



“My D&I Story” – My Son, Tilian

Courtney Ault – Digital Experience Coordinator



Tilian at the Williams Syndrome Clinic at Nationwide Children's

In an effort to help bring more awareness to Williams Syndrome, we are proud to have Digital Experience Coordinator, Courtney Ault share the story of her son, Tilian. Williams Syndrome (WS) is a genetic condition that affects 1 in 10,000 births, and is characterized by medical problems, including cardiovascular disease, developmental delays, and learning challenges. These often occur side by side with striking verbal abilities, highly social personalities, and an affinity for music. WS occurs equally in males and females and in all cultures worldwide. (williams-syndrome.org)

“Tilian was born in January of 2019, and while there were no signs of any issues outside of him measuring slightly small, his heart rate dropped with every contraction and required an emergency c-section. That is where the craziness started. He was taken to the NICU for low oxygen levels and remained there for four days. After that, he was rushed to Children's Cardiac Intensive Care Unit with a diagnosis of coarctation of the aorta, a condition described in comparison to putting a kink in a hose but instead of a hose, it was in the largest blood vessel in Tilian's body.

At just one month old, he had heart surgery which revealed a whole new diagnosis. The surgeon said that while he cut out the portion that was causing the issue, it was going to come right back because Tilian's connective tissue was not what was expected. A week later, and at just five weeks old, we had genetic testing done and Tilian was diagnosed with Williams Syndrome. He went on to have two heart catheterizations and open-heart surgery all within the first eight months of his life. He is currently two years old, and while he is behind on milestones and must attend four therapies a week on top of other appointments, he is the happiest kid in the world with the best smile! He is our world and I am so lucky to be his mom.

Although Tilian is only two years old, inclusion has already been a challenge for him. When you are pregnant, you dream of the playdates and fun things you are going to do with your child and all the friends they will make. None of that has happened for us. While we have great family support, many people in our lives have gone silent since Tilian's diagnosis. Even before COVID, we never received play date invitations, or invites to group outings to the zoo or aquarium. We also don't receive invitations to go to the park because there are no parks near us that are equipped for a two-year-old who, developmentally speaking, is only 10 months old.

Another thing that's been especially challenging is finding childcare. We have visited and interviewed what feels like a hundred places and we get the same response every time, 'I'm sorry, we just aren't equipped to handle your son's extra needs.' What's worse is that they all respond this way without even meeting Tilian or getting to know him. They just hear the word disability and automatically assume he will be too much for them. While I understand their thinking, he does have extra needs and they do have other children to care for, as a parent, it is really devastating to have someone decline your child care without even meeting them.



Tilian after open heart surgery



Tilian today

My main advice to others who are looking for ways to be more inclusive of those with Williams Syndrome would be to teach your children, your peers, and possibly yourself, that being different is okay. Although Tilian might look, talk, walk or act differently, he also has so much to teach those who are willing to give him the opportunity. Acknowledge someone's humanity first, not their disability.

Williams Syndrome is just a piece of who Tilian is, it isn't the whole puzzle. Treat those with disabilities the same way you would treat those without. Let them be part of the classroom, hire them, and allow them to learn and fully participate in society. Inclusion creates a sense of belonging, meaningful relationships, and opportunities to achieve dreams, and that is what every parent wants for their child.” For more information on Williams Syndrome, visit williams-syndrome.org