, hydrocephalus, and Arnold Chiari Malformation II.

Spina Bifida

Spina bifida is a neural tube defect. By the 28th day of conception; my spine didn't form correctly at the S2 sacral vertebrae. My mom and dad were told about my birth defect when she was 19 weeks pregnant with me. I have had a team of doctors at The Children's Hospital at OU Medicine since, and when I was born, I had a big surgery on my second day of life to fix my spine! My neurosurgeon saved my life!

Complications from Spina Bifida

I have neurogenic bowel and a trabeculated bladder and my sphincter muscles do not work correctly, the nerve endings were damaged because of my spina bifida. I'll utilize a diaper longer than the typical child. I have the best Urologist in Oklahoma making sure my kidneys stay healthy. I am cathed every 4 hours. I also take 3ml of Oxybutynin 3 times a day to help my bladder develop healthy. Kidney health is important and I need monitoring.

Hydrocephalus

My brain learned early on to produce too much cerebrospinal fluid, which is called hydrocephalus, or water on the brain. I had a VP shunt placed in my brain at 5 days old; my neurosurgeon gave me my first haircut and saved my life again! You might not notice the scars on the right side of my head there are two now because I've had a revision. My cool hair covers a lot! There's also a scar on my tummy near my belly button where they made a small incision to place the tube that connects to the shunt in my brain. The extra fluid in my brain is redirected to my abdominal cavity, where it's absorbed naturally.

Arnold Chiari Malformation II

Arnold Chiari Malformation II is where the cerebellum is pulled down into the spinal column. When I was born my ACMII was considered severe but since my closure and over time, it's got slightly better and I currently have no known side effects. In time this could cause me to have vision and balance issues or headaches.

Torticollis

In utero, most likely because of my hydrocephalus, I was twisted up and in a breech position, which caused severe torticollis. Torticollis is tension on one side of the neck. My muscles were so tight around my neck that it pulls on 3 plates in my skull which causes the shape of my head and face to be off center just a bit. I'm in physical therapy and am making great progress.

Hip Dysplasia and Low Muscle Tone

My Ortho doctor makes me wear a Rhino brace at night to keep my hips in correct position for proper development - they've come along way! I also have very weak muscles from my waist down to my ankles and need the assistance of AFOs and de-rotation cables. I also sleep with knee immobilizers at night. I have contractures in both knees and my left ankle. You might see me around in my gait trainer - this helps me be mobile while teaching me to walk. I have the coolest wheelchair available for kids and most the time I can get along just fine, I'll ask if I need help, I might even pop a wheelie for you. I utilize a mobile prone stander during therapy sessions which I attend twice a week. I was recently granted an Amtryk through AMBUCKS, I can ride a tricycle by myself now! I'm learning to keep up with my peers.

Hearing

I failed 13 hearing tests and have had tubes placed twice. I finally passed all hearing tests! My speech has been delayed, but I'm catching up. I just graduated from speech therapy after 2 years and am doing great at school. I'm in an Early Head Start program at EduCare Oklahoma City and I'll start PreK spring of 2020.

More About Me...

I am cognitively a typical, happy, and content little boy. I have a few physical limitations that make me appear different - as I grow these limitations may change, but please know that I like to be treated just like everyone else and I want to be included, and experience this life just like you! I like to ride my tricycle and I recently discovered frame football. I'm learning to play the ukulele and I love to laugh. I love popcorn, snuggles and a great movie with my family. I like to travel, camp, and play outside with my brothers and friends at Cub Scouts and I've recently become quite the chatter box and self-advocate! My mom and dad are always available for questions so please feel free to ask them anything about me. If you want to know more, I have a two group pages on Facebook, Max the Brave - my personal journey to rehabilitation, and follow my bill for adult-size changing tables, Max's Law, at our page: [OK Changing Stations!](#)

For more information on Max's Law, contact my mom: Audra Beasley (405) 474-8464 docprep@adbparalegal.com