

INSIGHTS

Family reflections: Weldon family journey

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Lauren is 9 years old and has Down syndrome. We had a prenatal diagnosis of Down syndrome via amniocentesis at 18 weeks pregnant. She was also born with a complete atrioventricular septal defect (AVSD) or AV canal, diagnosed prenatally at about 22 weeks gestation. Currently, Lauren has yearly follow-up with her cardiac team and a yearly echocardiogram.

When she was tiny, Lauren's heart defect caused heart failure very early. She was on Lasix by 5 days of age. We had visits with either cardiology or her pediatrician every other day until she was admitted to the University of Michigan Hospital for continued heart failure and failure to thrive at 3 weeks old. Feeds by nasogastric (NG) tube were started at that time. She ended up with sepsis we believe from an intravenous site that went unnoticed for a full day due to a tornado warning and the whole unit being evacuated into the hallways. It was a very chaotic few days! We were awakened when a team of nurses and physicians rushed into her room at around 2 a.m. due to concerns that a nursing student documented a high fever during an earlier shift without notifying a RN or her clinical instructor. A lumbar puncture

was done immediately. Lauren ended up with a peripherally inserted central catheter line placed at around 5 weeks old and received multiple doses of strong antibiotics. By 6 weeks old, she was maxed out on cardiac meds and in considerable heart failure. She was born at 6 lb 5 oz and 6 weeks later for surgery she weighed 6 lb 3 oz. She underwent open heart surgery at that time. Her surgery went well but was more complicated than expected due to an extra atrial septal defect found once the surgery started. She was taken to recovery and we got to see her after a few hours. Even with more tubes and wires than we'd ever seen, it was beautiful to see her skin look pink for the first time instead of blue or grey. She was able to be extubated within 2 days, but due to a collapsed lung was re-intubated, a bronchoscopy was done, and she was placed back on a ventilator for another 2 days.

She was discharged from the hospital at 8 weeks old, 5 weeks after admission. During this time, our then 2-year-old son was cared for by both sets of grandparents and his aunt. Family brought him to the hospital to see us almost daily. My husband worked to support our family and I, Lauren's mom, never left the hospital until after her surgery. At home, she was fed by a combination of NG tube and oral feeds until she was about 12 weeks old. At her most recent cardiac follow-up appointment, her team said her repair was one of the very best they've seen and she's doing absolutely beautifully from a cardiac standpoint. We had a cardiologist tell us a couple of years ago to "go home and read Psalm 100, a song of thanksgiving" because he'd never seen a repair like hers. We have been very fortunate. Today, Lauren is a happy and healthy 9-year-old who loves school, plays soccer, and wants to be a nurse when she grows up so she can help people feel better.

Research I'd love to see would be in long-term outcomes into adulthood of people with complete AVSD repairs and need for further surgical intervention. I'd also love to see research into less invasive options for repair and subsequent valve procedures later in life after AVSD repair. My biggest concerns for Lauren's future from a cardiac standpoint are of course needs for further surgical intervention and likely outcomes of such interventions. As medical research, treatments, and access to care for people with Down syndrome improve, I'd love to see research teams delve further into life expectancy of people with Down syndrome and congenital heart defects. To those who devote their careers to such research, I'd like to say thank you for realizing the value of my beautiful daughter and others who share her unique needs!

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