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Subject: Fall 2019 FWGBD Newsletter - Upcoming Programs, Resources, RFA
From: "Foundation for Women & Girls with Blood Disorders" <kfunkhouser@fwgbd.org>
Date: Thu, Oct 10, 2019 5:02 am
To: <kroque@fwgbd.org>



FOUNDATION FOR
Women & Girls
 with Blood Disorders

Fall 2019 - Learn, Integrate, Collaborate

Educating Providers. Changing Lives.

Live Webinar: Connective Tissue Disorders and Ehlers-Danlos Syndrome

When: November 15, 2019
Time: 12:00 - 1:00 PM EDT
Faculty: Dr. Pamela Trapane and Dr. Sarah O'Brien



This state-of-the-science Webinar will explore the care of women and girls with connective tissue disorders, including a special focus on Ehlers-Danlos Syndrome. The faculty will address specific issues and needs that individuals with connective tissue disorders may have; the medical and treatment strategies that are in use and recommended; and the necessary collaboration between disciplines for effective management and treatment.

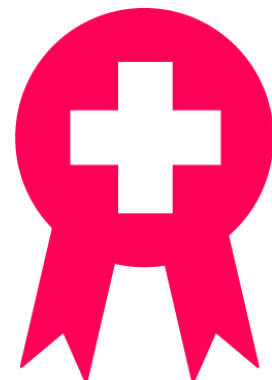
Our Webinars are free and open to all healthcare providers.

[Register Today](#)

FWGBD Announces Second 2019 Research Fellowship Award Opportunity

*Promoting XXcellence in Women's Health:
 Optimal Management of Women and Girls with
 Bleeding Disorders*

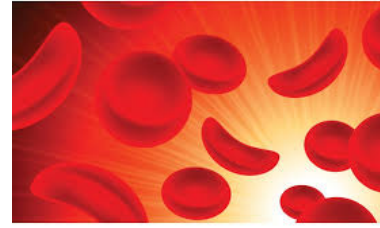
Applications are being accepted now through November 1, 2019, for a special one-year award to support research on women and girls with bleeding disorders by new fellows or faculty. For more information on criteria, timeline, and application process visit our website.



Find Out More

2019 SCDAA National Convention Reproductive Options, Preservation, and Genetic Testing in Women with SCD

Are you planning to attend the [2019 SCDAA convention](#) in Baltimore, Maryland in October? Please join us for FWGBD's session on **Friday, October 11, from 10:30-11:30 am**. Kristin Paulyson Nuñez, MS, CGC, Senior Genetic Counselor at Duke University, will offer a presentation on "Reproductive Options, Preservation, and Genetic Testing in Women with Sickle Cell Disease."



Meet Us at ASH December 7-10, 2019: Orlando, FL

If you will be attending the [ASH 61st Annual Meeting](#) in Orlando from December 7-10, FWGBD will be at Booth #2118, so please stop by and say hello!

New Resources

Recorded Presentations

- [Uterine Hemostasis Colloquium II: Preceding HTRS/NASTH 2019 Scientific Symposium](#)
 - [Role of Complement in Uterine Hemorrhage](#) (Gowthami Arepally, MD)
 - [Role of Inflammation in Heavy Menstrual Bleeding](#) (Maureen Baldwin, MD, MPH)
 - [Unanswered Questions in Use of Tranexamic Acid \(TXA\) in Postpartum Hemorrhage](#) (Luis Pacheco, MD)
 - [RFA Recipient: Sex Dismorphisms in Trauma-Induced Coagulopathy: A Mechanistic Exploration of a Sex-Specific Survival Benefit](#) (Julia Coleman, MD, MPH)
 - [Managing Heavy Menstrual Bleeding in Women on Anticoagulants](#) (Sarah O'Brien, MD, MSc)
 - [Latest in Management of Postpartum Hemorrhage](#) (Chad Grotegut, MD, MBA, MHSC)
 - [Case-Based Discussion #1: Inherited AT Deficiency](#) (Andra James, MD, MPH for Ateefa Chadhury, MD)
 - [Case-Based Discussion #2: FXIII Deficiency and Pregnancy](#) (Rebecca Kruse-Jarres, MD, MPH)
 - [Case-Based Discussion #3: Women with Hemophilia/Genetic Carrier](#) (Robert Sidonio, Jr., MD, MSc)

On Demand Webinars

- [Caring for Transgender Individuals at Risk of Thrombosis](#)

Faculty: Dr. Barbara Konkle and Dr. Joshua Safer
Moderator: Kimberly Roque

Participate in Peer Research Studies

I. LNGIUD in Patients with HMB: Research Study
Allison Wheeler, M.D., from the Division of Hematology Oncology at Vanderbilt University School of Medicine, Claudia Borzutzky, M.D., from the Division of Adolescent Medicine at Children's Hospital Los Angeles CHLA, and Oluyemisi Adeyemi, M.D., from the Department of Obstetrics and



