

Lillian's Courageous Kids Story

Lillian on the outside looks like your average 9 year old girl. On the inside she has been fighting numerous health conditions since birth. Lillian stopped growing and gaining weight at 4 months-8 months old that's when our Pediatrician sent us to an Endocrinologist who heard a heart murmur and sent us to a Cardiologist. We discovered Lillian had AVSD (Atrioventricular Septal Defect) her valves were leaking and there were holes in the walls between the right and left atrium and ventricle. This began a long journey. Lilly was put on Lasix and then stopped eating completely we were in and out of hospital for dehydration every couple days for over a month and we fought for a feeding tube. We were taught how to put the feeding tube in and out and we tried to get as many calories during the day lots of milkshakes and heavy whipping cream and she was tube fed overnight. Lilly was out of breath a lot and not crawling and moving like other kids. We had to wait for her to gain weight to do surgery it took months Dec- April to go from 12lbs to 16lbs. She had open heart surgery April 9, 2018 and has been doing great ever since. She finally walked at 17 months. Lilly was also diagnosed with Addison's disease-this is when your Adrenal glands make too little of the hormone cortisol. A flu can send her into an adrenal crisis where she would have to have a shot and be hospitalized because her body can't fight it, she takes twice daily steroids to keep her healthy. She was also diagnosed with the following Growth Hormone Deficiency she takes weekly shots because her body can't grow on its own at 2 yrs old she was the size of a 9 month old. I remember it taking years to get her to 50lbs. She also has Hypothyroidism and an Ectopic pituitary gland which none of her hormones work by themselves. Lilly is the strongest girl I know she tries her best to keep up with the other kids and always has a smile on her face, she is a great friend to everyone she loves to stay busy swimming and when you don't see her swimming you will find her ice skating at the rink!