



Madonna M. S.

Common Factors® Advocate

My life at a glance

I live with my husband and our three children in Corvallis, Oregon. We are a close-knit family. Our kids are like millions of other kids—active and busy—and I spend most of my free time in the car driving them to various activities. In fact, all three of our children are competitive Irish dancers.

My husband and older daughter have a milder version of type 1 VWD. My son and younger daughter have a much more severe form of type 1 VWD. We discovered the VWD in our family by accident when my son was 2 years old in 2004. Through the help of friends and our hemophilia treatment center, we have learned to live with the complications of VWD. All three of our children bleed differently and therefore need three different kinds of treatment protocols. Although we have experienced some very difficult times, we manage to live healthy, active lives.

I am dedicated to helping improve the lives of families affected by bleeding disorders. I have the honor to work for the Hemophilia Foundation of Oregon. By using my experience and sharing our family story, it is my goal to provide others with encouragement, information, and reassurance.

As a speaker, preferred topics include

I like to assure people that they're not alone. Many families feel overwhelmed and isolated by a new diagnosis. By sharing my family's experience, I try to help others realize that the strength of loved ones and the support of the bleeding disorders community can greatly ease the burdens of VWD.

I also speak to the importance of advocating for yourself or your child. This can be difficult, especially in unfamiliar, hectic environments, such as the emergency room. But effectively communicating your needs to the team around you—health care professionals, teachers, employers, and others—can make the disease easier to manage.

My message to you

"My husband and I see our kids as perfect. VWD can't change the essence of how wonderful and smart they truly are. It will never dictate who they will become. I believe that holds true for all of us, patients and families, in the bleeding disorders community."

—Madonna

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