Gynecology at Baylor College of Medicine are leading a survey on healthcare providers' attitudes and practices regarding using levonorgestrel-releasing intrauterine device (LNGIUD) in appropriate candidates with HMB (heavy menstrual bleeding), including adolescent girls. Currently there is no standard protocol regarding pre-medication, insertion and postprocedure practices for LNGIUD amongst providers who provide care to this special population. It is their goal to eventually produce a uniform approach that may improve quality of care in patients with bleeding disorders who choose the LNGIUD to control HMB. Participants are still needed to complete this online survey. If you volunteer to participate in this study, you are free to skip questions that do not have asterisks by them, or discontinue the survey at any time. The survey will take approximately 10-15 minutes to complete.

Link to survey: <https://www.surveymonkey.com/r/3B6JWNK>

II. Survey on Animation in Primary Hemostasis for Hematology Courses

Many of you may know Evelyn Lockhart, MD, a current FWGBD MAC member and former FWGBD board member. In addition to her role as Clinical Associate Professor of Pathology, University of New Mexico Health Science Center, Dr. Lockhart is a Master of Science in Biomedical Communication candidate at the University of Toronto. For her master's program, Dr. Lockhart is developing an animation on primary hemostasis to use in medical school hematology courses. As part of that work, she is trying understand the learning objectives that are most important for medical students. If you work with medical students, please provide your insight by completing a very short survey that will take no more than 5 minutes. [Dr. Lockhart may be reached via email](#) for additional questions.

Link to survey: <https://www.surveymonkey.com/r/GBYVCQZ>

III. Hydroxyurea Exposure Limiting Pregnancy and Follow-up Lactation (HELPFUL) Research Study

HELPFUL (ClinicalTrials.gov NCT04093986) is a new research project to identify women with sickle cell disease who have had hydroxyurea exposure during pregnancy and lactation. Both healthcare providers and female patients can enroll to share their experiences. There is a central REDCap database that allows data entry and provides an e-consent option. The database is now 'live' and we need to get the word out, so please consider participating in and sharing the following details. If you would like the IRB approval so other sites do not need their own local approval, please contact [Kim Roque](#).

Also, if a medical team wants to provide documents on a mother with hydroxyurea exposure during gestation and lactation, healthcare providers may submit this information here:

MEDICAL TEAM SURVEY: https://is.gd/HELPFUL_Record_Upload

Should mothers with sickle cell disease want to submit their experiences with hydroxyurea during pregnancy or breastfeeding, mothers may submit information here:

MOTHER SURVEY: <https://is.gd/HELPFULPregnancySurvey>

Spotlight on September: Learning Action Network Meetings for Healthcare Providers September 15-17, 2019 Kansas City, MO



FWGBD recently hosted the Education & Clinic of Excellence Workshop convenings for our two Learning Action Networks (LANs) for [Women/Girls with Bleeding Disorders and Sickle Cell Disease](#) in Kansas City, MO, from September 15-17, 2019. The LAN meetings provided attendees with an outstanding educational experience that examined the latest clinical advances in females with bleeding disorders and with sickle cell disease and explored the critical elements of Clinics of Excellence. We were pleased to have record attendance for both meetings: the [WGBD LAN](#) meeting drew 100+ attendees, and the [WGSCD LAN](#) meeting attracted 35.

The LAN meetings are designed to harness the power of collaboration among healthcare providers, spread practical implementation of best practices, and connect participants to national initiative activities and resources - all with the aim of achieving bold improvements in the quality of care for females with bleeding disorders and sickle cell disease.

For more information on the WGBD or WGSCD Learning Action Network meeting materials, please contact Kimberly Roque at kroque@fwgbd.org.

Spotlight on August: NHLBI's 2019 Annual Sickle Cell Research Meeting

FWGBD recently hosted an afternoon symposium as part of the NHLBI's 2019 Annual Sickle Cell Disease Research Meeting on August 27, 2019, in Bethesda, MD. Faculty included Andra James, M.D., M.P.H.; Russell Ware, M.D., Ph.D.; Bimpe Adesina, M.D.; Kelly Acharya, M.D.; and Kristin Paulyson Nuñez, M.S., CGC. A special thanks to our terrific faculty; due to their efforts, FWGBD has already been invited to develop another program for the 2020 meeting.



Contact

info@fwgbd.org

FWGBD.org

Stay Connected



Our Vision:

We seek to ensure that all women and girls with blood disorders are correctly diagnosed and optimally managed at every life stage.

Foundation for Women & Girls with Blood Disorders, PO Box 1358, Montclair, NJ 07042

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