

## Meet Jamie & Kyle.

### What is your family's diagnosis story?

When Connor was 14 months old, he got a cold and we took him into the pediatrician to have him checked out. He got his ears cleaned and later that day, we noticed he had blood coming out of his ear. We had no idea why. We took him to the ER and the ER referred us to see the ENT. At 2 years old, another cold, another ear cleaning and another ear bleed. When we went in for a checkup, our head doctor asked if he bled at his circumcision. We said yes, and she ran a blood test on him. The results came back as a factor 8 deficiency, and we were referred to a hematologist, which was Amber. He was diagnosed with Hemophilia A at 2 years old. We have learned SO much in so little time! After more tests, we've learned that I am a carrier for hemophilia and myself and my 3- year-old daughter have mild hemophilia A.

### How did the diagnosis impact you & your family's everyday life?

At first, Connor received treatment only when needed as we had Amicar on hand. At 4 years old, we decided it would be best for Connor to receive weekly treatment as he is an active little boy in Pre-k. After receiving 5 weeks of training to learn the infusion process, I am now able to give my brave little boy weekly infusions in the comfort of our own home. I can honestly say that he does very well with these infusions and doesn't cry which makes me a very proud parent as he is only 5 years old. He likes to help mommy get all the supplies ready and open everything up.

This has affected our lives in countless ways and one way in particular that has given us the most stress in going down to a one-person income. Before Connor was diagnosed, I was able to work and help my family financially. My husband and I were working to pay off some debt and save up for a house and a more reliable car. Since Medicaid and insurance have such strict policies; I had to become a stay at home mom in order for Connor to receive the required medicine and treatment to live a somewhat normal life.

**“Learn all that you can, and never stop!  
ADVOCATE!  
Make your voice heard!”**

Now you may ask yourself if we are able to survive on one income and the answer is yes, to an extent. We are grateful to have a roof over our heads, food in our refrigerator and are generally in good health, but I would be lying if I said that our life was perfect. There are absolutely some hard days and nights that we go through. Being on one income has made it extremely difficult to envision now what we were planning on having some years ago such as our own home.

### What advice would you give to someone newly diagnosed with a bleeding disorder?

My advice for parents and children who just found out about their bleeding disorder is to honestly take it one day at a time. The support system surrounding bleeding disorders is INCREDIBLE. There are support groups on social media that I have joined, and they have so much advice. It is so hard learning about your child having a chronic disease. You, as a parent, just want to take all the pain of infusions away and make it all better. It does get better with time and easier to manage. Learn all that you can, and never stop! ADVOCATE! My family recently went to Carson City, NV to advocate for bleeding disorders and meeting with the Senators and District Assembly Members, is something I will NEVER forget. They listened to our stories and understood what we wanted. We are also going to be attending the National Hemophilia Washington days in DC, and we cannot wait to advocate there! Make your voice heard!

