

Izzy Snow

Izzy was born on July 1st, 2021 and was welcomed into the world by her mom, Summerly, her dad, Sterling, and her big brothers, Kam and Eli. Izzy is a happy baby, always smiling and bouncing. She loves to move and loves her family. She is the perfect addition and brings light to every day.

Izzy was diagnosed with a rare genetic disorder, 22q11.2 deletion syndrome, when she was 22 days old. While there seemed to be no complications at birth, Izzy's parents quickly realized something wasn't right when they took her home. It started with seizures, which led to a neurology evaluation at Akron Children's, and from there, Izzy was put through an 18-day stay of extensive tests and procedures to finally get the result of her genetic condition.

In those diagnosed with 22q11.2 deletion syndrome, a tiny piece of chromosome 22 is missing. This can affect every system in the human body with nearly 200 mild to life-threatening symptoms. This disorder is lifelong and has no cure, but many of the issues can be treated, especially if found early. 22q11.2 deletion syndrome is also commonly referred to as DiGeorge syndrome, but according to Izzy's geneticist, the term 'DiGeorge' is more historical and more narrowly defined than 22q.

Izzy is a very cherished little girl by her family, friends, and doctors. Her medical care team is made up of 11 specialists consisting of her pediatrician, geneticist, plastic surgeon, speech therapist, nutritionist, gastroenterologist, immunologist, neurologist, endocrinologist, ophthalmologist, and her developmental specialist through Help Me Grow.









Since the symptom and severity spectrum of 22q11 is extremely variable, only time will tell as Izzy gets older if she will need more or less help. Currently she deals with a history of seizures, a history of breathing difficulties and aspiration, low calcium and high phosphorus in her blood (hypocalcemia), low parathyroid hormone (hypoparathyroidism), feeding intolerance, reflux, developmental delays, T cell deficiency, and she is very small in stature, putting her on her own personalized growth charts.

Izzy's journey with Stark County Early Intervention/Help Me Grow is relatively new, but has already helped tremendously. Izzy's development is not all-inclusive, so it's hard to put a single month measurement on her as a whole, but she had shown delays in rolling, sitting, scooting, and crawling. Working with Amanda Haga, Stark DD Developmental Specialist, every other week, Izzy has put a lot of hard work into various exercises & tummy time to help strengthen her muscles. Just recently she has learned to pull herself up to standing with assistance and she is officially a crawler!

Izzy has overcome so much in such a short period of time. She is strong, brave, and resilient. Her family looks forward to watching her succeed in all that she does. With Izzy's diagnosis, her parents have created a website and platform to share their daughter's story in hopes of educating others on 22q11.2 deletion syndrome. Their ultimate mission is to raise awareness, help families cope & find understanding, and pay it forward to the genetic divisions of children's hospitals. They welcome you to join & learn more at www.my22qt.com.





