



Axel's Story

Misti and husband Scott found out they were pregnant with their third child a week after Misti's thirty-fifth birthday. Her doctor's office offered the prenatal screenings for "increased maternal age," and she agreed, never imagining they would ever come back "abnormal."

At her twenty-week appointment, the family eagerly watched the ultrasound, and without a doubt, it was a boy! Big sister Aleigh was elated, but Abree cried; she wanted a little sister. With pictures in hand, Misti sent her family home, and there was no reason for them to join her in the tiny exam room for the five-minute checkup with the doctor.

Then in that small exam room, her doctor talked about her quad screen and some markers found on the ultrasound. The quad screen came back abnormal, and her baby boy, Axel, had some spots on his kidneys that were indicative of soft markers associated with Down syndrome. Now the baby went from having a 1 in 350 chance to a 1 in 30 chance of living with Down syndrome.

At 38 weeks, Misti had an emergency c-section at United Regional on June 17, 2017. Axel was born with Down syndrome and spent the first 24 hours of his life on supplemental oxygen in the Level II Special Care Nursery. Axel's hypotonia, a secondary diagnosis associated with Down syndrome, has resulted in low muscle tone. This has contributed to frequent respiratory infections caused by his inability to cough effectively without muscle tone in his core. Axel has contracted pneumonia many times, which resulted in multiple hospital stays longer than a week. He was also diagnosed with mild sleep apnea in July 2018, asthma in April 2020 and celiac disease in August 2020.

Even with the multiple diagnoses, Axel continues to be a vibrant, incredible little boy. **"His life has been full of therapies and inhalers, hospital stays and doctors' visits, yet he is pure joy, no matter the occasion,"** said Misti.

Since birth, Axel has benefited from Children's Miracle Network, and he will most likely continue to need the specialized equipment and programs CMN provides. From a giraffe bed that provided him the perfect neonatal environment as a baby to the vein finder, activity packs, and playroom, he has used more recently in the pediatric unit.

Misti said the caring staff at United Regional makes each visit better. "No one wants to experience prolonged stays in the hospital; it is even more difficult to see one's child, lying listless in a crib wearing a highflow nasal cannula and watching his oxygen saturations rise and fall. **The staff on the pediatrics floor is aware of this and has always taken every measure possible to ensure my family's comfort each time Axel has been hospitalized.**"