

# WGPPM Summit



NATIONAL BLEEDING DISORDERS FOUNDATION

## WGPPM INITIATIVES & RESOURCES FROM ATTENDEES

# CONSUMER-PATIENT EDUCATION & AWARENESS

### ASOCIACIÓN PUERTORRIQUEÑA DE HEMOFILIA Y CONDICIONES DE SANGRADO

- We have organized a women's retreat and developed programs specifically designed to address the challenges faced by women with blood disorders. Our aim is to create a supportive and empowering environment where women can come together, share their experiences, and find solace in knowing they are not alone. We provide a safe space for women to share their stories, express their concerns, and seek guidance from healthcare professionals and fellow participants. Through these conversations, we aim to raise awareness, reduce stigma, and improve understanding surrounding women's health issues, particularly those related to blood disorders and menstruation.
- Recognizing the financial burdens that often accompany blood disorders, we have established a financial assistance program. This program provides women with resources to help alleviate the costs associated with managing their blood disorder, including expenses related to their period problems. We understand the importance of financial support in accessing necessary medical care, treatments, and other essential resources. [Patients Assistance Program : What We Do : In English : Asociación Puertorriqueña de Hemofilia y Condiciones de Sangrado \(hemofiliapr.org\)](#)

### BRIGHAM AND WOMEN'S HOSPITAL BOSTON HEMOPHILIA CENTER

- Our center has launched a Women's Thrombosis and Hemostasis Clinic. There are two sites (one for adolescents; one for adults) and there is increasing education being done to educate patients about these conditions.

# CONSUMER-PATIENT EDUCATION & AWARENESS

## CENTERS FOR DISEASE CONTROL & PREVENTION

- The CDC offers cooperative agreements that have a focus on both diagnosis and clinical management for women and girls with bleeding disorders. The CDC partners with both NBDF and HFA on their cooperative agreement initiatives. CDC has worked with NBDF as their partner in their development of consumer education to increase knowledge about the signs and symptoms of bleeding disorders among the general public of women and girls through the Better You Know campaign; as well as their efforts to increase the number of women with symptoms to seek care through the Journey to Know campaign.
- CDC aims to increase awareness and provide credible health information related to women and girls through the CDC websites and communications.
  - [Learn More About Bleeding Disorders in Women | CDC](#)
  - [Real Stories of Women Living with Bleeding Disorders | CDC](#)
  - [New social media campaign for teen girls: Information for Adolescents | CDC](#)

## CHILDREN'S HOSPITAL OF MICHIGAN

- Community outreach program: High School Education on recognition of heavy menstrual bleeding in partnership with Detroit Public Schools
- Healthy Vibes: a program encouraging and empowering a healthy lifestyle in children with bleeding or clotting disorders.

## DR. PERIOD HACKERS

- [@DrPeriodHackers](#) / [Twitter Educational twitter account](#)

## FOUNDATION FOR WOMEN AND GIRLS WITH BLOOD DISORDERS

- <https://www.fwgbd.org/clinics>
- <https://www.fwgbd.org/resources/7-2-1-podcast>
- <https://www.fwgbd.org/resources/provider-handouts>

## HEMOPHILIA FEDERATION OF AMERICA

- Offer and e-learning platform for education and awareness about bleeding disorders and related information: <https://www.hemophiliafed.org/learning-central/>
- Multiple resources & tool kits for consumer education and advocacy on our website: <https://www.hemophiliafed.org/resources/>
- Webinars, Symposium, and various year-round events. [Events - Hemophilia Federation of America](#)
- Sister Space monthly online gathering and in person opportunities [SisterSpace Monthly Chat - Hemophilia Federation of America](#)
- Women's Health Month Social Media Campaign
- Mild Matters Patient Summit [Mild Matters - Hemophilia Federation of America](#)
- Grant opportunities for HFA's Member Organizations supporting programming for WGPPMs

## HEMOPHILIA FOUNDATION OF MICHIGAN

- [Hemophilia Foundation of Michigan \(hfmich.org\)](https://www.hfmich.org)
- Annual Women's Retreat
- Ruby Connection Women's Group
- National Conference for Women and Teens with Hemophilia and Rare Factor Deficiencies
- HFM offers additional women's programming via SpringFest, bi-annual VWD Symposium, summer camps, and other activities

