Women Bleed Too ToolKit

Women can and do have bleeding disorders. Bleeding disorders among females may cause special challenges because of the bleeding associated with menstruation and childbirth. Menorrhagia is an abnormally heavy and prolonged menstrual period and is the most common symptom among females with a bleeding disorder.

It is important for women who suspect a bleeding disorder to be seen by a physician for testing, diagnosis, and treatment. Proper treatment and care for women with bleeding disorders is available and can greatly impact and improve the quality of life.

This toolkit contains resources, specifically for women, to help with taking that first step toward finding answers to their bleeding issues. Tools that are included in this kit:

- Presentations (recorded webinars & videos).
- Tools (mobile app, online assessments, directory of providers).
- Articles and PDFs (articles, brochures, documents).
- Links to other resources.

PRESENTATIONS

Empowering Women with Bleeding disorders
https://www.youtube.com/watch?v=jqw9Jq9guEg

In this Blood Sisterhood webinar, The Foundation for Women and Girls with Bleeding Disorders presented about their organization's mission, reviewed studies they have conducted, and provided effective ways for women to better collaborate and communicate with their providers.

It's Genetics Baby!
https://www.youtube.com/watch?v=zrggqFhWuFs&feature=youtu.be

In the ever-changing bleeding disorder landscape, it is comforting to be prepared. Meg Bradbury, genetic counselor, presented an overview of bleeding disorder genetics, genetic counseling, and testing options. Meg also shared the benefits of genetic counseling.

Diagnosis in 16 Years: A Woman's Health, Public Health Crisis
https://www.youtube.com/watch?v=E7Yd1-oQOCM&t=95s

Quality clinical services, specifically for women and girls with bleeding disorders, are key to accurate diagnosis, reducing complications and diminished quality of life, and improving women's health. The Hemophilia Federation of America's (HFA) Blood Sisterhood program in partnership with the Foundation for Women & Girls with Blood Disorders (FWGBD) produced this important webinar to learn how the FWGBD is working to ensure proper diagnosis, optimal management and treatment of women and girls with blood disorders through special initiatives with the 135 federally funded Hemophilia/Hemostasis and Thrombosis Treatment Centers (HTCs) across the country. This webinar provides an introduction and overview of WGBD Clinics of Excellence Initiative and Directory Project. The Directory identifies HTCs that offer services for women and girls, and those that have specific Women & Girls Bleeding Disorder Clinics.

PRESENTATIONS

Managing Care for Women with Bleeding Disorders
https://www.youtube.com/watch?v=jqw9Jq9guEg

It is important and vital that women who are symptomatic carriers, have hemophilia, von Willebrand Disease (vWD), or other rare clotting conditions have a voice in the bleeding disorders community. During this Blood Sisterhood webinar, Dr. Robert Sidonio from Vanderbilt University discusses treatment and management options for women with rare bleeding disorders and shares the results of recent studies that he just conducted.

Women and Bleeding: Challenges of Hemophilia Carriage, VWD, and Other Rare Bleeding Disorders
https://www.youtube.com/watch?v=zrgggFhWuFs&feature=youtu.be

This program provides evidence-based, practical information on the signs and symptoms of bleeding disorders, specifically Hemophilia Carriage, VWD, and other rare bleeding disorders, in women and girls. It will discuss the prevalence of these symptoms, and describe the accurate evaluation of, including laboratory assessment of, and the clinical management of these bleeding disorders among women and girls for optimizing their quality of life. The discrete impact of these conditions on women and girls, as well as the best diagnostic tools, optimal therapies, and treatment guidelines, will be presented. Healthcare providers will also be introduced to the Hemophilia Federation of America's approved mobile application as an important collaborative tool that they can put into the hands of their patients to help them more effectively track their bleeding.

PRESENTATIONS

Raising Girls With Bleeding Disorders
https://www.youtube.com/watch?v=NVcBg21LA8A

Raising girls is a tough job. It is an even tougher job when your daughter has a bleeding disorder. Please join us for this opportunity to hear from parents and women and learn how they've tackled some of the biggest challenges women and girls face in the bleeding disorder community. Panelists will share stories of: • A day in the life of raising a daughter with a bleeding disorder • Self-infusion/treatment • Issues in accessing care for girls • Coping with puberty/menstruation • Managing school issues. Panelists will discuss the difficulties they have faced and how to remain resilient when facing these challenges. Listening to other parents and women who have shared similar experiences can help ease your nerves and concerns you may have while raising your daughters.

RESOURCES

Hemophilia Federation of America Blood Sisterhood Program
www.hemophiliafed.org/join-blood-sisterhood

Women have been the silent "carriers" of hemophilia and lived with undiagnosed bleeding disorders for too long. HFA[RK1] [RK2] is committed to providing women with the information and support they need to reach a diagnosis and continue that support through the stages of their life with a bleeding disorder.

RESOURCES

The Blood Sisterhood program was established to help meet this need for women. A main component of the program is a peer network of women who support women with bleeding disorders on their life's journey through diagnosis, treatment and day to day living. Ultimately, through furthering the conversation among women, we seek better health outcomes and a better quality of life for women with bleeding disorders.

Foundation for Women and Girls with Bleeding Disorders
www.fwgbd.org

A single site, single source for physicians and healthcare providers. Provider education across disciplines is the focus of the Foundation. This benefits women and girls by educating their providers.

Let's Talk Period
www.letstalkperiod.ca

Let's Talk Period aims to increase awareness of the signs and symptoms of bleeding disorders. Through her internationally recognized research program at Queen's University, Dr. James, Hematologist at Kingston General Hospital, and her team have developed a self-administered bleeding assessment tool (Self- BAT) that will help inform people about their bleeding and guide them toward the help they need.