Community Spotlight: The Hendrickson Family

Life with A Bleeding Disorder: A Look into The Hendrickson Family
By Kayla Faasse

Bleeding disorders are a group of conditions that result when the blood cannot clot properly. There are different types of bleeding disorders, but the two most common ones include Hemophilia and Von Willebrand’s Disease. With these kinds of diseases, you are very lucky if you can know about it from a young age because the sooner the better.

Jillian Hendrickson was one of those lucky people who knew she had Von Willebrand’s disease when she was a kid. The Nevada Chapter of the National Hemophilia Foundation is the first organization that the Hendrickson family has truly been involved with and “it has been life changing.”

What kinds of obstacles do you face daily?

Jillian: “The challenges of going to school and work and having issues with nosebleeds and bruises. We have to take medication all the time for that and I have to take infusions one to three times a week.”

What are your concerns with your son being at school?

Jillian: “At school a lot of people disregard it and it’s just not taken seriously. The HTC center is actually going to his school to do a skills and education session with the nursing staff, principal, and all the staff members so that they can take better care of Parker and any other child with bleeding issues. Everything is treated a little differently with him.”

How does it impact each of you differently? What are your different perspectives on it?

Parker: “When people bump into me or I hit the wall, I can get bruises from that and it’s really unfortunate, but I heal. In PE sometimes I don’t want to participate because I feel like it’s too rough for me, like flag football or any games that involve contact. I often don’t want to play those but they kind of force me to because it’s mandatory and school rules. If I get hit or something or it’s related to my Von Willebrand Disease I must sit out. I don’t feel left out when I sit out, because I’m used to it. At least I can see what’s happening, I’m not just stuck in a room and I get some fresh air.”

Robert: “When I first met them, I didn’t really understand the severity of it, but now I’m learning from the HTC and the Chapter. I’ve learned so much about it in this little time we’ve been here, and I feel bad for them all the time. I wish I could take it away and I could have it because it just stinks. I’m trying to voice it and get the word out. I’m trying to know more about it so I can help them in emergency situations. This is no joke from what I’ve been learning.”

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Jillian: “Some of my biggest challenges are with work. Not only do I have a severe bleeding disorder, but I am a mother of someone who has a bleeding disorder. My genetic testing revealed that I have three different types of Von Willebrand’s—which is extremely rare. Often people don’t understand the severity of it and tend to brush it off. Explaining that even though I look fine, I have a very severe disorder is the hardest thing. It’s hard to explain to my boss that I must leave for my son or for myself to take medication or go and get factor treatments. I have to maintain a full-time job and still be chronically sick.”