# CONSUMER-PATIENT EDUCATION & AWARENESS

## HEMOPHILIA FOUNDATION OF NORTHERN CALIFORNIA

- HFNC hosts The Female Factor Retreat each year for those in our community that are affected and connected. We bring in local HTC treaters for infusion training, teen sessions, menstruation, genetics and family planning and more and we bring in national speakers for sessions on treatment options, K-Taping, physical therapy, nutrition, fitness and more. This event is like camp for the females in our community and many have expressed the life changing effect the event has had on them. Many have gained access to diagnosis, care and treatment by attending this annual event. The Female Factor : Programs & Services : Programs : Hemophilia Foundation of Northern California ([hemofoundation.org](http://hemofoundation.org))

## HEMOPHILIA OF GEORGIA

- [HoG Handbook > Hemophilia of Georgia](#)
- Outreach nurse to travel the state to educate medical providers, clinics, hospitals, schools and consumers about women and girls with bleeding disorders

## SHEMATOLOGIST, MD

- [\(@acweyand\) / Twitter Social media education and outreach via Twitter account](#)

## ST. LUKE'S HTC IN BOISE, ID:

- Offers "bleed bag" for menstruation. Women's Retreat.

## WORLD FEDERATION OF HEMOPHILIA

- Launched a global initiative on WGBD [Treatment and care – WFH - World Federation of Hemophilia](#)
- Organizes biennial global summit [Highlights from the first-ever WFH Global Summit on WGBDs – WFH - World Federation of Hemophilia](#)
- Dedicated track on WGBD at its World Congress
- Offers Susan Skinner Memorial Fund Fellowships to support participation of WGBDs that the World Congress. [Susan Skinner Memorial Fund Scholarship – WFH - World Federation of Hemophilia](#)

## INDUSTRY SPONSORS RESOURCES

- [www.HerHemophilia.com](http://www.HerHemophilia.com)
- <https://www.roche.com/xproject/>

# CONSUMER-PATIENT EDUCATION & AWARENESS

## NATIONAL BLEEDING DISORDERS FOUNDATION (NBDF)

- **Clinical trials Essentials:** <https://www.hemophilia.org/research/research-projects/clinical-trials-essentials>
- **Better You Know** campaign and materials to raise awareness of signs and symptoms of a bleeding disorder and support women on their path to diagnosis.
  - [Risk Assessment Interactive Tool / Quiero Saber](#)
  - [How to Prepare for a Doctor Visit / Preparación para la visita médica](#)
  - [Healthcare Diary / Diario de atención médica](#)
  - [Lab Test Log / Registro de pruebas de laboratorio](#)
  - [Menstrual Chart & Scoring System \(fillable\) / Cuadro del ciclo menstrual y Sistema de puntuación](#)
  - [What You Should Know: Your Guide to Lab Tests, Screening Tools & Health Exams / Lo que las mujeres y las niñas deben saber sobre hacerse pruebas por síntomas hemorrágicos](#)
  - [Teen Girls: Its Your Health. Own It. Period / Folleto de la niñas adolescente](#)
  - [Journey to Know](#) 3 month virtual program to support women on path to diagnosis
    - [New video series](#) on bleeding symptoms, communicating with doctors and more
  - Ongoing [social media](#) and paid ad search campaigns
- Partnerships to help spread the word and raise awareness – most recently with
  - Healthy Women
    - [People Diagnosed With Bleeding Disorders Must Balance Priorities to Live Full – Not Fragile – Lives - HealthyWomen](#)
    - [Bleeding Disorders in Girls and Women - HealthyWomen](#)
    - [Bleeding Disorders and Women: Could You Be at Risk? - HealthyWomen](#)
  - Clue period tracking app
    - Added [new section on Bleeding Disorders](#) with two articles and social media
  - [Core2Ed Preparing Girls with a Bleeding Disorder for Menarche | COR2ED](#), [Raising Awareness of Heavy Menstrual Bleeding | COR2ED](#)
- **Victory For Women**
  - [Community sharing website](#) – ask the experts
  - Track at NBDF's [Bleeding Disorders Conference](#)
  - [Educational Workshops](#) for Women at Chapter Events
  - [Publications, News, & Webinars](#)
    - [Time to Talk Puberty: A Guide for Girls with Bleeding Disorders](#)
    - [Time to Talk Puberty: Tips for Parents & Caregivers](#)
    - [VWD Toolkit for Women, Girls, and Individuals with the Potential to Menstruate](#)