

Meet Emily, Jeff, Ethan & Samantha.

What is your family's diagnosis story?

Due to family medical history, Ethan was tested before his circumcision, and our pediatrician came back with a scary diagnosis...they said Ethan had a severe bleeding disorder and only 14 years to live. It was terrifying to hear. Sam, Ethan's older sister, was only 7 and she just wanted her brother to be healthy. We were sent to Dr Bernstein. Dr Bernstein diagnosed Ethan with VWD, which is less severe. I then called my father and found out that not only did VWD run in the family, but several other family members had it. Even with the less severe diagnosis, we were blindsided. The circumcision procedure was nervewracking because you worry that the doctors won't know how to deal with bleeding disorder complications, but the procedure was short and everything ended up being fine, which was a huge relief.

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

Ethan is a firecracker of a child. He's very active. When he started preschool, before he got his helmet, he hit his head on concrete two times in one week! These instances helped me to be proactive and advocate for my children. I am on a first-name basis with the school nurses.



Samantha, Ethan & Jeff Wolff

One time he fell and a teacher's assistant carried him and ran with him through the school to the nurse. This urgency and care from the school is exactly what a parent with a bleeding disorder could hope for. Sam also has VWD but it's less severe and she has taken more of a caretaker role, which has been really sweet and helpful.

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

Remember that you're the parent and if for some reason you don't trust what's happening, get a second opinion. Look up networks of people who are going through the same thing, and go to their events, because it's a place to breathe. Socializing at events has helped our kids learn things like empathy and gratitude.

Please share a little about your involvement with the chapter.

We show up to chapter events and represent. We've gone to Women's Retreats, Couples Retreats, PEP, Spring Fest, Family Days, the Annual Meeting and Holiday Parties, Camp Independent Firefly, and more. Sometimes it's hard to go out but it's always worthwhile to connect. We like to welcome new families because we remember how good it felt when Kelly Gonzalez welcomed us. Being involved in a community takes away the fear of being alone.

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