



Parents in the Bleeding Disorders Community Share Their Best Advice

HemAware asked parents for their best advice on what has helped them navigate their children’s bleeding disorders in the first few years after diagnosis.

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Family Matters

Learning that your child has an inheritable blood or bleeding disorder can cause stress and anxiety for many parents. Your mind can race from what life will look like for them and how you’ll care for them to what the future holds. Here are some tips for handling the unknowns and the day-to-day from parents who’ve been there.

Lauren Holomalia

Wai’anae, Hawaii

Son Mason, 10

Diagnosed with hemophilia before birth

When my grandmother found out, she told my mother that I was going to have a hard life. My uncle who had hemophilia died in his early 50s. My grandmother remembers the struggles of taking care of him as a child. Their comments really scared me.

My son’s hematologist was very encouraging in letting me know that technology and treatments have come a long way. She also offered to speak to my family. That’s what really turned them around on the whole situation. Through being educated, they became much more supportive of me.

If you’re in a similar situation, educating your family members is important. Invite them to chapter meetings and NHF family events so they can learn about hemophilia.

I’ve also taught my son from a very early age to own the fact that he has hemophilia and be empowered by it. We embrace any opportunity to educate others so that it’s not a shameful thing. It’s not a secret. I know some people are more private, but that has helped my son really be more aware of things that he shouldn’t do and know what he can do safely. It’s all about being aware and building confidence.

Talk to your child’s school. Go in calmly and explain the situation. When you’re comfortable, they’re comfortable. It helps defuse the panic they feel when they hear “bleeding disorder.” I’m a teacher, so I created a binder that I gave to the school nurse. It has a picture of him, his name, date of birth and very specific steps to follow in case of an emergency. I learned very early on that not all hospitals or doctors know very much about hemophilia or how to infuse.

Jodi Rudell

Cheyenne, Wyoming

Daughters Hannah, 23, and Emma, 19

Diagnosed with von Willebrand disease at ages 12 and 8, respectively

Our older daughter’s fifth period is what triggered the diagnoses for our family. I have it too, and my husband was a carrier, but we didn’t know it.

Ultimately, what helped us was reaching out and connecting with a local chapter and community through our hemophilia treatment center (HTC) in Denver. That’s my biggest piece of advice to new parents: Connect with your HTC and local chapter. They have the best resources.

Be involved with your bleeding disorder community. Without it, I don’t know where I’d be. While my best friends are my support system in life, they don’t understand bleeding disorders. And that’s the difference. It’s a huge stress to have a chronic, rare disorder. My “bleeder moms” understand what I’m going through more.

Our medical bills were outrageous. I, fortunately, had never been in a position to ask for money before, but I found that our chapter had a patient assistance program. So, I wrote a five-page letter explaining what was going on. When Hannah had that heavy period, nobody knew what was happening. There was not a hematologist in Cheyenne at the time. Hannah was in the ICU here and had to be transferred to the ICU at Children’s Hospital in Denver, which is connected to the HTC there. I asked for \$500 for the ambulatory fees, and the chapter gave us more, which was absolutely helpful.

Cristel Peake

Northfield, New Hampshire

Son Seth, 17

Diagnosed with hemophilia A before birth and diagnosed with an inhibitor at age 2

I didn’t know very much about how inhibitors occurred. It took a few years to learn he had inhibitors. He’s had issues with venous access, joint surgeries, you name it. He uses a wheelchair now. Had I known how serious it could become, I would have monitored him more for inhibitor formation.

I didn’t know to press the doctors to check for inhibitors. That’s something I think parents should be aware of. If caught early, new treatment options for inhibitors can reduce the risk of serious joint issues.

Always follow your instincts. You know your child best. If the doctor doesn’t believe you, press it and fight.

Make sure to have your other children tested, even if they’re older and their symptoms are unclear. My 26-year-old daughter, Jess, was recently diagnosed with mild hemophilia A.

Samantha Javorka

Summerville, South Carolina

Daughter Daphne, 8

Diagnosed with von Willebrand disease type 2B and thrombocytopenia at age 2

Learning to treat with prophylaxis at home was the best piece of advice we got. At the time (of diagnosis), that was uncommon for people with von Willebrand disease. We had a really open-minded doctor in Michigan, where we moved from, who was up on all the current treatments and who supported our decision. In the past six months, NHF has released new guidelines for people with von Willebrand disease saying that there are positive results with prophylactic treatment.

Get advice from someone who lives with the condition every day—a parent or a child. When my daughter had pain from the car seat strap over her port, parents who experienced similar situations gave us different suggestions.

Showing our daughter videos of other kids getting infused took the fear out of it for her. We’ve also learned that sucking on a lemon wedge helps. There’s something about the connection between your brain that focusing on the sour takes priority over focusing on the pain.

To handle the unknowns of emergency room visits, ask to set up a tour of the ER. We took our daughter when she was not having a bleed, so she could meet the nurses, see the facility and feel comfortable if she ever needed to go in. The lead nurse updated my daughter’s online chart so now it flashes red with information to call our hematologist. Before that, if we went to the ER, I would have to call my doctor and hand over my cellphone to make sure they called. I’d overheard nurses joking before, “It’s just a bloody nose. Who comes to the ER for a bloody nose?” But the flashing screen validates us.

Maggie Carruth

Jackson, Wyoming

Son Teddy Taylor, 17 months

Diagnosed with severe hemophilia A at birth

The most helpful thing for us after our son’s diagnosis was meeting with other hemophilia families. Our local NHF chapter connected us to several parents who had older boys. It helped to talk to them about what kind of treatment options worked for them, and the pros and cons between getting a port for prophylaxis or using medication subcutaneously.

Staying off Google helped. I’m not joking. It can create unnecessary anxiety. Talk to the professionals—the nurses and doctors who treat hemophilia—instead.

One piece of advice that stuck with me: They don’t necessarily bleed faster. They just bleed longer. I had this vision there would be blood gushing everywhere. The reality is that it takes much longer for their blood to clot, depending on the severity.

Learning as much as I can about my son’s condition has helped me advocate for him. If we do find ourselves in an emergency room, we know what should happen. We have a care plan. We’re prepared.

Cristina Ruiz

West Allis, Wisconsin

Son Yadir, 10

Diagnosed with severe hemophilia B before birth

I had already been involved with the hemophilia community because of my nephews. The community support helped me so much during those first few months and years after diagnosis. The hemophilia moms would meet once a month for breakfast and talk about anything on our minds.

One thing parents need to keep in mind: Even if your child has other family (members) with hemophilia, they all bleed differently.

Keep the lines of communication open and check in with your kids. Some kids don’t let you know when they’re hurting or bleeding. We tell our son, “It’s OK to feel what you’re feeling.” I think he thinks it’s a bad thing that he needs to get infused. We tell him it’s not his fault; it’s just something we have to do.

Managing financial logistics, like health insurance, can be challenging. The information I got through the hemophilia community helped. I also let my hematologist know if there were ever any billing and insurance issues.

Advocate for your child, especially in the ER. They just aren’t very aware of what they should be doing. If you see something that doesn’t seem right or doesn’t look right, you should speak up.

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