

## MEET THE YOSTS



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### IN HER OWN WORDS – A FAMILY’S STORY ABOUT LIVING WITH VON WILLEBRAND DISEASE

by: Katie Yost



We knew our daughter, Adelaide, had von Willebrand Disease (VWD) from the day she was born. She bled profusely when they pricked her heel for her infant screen test in the hospital. Having VWD myself, I understood that there was a 50% chance she had inherited it. When I was born, my mom knew there was a chance that I would have it as well — just like her. When Adelaide was old enough, the tests confirmed she had type 2a. Three generations with the same diagnosis, but three very different experiences living with it.

I thought I knew everything about the challenges of living with our disorder. But I had a much easier time than my mother did growing up. I remember all the stories about the risks of receiving blood transfusions that she shared with me. It wasn't until I was older that new ways of treating our disorder were developed.

Drawing upon my own experiences and my mother's experiences, I was comfortable and confident as a parent to our now very active 5-year-old living with a bleeding disorder. That was until this past winter when Adelaide experienced three life-threatening spontaneous bleeds in a row. It was the scariest time in our lives. The many days spent in the hospital allowed me to reflect on how fortunate we were to have the resources available to treat our daughter. I learned that these resources aren't as readily available, if at all, in other parts of the country and world.

It was equally unnerving to learn that Adelaide's doctors recommended a prophylaxis approach to her care going forward. Before I could even wrap my thoughts around what this meant, our Hemophilia Treatment Center (HTC) was scheduling in-home visits with us to teach us how to infuse our daughter intravenously. It was not an easy process but with persistence and support, we were ready to infuse her by ourselves every other day at home. During this ordeal I felt lost and for the first time, uninformed about our condition and simply not in control of it. Immersing ourselves in the bleeding community proved to be exactly what we needed to feel comfortable and confident once again. I was grateful to be connected with another parent who also infuses her son who is a similar age as Adelaide. Our conversations and her reassurance were invaluable.

Some of our worries were put to rest when we attended GLHF's Family Camp. At Family Camp, we did every activity you could imagine. It was exactly what we pictured a normal camp to be like. Now we have things to look forward to in her future — like having Adelaide attend GLHF's Camp Klotty Pine by herself when she's old enough. We're excited about participating in upcoming GLHF events to continue making connections with other families affected by a bleeding disorder. I certainly don't feel alone in the challenges we have to face, and our confidence as a family living with our disorder grows daily!