

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



Black Women with Bleeding Disorders Are Striving to Be Seen and Heard

For many women with a bleeding disorder, finding a doctor who will listen and take your concerns seriously is a real challenge. This is especially true for women of color, and with April 11th-17th being Black Maternal Health Week, we wanted to share this article from HemAware about the specific struggles Black women face while seeking care for their bleeding disorder. <u>Read about it here.</u>



What to Expect During Your First Gynecological Exam



Great Resources from HoG

Hemophilia of Georgia (aka HoG) has a library of resources for women with bleeding disorders including <u>this guide</u> for girls with bleeding disorders who are getting ready for their first gynecological exam. To see their whole list of resources, <u>visit their website here</u>, and scroll down to the bottom for the lady specific section.



Study Finds Many Mothers of Children with Hemophilia Experience Guilt

Researchers from the Children's Healthcare of Atlanta and Emory University recently published the results of <u>a small study</u> investigating the subject of guilt in mothers of children with hemophilia (CWH). They found that even though mothers perceived their children to have about the same level of life satisfaction as children not affected, about 40% of mothers did have increased guilt. Common specific reasons for guilt that were expressed by mothers involved a sense of causing their child to experience pain through infusions or a sense of having given their child an X chromosome associated with hemophilia.

The authors suggested some positive takeaways: "Community immersion was beneficial, as other mothers in the community served as a source of social and educational support. Most mothers did not report guilt, illustrating the adaptability and resilience of the hemophilia community," concluded the authors.

Don't be afraid to pick up the phone and talk out your feelings with other moms in the community or talk to your HTC social worker about strategies to manage guilt.

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.