The Monthly PERIODical

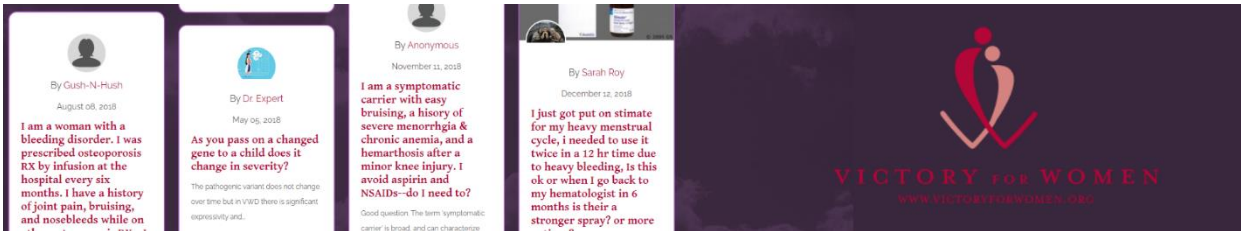
Welcome to November's Monthly PERIODical Newsletter, written specifically for women, girls, and people with the potential to menstruate.

West Virginia Women's Event

WOW for Women!

Our first ever WOW Women's event was a success with 8 women in attendance for the virtual talk. Conversation got deep quick, as we discussed mental health topics like depression, stress of being a caretaker while experiencing symptoms yourself, and how hard it can be when kids grow up and move out. Participants at the event will be receiving a giftbox of goodies thanks to a grant from NHF.

We plan to have another event in December which won't have a sponsor or a specific topic. It's just a place to hang out and get to know other women in the chapter and share about our experiences. Check out our events calendar for more info or to register.



By Gush-N-Hush

August 08, 2018

I am a woman with a bleeding disorder. I was prescribed osteoporosis RX by infusion at the hospital every six months. I have a history of joint pain, bruising, and nosebleeds while on

By Dr. Expert

May 05, 2018

As you pass on a changed gene to a child does it change in severity?

The pathogenic variant does not change over time but in VWD there is significant expressivity and...

By Anonymous

November 11, 2018

I am a symptomatic carrier with easy bruising, a hisory of severe menorrhgia & chronic anemia, and a hemarthosis after a minor knee injury. I avoid aspirin and NSAIDs--do I need to?

Good question. The term 'symptomatic carrier' is broad, and can characterize

By Sarah Roy

December 12, 2018

I just got put on stimate for my heavy menstrual cycle, i needed to use it twice in a 12 hr time due to heavy bleeding, Is this ok or when I go back to my hematologist in 6 months is their a stronger spray? or more

A Place Just for Women

Victory for Women is a place for you to share your creative expression of all kinds: photography, blog posts, stories, poems…whatever you feel captures you. A place where women in the community can express themselves, ask their questions, share their challenges, and above all, celebrate the victory of standing up and being heard. There's also a great section where you can ask personal questions (anonymously if you want) and get answers from medical professionals in the community. If you want to see what's going on with others like you, check it out.

Paige's Story

Paige is a student at WVU. She shares her story below about growing up with VWD and the connections she's made through the community.

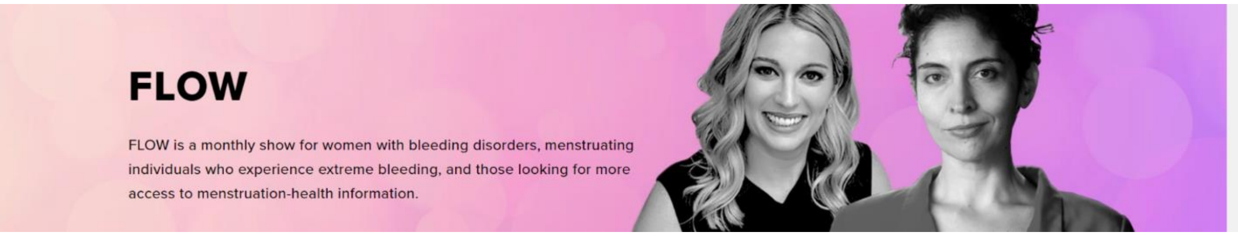
They diagnosed me with Von Willebrand Disease at five years old. This means that I have lived with this disease for as long as I can remember. I really don't know a life without it. This disease has dictated my life.

When I first learned of my diagnosis, I didn't quite understand what it meant. The most memorable thing about having Von Willebrand Disease was the constant poking of needles in my arms. I recall sitting down with my parents after dinner and having them explain to me what this diagnosis meant. It meant that for the rest of my life, I would have to be extremely careful each day to ensure my safety. This was the first time I felt sad about my blood disorder. I felt different. My friends could play soccer during recess without the fear of getting hurt. My siblings could play fight without having bruises cover their arms. It felt like this disease was going to be a constant struggle throughout my life.

Adapting my hobbies to fit with life with Von Willebrand Disease was the biggest challenge. I am a very competitive person, and I loved playing contact sports like basketball and softball. Since my blood disorder meant I was very susceptible to injury, my parents decided it was a better idea to not play sports where I had an increased chance of getting injured. While sad at first, I cheered up when my parents enrolled me in dance. From my very first ballet class, I knew that dance was for me. I also enjoyed more artistic hobbies, such as singing, playing the ukulele, and drawing. These hobbies are the perfect way to express myself, without worrying about my safety. While this disease closed many doors for me, it opened others up. I now have many hobbies that I cherish today and will do so for the rest of my life.

Because of this disease, I have attended events, such as summer camps, with people who also live with blood disorders or cancer. Connecting with people who are like me has created some of the best lifelong friendships. But I have also had to deal with loss at an early age. People that I have connected with and formed a deeper, more bonding relationship have died way too early. It’s unfair. It’s changed my perspective for the better, as I value the relationships and the time I have with those whom I care for. It has also aligned my personal and professional goals to help the next generation of those who are like me.

Being diagnosed with Von Willebrand Disease was an enormous shock. All I could think about was the negative impact it would have. As I matured, I realized I cannot control whether I have it. I learned I needed to adapt to it while still enjoying the best parts of life. While it has dictated many aspects of my life, I won’t let it dictate my happiness.



FLOW

FLOW is a monthly show for women with bleeding disorders, menstruating individuals who experience extreme bleeding, and those looking for more access to menstruation-health information.

Period Podcast

Have you ever wanted to learn more about periods, but felt kind of awkward talking about it? If so, check out this podcast. FLOW is a monthly show for women with bleeding disorders, menstruating individuals who experience extreme bleeding, and those looking for more access to menstruation-health information. Their episodes cover a variety of topics including Sexism, PMS’ing, and Periods+Pop Culture. You can listen to them online, or wherever you normally stream music and podcasts. Find out more here.