

# The Monthly PERIODical

**Welcome to our new Monthly PERIODical Newsletter, written specifically for women, girls, and people with the potential to menstruate.**

We know that there are special challenges for women who are affected with a bleeding disorder, whether you have been fully diagnosed, suspect you may be affected, or are labeled with the dreaded “symptomatic carrier”.

Each month we’ll send out this newsletter with info, resources, and stories as part of our new WOW West Virginia Women's program. The WOW program will include educational workshops, activities, and get togethers for us ladies, and will culminate in a Women’s Retreat next spring, so be on the lookout!



## **First WOW Women's Event: Balancing Emotional Wellness**

Join our friends at Pfizer as we talk about how emotional health impacts women and girls in the bleeding disorders community. This is a virtual event, so bring your mothers, sisters, daughters, and girlfriends for a night of great conversation.

This is our first West Virginia Women’s WOW event, geared towards women and girls impacted by bleeding disorders. Thanks to a grant from NHF, ladies who attend this event will receive a small care package afterwards.

The event is virtual, Wednesday, November 16, 2022 at 6:30PM. Register on our [events calendar](#).

# Personal Story



## Kristen's Story

Kristen is a community member from Harrison County, WV. She shares her story below about issues she's had during childbirth after being labeled a "symptomatic carrier" of hemophilia.

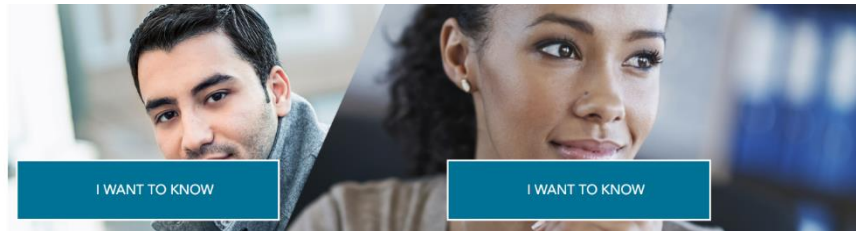


Hi, I am Kristen. I am a carrier for Hemophilia A (labeled as a symptomatic carrier). My father had Severe Hemophilia A. All my life I was told I was a carrier for Hemophilia but was never educated on what it was. I was only told stories about my father because he passed when I was young from contracting HIV from factor replacements. I have always had heavy periods, nose bleeds, and joint pains, but when I started having children is when the symptoms really started.

When I got pregnant with my first child it was a girl. When I asked about me being a carrier, I was told it is not a concern because you are having a girl, but boy was they wrong. I had bleeding off and on my whole pregnancy and then once she was born, I was readmitted for too much bleeding. My daughter was born with multiple health issues so at the time I had no concerns for myself and just wanted to get well for her.

Then I had my second child and once again was told "you're having a girl so it's no issue". She was born and I hemorrhaged. Still no answers as to why, I was treated accordingly and sent home. A few years later I got pregnant with my son. Still not educated on hemophilia, I was told by my OB that there was no concern, and nothing could be done 'til he was born. I went into labor with my son right when the pandemic started, and they shut down everything. He got stuck in the birth canal and after 2 hours they decided to do an emergency c section. After my son was born, I was in surgery for an additional hour. I remember looking over at my husband telling him I did not feel well and then him asking the surgeons what was going on and taking so long. That's when they told him they were having a hard time getting my bleeding to stop and that I was a Symptomatic Carrier of Hemophilia. I received a blood transfusion and was released 3 days later. But my son was not because we found out he had Severe Hemophilia A. At the same time we were notified he had a brain bleed from being stuck in the birth canal. My son is now 2 years old and thriving.

When I was a kid, I was told women could not be Hemophiliacs, as hemophilia only affects males. I am sitting here now, I'm going no, that's not accurate, and it's sad. It is so damaging. This belief that women aren't affected by hemophilia is still there among the medical community. Doctors look at you like you don't know what you are talking about and are making this up. Therefore, I share my story with you because you have a voice, your concerns do matter, and you are not making this up!



## Do you know if you have a bleeding disorder?

Better You Know is an initiative from the NHF Education Team to help people who think they might be affected by a bleeding disorder start their journey towards getting some answers. It includes a risk assessment specifically for women to help determine if the issues you are experiencing are normal or may be due to an undiagnosed bleeding disorder. There are also resources for how to talk to doctors, how to prepare for lab tests, and there are options to set reminders and check-ins while you go through the steps of diagnosis. Visit [the website](#) to take the assessment and check out [Journey to Know](#) to enroll in the support program.