

# The Monthly PERIODical

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



## Women's Retreat Recap!

Over the past few years, we've heard lots of stories from women who have been ignored or dismissed when talking about their symptoms. This is why we held the chapter's first ever Women's Retreat. Ladies came from all over West Virginia and Ohio to get to know each other, swap stories, and learn more about the specific ways bleeding disorders affect women. It was really nice to get to meet everyone and we are hoping to have an even bigger retreat next year.





**WBDR**  
WFH WORLD BLEEDING  
DISORDERS REGISTRY

Now enrolling  
people with  
**VWD**

## World Bleeding Disorders Registry Now Includes VWD

In 2018, the World Federation of Hemophilia (WFH) launched the World Bleeding Disorders Registry to provide doctors and HTC's with easily accessible data to help launch better treatments for patients. Until recently it was just for people with hemophilia, but now they have expanded to collect data from people with von Willebrand disease (VWD).

A WFH representative had this to say about the expansion “While von Willebrand disease is the most common inherited bleeding disorder, there is a great deal of variability in how VWD is diagnosed and managed around the world. The inclusion of VWD in the WBDR will allow scientists, policy makers, and stakeholders to better understand the ways in which care for VWD is delivered, while helping them work toward improved care and quality of life globally.” Learn more about the research efforts [HERE](#).



# Community Voices in Research

## NATIONAL HEMOPHILIA FOUNDATION



### Enroll in Community Voices in Research

While the Bleeding Disorders Registry (noted above) has data entered and accessed primarily by HTC's, Community Voices in Research (CVR) is a way for YOU to participate in data collection that can be used to help researchers improve treatments. CVR is an NHF initiative that gathers info about what it's like to live with a bleeding disorder and is open to everyone affected by a bleeding disorder, as well as their non-affected family members. Learn more about the [CVR program here](#).

### NHF Resources

As always don't forget about the great NHF resources available to help you get a diagnosis and share your story.

[Better You Know](#): Guidance on symptoms, testing, and getting diagnosed.

[Victory for Women](#): A place to share your story and get questions answered.