



Julie H.

Common Factors® Advocate

My life at a glance

I am happily married and the mother of 2 teenage boys. We live in Arizona, where I am currently studying for my BSN.

My areas of interest include traveling, art, photography, hot air ballooning, and pursuing new adventures. And, of course, I love spending time with my family!

I am very active in the bleeding disorders community. Working with my local chapter, I helped to create and develop a successful program called BleedHERS. I also serve on the NOW planning committee, assisting in the development of this popular conference.

My son and I both have Type 1 VWD (severe), with a platelet aggregation dysfunction.

Surprisingly, my VWD was not diagnosed until I was pregnant with my first child. There was always the belief that something must be wrong with my blood because of the severity of my bleeding and bruising when I was younger. But a diagnosis was not made until a concerned gynecologist ordered the test.

As a speaker, preferred topics include

One of the most important messages that I would like people to get from listening to me speak is my belief that it is okay to complain about a problem as long as you are willing to step up and become part of the solution. In the many struggles that I have faced to come back from life-threatening bleeds and endless hospitalizations, that has been the one message that has kept my vision clear and strengthened my resolve to help make a difference for others. I started out eager to volunteer for anything that I could do to help, not knowing that it would be one of the most healing things my family would do. Anger and frustration were slowly replaced with understanding and coping strategies.

Some other topics I enjoy discussing are personal experiences in medical records management and the importance of maintaining your own copies, travel considerations, communicating effectively with your doctor, and helping others recognize that both men and women are affected by VWD.

My message to you

"Education, empowerment, and advocacy are core components to help you and others 'Survive and Thrive' living with VWD."

-Julie

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