

Surviving & Thriving

Living with von Willebrand's Disease and Platelet Aggregation Dysfunction

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As a child and young adult, I had frequent episodes of sudden and severe bleeding that were often difficult to control. The bleeding that occurred as an adolescent was accompanied by frequent trips to the nurse or doctor. However, doctors were still unable to provide answers because "I was a girl, and girls didn't have bleeding disorders". At 19 years old, I learned that I had von Willebrand's disease (VWD) and was given a small bottle of nasal spray to use whenever I had "too much bleeding."



My diagnosis became a reason why bleeding had always interrupted my life. Unfortunately I failed to realize just how serious VWD could be.

At the age of 23, my lungs hemorrhaged...and it was in this very moment that the severity of my bleeding disorder crystallized. The next month was spent on a ventilator with a grim prognosis.

This event complicated by VWD was the beginning of many years of poor health, frightening bleeds, and several complicated surgeries. The most severe episode resulted in an intracranial hemorrhage in 2006 which left me grateful to regain most of my vision and the ability to walk. At 36 years old, I was also diagnosed with a platelet aggregation dysfunction, further explaining atypical bleeding episodes.



In years past there was a period of time that I spent frustrated and confused because I repeatedly heard that "women don't have bleeding disorders" or that "bleeding from VWD should be mild." I began to realize that if I had any hope to "survive and thrive," I would need to change my thinking. I had to dispose of the victim mentality and instead start living as a survivor. I needed to become part of the solution.

"We don't know what's wrong with her...she's a girl; girl's don't have bleeding disorders"

My husband and I started volunteering for the Arizona Hemophilia Association with the intention to raise awareness for women with bleeding disorders as well as those affected by VWD. We eagerly signed up to volunteer for any fundraising and advocacy opportunities that were offered. We didn't realize that by becoming active we were healing ourselves. By learning new coping strategies and finding ways to laugh rather than cry, we slowly replaced grief and frustration with compassion and understanding.

I continue to educate myself at local, national, and international conferences, as well as attending local and national advocacy campaigns. I have helped create meaningful programs such as BleedHERS for women and the NOW (National Outreach for von Willebrand's) conference.

The experiences and lessons I have learned from the challenges faced have become tools and resources for my son Chad who also has VWD and platelet aggregation dysfunction. I have had years of health issues, some of which have nearly cost me my life. I am now seeing some of the same health issues affect my son. But I am no longer ignorant or an uneducated patient and consumer. I have strived to learn so much over the past 15 years, partly for a better life for me, partly because I couldn't bear to watch my son go through what I went through.



My story and the stories of others like me who have overcome hardships should be stories of inspiration and hope...the ability of the human spirit to overcome life's challenges. I am no longer just surviving, but thriving. I have become part of the solution.

