

Alessia Fiorilli's Story



When Alessia was born, I can still recall someone telling me about the poem “Welcome to Holland” by Emily Kingsley and comforting me with its words. The problem was that I did not want to be comforted. I wanted my daughter to be whole and healed. I wanted my prayers for a healthy baby girl to be answered. Instead, the reality was our little girl had Down Syndrome. With the support of family and friends and our faith in God, we embraced this new journey with open arms and a lot of questions.

Children with Down Syndrome have an extra copy of chromosome 21. Having this extra copy causes mental and physical challenges. Alessia has significant delays in the area of cognition, language and has health concerns. One issue many children with Down Syndrome deal with are heart defects. Alessia was born with a large primum atrial septal defect, a hole between the two upper chambers of the heart. She also has a heart murmur and some degree of leaking. Alessia underwent open heart surgery at the age of one at The Children’s Hospital of Philadelphia for a partial ASD repair. Upon a recent visit to her cardiologist, it was discovered that the gradient was thicker, the murmur significantly worse and she needed to have a cardiac catheterization done to explore what was happening. In addition to the anxiety of another surgery and what they might find, was the overwhelming stress of what it would cost under our new insurance plan. “Great news,” the man on the other end of the phone said, “It is an \$80,000 surgery, but your cost will be approximately \$6,000.” For us, who are struggling to pay the bills as it is, it was an overwhelming amount. Alessia returned to CHOP this past April and underwent surgery for the 2nd time. At the conclusion of this surgery, the surgeon informed us that he was uncertain how complicated a second open heart surgery would be due to the potential involvement of the mitral valve. He has recommended holding off on a second open heart surgery and instead he would like to continue to monitor her.

As we thanked God for having his hand on her during that surgery, prayers continued for her to speak. What I wouldn’t give to hear her say, “mom” or “I love you.” She has approximately three to five words that she uses daily and not everyone would even be able to understand her. We taught her a variety of signs to communicate and secured an augmentative device for her. It is difficult because she is not able to get her point across and it results in a great deal of screaming, tantrums and frustration for her. Insurance will not cover hippotherapy. Therefore, we took her for private speech therapy, but due to the rising cost of insurance, we were not able to continue services for her. She still goes to her device and hits, “Go to speech with Miss Laura.”

Alessia has difficulty with eating as well and eats approximately ten foods. At the age of five, she is still not able to drink from a cup and can only eat soft foods. Alessia needs a feeding evaluation and feeding therapy to address these issues that most of us take for granted. She has had her share of illnesses along the way, being hospitalized for benign infantile spasms, which have completely resolved, reactive airway disease, RSV, croup and pneumonia. Alessia was diagnosed with strabismus, a condition where the eyes do not properly align with each other when looking at an object, at a young age and eyeglasses may be a future possibility. Most recently, we noticed Alessia’s hips were clicking and it is happening every time she moves her legs. She has an appointment scheduled with an orthopedic at CHOP this summer.

“Where do you find the strength?” people ask. Romans 8:28 says, “In all things, God works together for good.” Even though she cannot talk like us or do many of the things a little girl her age can do, she is always happy. She loves to dance, is always smiling and her joy is contagious. As parents, it is heartbreaking to want to do all you can for your child, but to be financially bound. We pray we will eventually be able to pay off her medical bills and get her the therapy she deserves.

