

WGPPM Summit



NATIONAL BLEEDING DISORDERS FOUNDATION

WGPPM INITIATIVES & RESOURCES FROM ATTENDEES RESEARCH

BRIGHAM AND WOMEN'S HOSPITAL BOSTON HEMOPHILIA CENTER

- Work on guidelines on the treatment and management of VWD

DR. PERIOD HACKERS

- [@DrPeriodHackers](https://twitter.com/DrPeriodHackers) / Twitter
- The focus of my research is uterine hemostasis. I have several ongoing studies looking at how best to measure menstrual blood loss and specific cells and proteins in the uterine lining that may contribute to bleeding.

FOUNDATION FOR WOMEN AND GIRLS WITH BLOOD DISORDERS

- <https://www.fwgbd.org/fwgbd-research-awards>
- <https://pubmed.ncbi.nlm.nih.gov/32419248/>
- [https://www.fwgbd.org/library?sort=&type=&category\[\]=wgbd-clinics-lan](https://www.fwgbd.org/library?sort=&type=&category[]=wgbd-clinics-lan)

HEMOPHILIA FEDERATION OF AMERICA

- Community education regarding patient centered outcomes research and creating and agenda for research for women with BD: <https://www.hemophiliafed.org/females-in-research-sharing-and-translation-first-project/>

SHEMATOLOGIST, MD

- [@acweyand](https://twitter.com/acweyand) / Twitter
- Co-directing a clinical consortium to support an NIH funded study on mother/baby pairs and plan to expand this to support other research studies

WORLD FEDERATION OF HEMOPHILIA

- The WFH systematically collects and analyses data on WGBD through its [Annual Global Survey](#) and the [World Bleeding Disorder Registry](#)

RESEARCH

NATIONAL BLEEDING DISORDERS FOUNDATION (NBDF)

- **NBDF's State of the Science (SOS) papers:**
<https://www.tandfonline.com/toc/ierr20/16/sup1>
- **National Research Blueprint (NRB):**
<https://www.hemophilia.org/research/national-research-blueprint>
- **Community Voices in Research (CVR):**
<https://www.hemophilia.org/research/community-voices-in-research> and https://youtube.com/playlist?list=PLOW1MbrjQLYSNyPL4egcp8g_Kq4xf6sti