



FOUNDATION FOR  
**Women & Girls**  
with Blood Disorders

## *Spring Newsletter*

April 2023

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## Upcoming Events

### **Live Webinar: Contraception, Thrombosis & Sickle Cell Disease: Considerations for Optimizing Comprehensive Care**

When: Monday, June 12th, 2023

Time: 1:00 PM ET (12:00 PM CT, 11:00 AM MT, 10:00 AM PT)

Faculty: Dr. Lydia Pecker

Moderator: Dr. Andrea Roe

This webinar will address the following learning objectives:

- Describe hormonal contraception considerations for people with sickle cell disease
- Discuss how to balance thrombotic risks associated with treatment on the one hand and high-risk pregnancy on the other
- Explain how progesterone-only contraception is the preferred hormonal contraception for people with sickle cell disease

[Register  
Today](#)

## Previous Programs

### **Case Conversation: COVID-19 Vaccination & ITP**

Presented live on February 28th, 2023, Drs. Hanny Al-Samkari and Jim Bussel discussed recent evidence related to COVID-19 vaccination and ITP, and evidence related to ITP treatment in adolescent females and women.

*The production, accreditation, and archiving of this program were made possible through a sponsorship from Sobi.*

[Watch the recording here.](#)

## Uterine Hemostasis Colloquium IV: Hemostasis in Women and Girls

Preceding HTRS 2023, FWGBD convened in Orlando, Florida for the fourth Uterine Hemostasis Colloquium. Leading faculty gathered to present and discuss current knowledge and practice in applying approaches to urgent bleeding events, critical bleeding and clotting events through pregnancy and delivery, the management of delivery for women with congenital or acquired blood disorders, and hematologic management through COVID.

[The archived program and session recordings are available here.](#)

### New *Ask-the-Experts* Video

#### Dosage and Heavy Menstrual Bleeding

**Q: Are there specific recommendations you give to adolescents to mitigate the effects of heavy menstrual bleeding? Do you adjust dosage prior to the start of menses? For how long?**



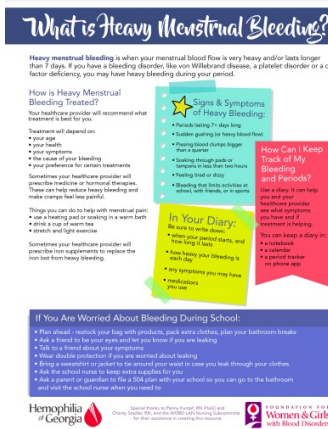
Video may also be viewed on the FWGBD YouTube Channel [here](#)

**Answered by:**

Jacquelyn Powers, MD, MSc, Director, Iron Disorders and Nutritional Anemias Program, Co-Director, Young Women's Bleeding Disorders Clinic, Assistant Professor, Department of Pediatrics, Section of Hematology/Oncology, Baylor College of Medicine, Texas Children's Hospital

***Ask-the-Experts** is a resource for healthcare providers to ask questions of the Foundation's Board, Medical Advisory Committee, and our network of experts. These expert practitioners have recorded a set of Ask-the-Experts videos to answer the most pressing questions. To ask your own question, please [complete this form](#).*

## Resources Developed by our LAN



Streaming now!

7-2-1: All you need to know about periods is available for listening today. Visit the podcast page on the [FWGBD Website today.](#)

The WGBD LAN Nursing Subcommittee has developed the following resources for patients to address heavy menstrual bleeding.

The following guides are available for download [here](#):

- About Your Period
- What is Heavy Menstrual Bleeding?
- Iron Deficiency
- Menstrual Product Options

## Partner Programs

### Oncofertility Webinar:

#### Fertility Preservation in Patients with Sickle Cell Disease

Date: 5/2/23  
Time: 2:30 PM ET

Please join the Oncofertility Consortium for an upcoming Webinar on Tuesday, May 2nd, 2023 at 2:30 PM ET. Details can be found [here](#).

### NHLBI Reproductive Health in Women and Girls with SCD: Gaps to Solutions

Date: 5/11/2023-5/12/2023

Please join FWGBD in supporting our newest MAC Member, Dr. Lydia Pecker, and the NIH, for this hybrid workshop. Held at the Natcher Conference Center (45 Rockville Pike, Bethesda, MD 20892) on Thursday, May 11 and Friday, May 12, 2023, the workshop's first day themes will include ovarian reserve, menstruation, and contraception. On day two, many dimensions of high-risk pregnancy will be addressed.

Overall, this workshop is the opportunity to discuss gaps and research questions, and build a consensus statement directing integration of reproductive health into comprehensive SCD. The workshop could assist in providing guidelines for generations to ensure holistic, individualized care and will help identify the crucial and unmet research needs for people with SCD.

[More information and registration found here.](#)

Join us at ISTH 2023!



Please join FWGBD at ISTH 2023 in Montreal! We are thankful for the opportunity to be able to learn and connect at ISTH this year.

FWGBD will be in the exhibit hall from June 25<sup>th</sup> – June 27<sup>th</sup>. Discounted registration rates are available until April 20<sup>th</sup>. Visit the [registration page](#) for more information.

We look forward to seeing you there!

Are you planning to attend ISTH 2023?

Yes

No

## Recent Publications

Liberty A, Samuelson Bannow B, Matteson K, Edelman A, Colwill A. Menstrual Technology Innovations and the Implications for Heavy Menstrual Bleeding. *Obstetrics and Gynecology*. 2023; 141(4):666-673, DOI: 10.1097/AOG.0000000000005126

Pacheco LD, Saade GR, & James AH. Von Willebrand Disease, Hemophilia, and Other Inherited Bleeding Disorders in Pregnancy. *Obstetrics and Gynecology*, 2023; 141(3):493–504. <https://doi.org/10.1097/AOG.0000000000005083>

Roberts JC, Kulkarni R, Kouides PA, Sidonio RF, Jr, Carpenter SL, Konkle BA, et al. Depression and anxiety in persons with von Willebrand disease. *Haemophilia*, 2023; 29(2): 545–554. <https://doi.org/10.1111/hae.14725>

Samuelson Bannow B, Federspiel JJ, Abel DE, Mauney L, Rosovsky RP, & Bates SM. Multidisciplinary care of the pregnant patient with or at risk for venous thromboembolism: a recommended toolkit from the Foundation for Women and Girls with Blood Disorders Thrombosis Subcommittee. *Journal of Thrombosis and Haemostasis*. 2023; S1538-7836(23)00246-5. <https://doi.org/10.1016/j.jth.2023.03.015>

*We welcome and encourage you to share the resources with your networks.*

## Welcome to Our New Lifetime Member!

Our sincere thanks to all of our members, and especially to our Lifetime Members for their dedication to the field and to our mission.

FWGBD is proud to welcome our newest Lifetime Member:  
***Amina Rafique, MD***

Interested in becoming a Member of FWGBD?

Visit our [Website](#) to learn more about the benefits and various membership opportunities.  
Questions? Contact Jennifer Longo, Database and Membership Services Manager,  
at 845-642-2925 or [membership@fwgbd.org](mailto:membership@fwgbd.org).



**FWGBD has been doing some spring cleaning!**

**Please stay tuned for something fresh in the coming weeks!**



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