FOUNDATION FOR WOMEN & GIRLS WITH BLOOD DISORDERS

# Welcome to Membership!

### **Our Mission**

The Foundation for Women & Girls with Blood Disorders seeks to ensure that all women and girls with blood disorders are correctly diagnosed and optimally managed at every life stage. FWGBD:

- Raises awareness and educates key healthcare professionals
- Translates and disseminates information and research
- Nurtures future healthcare leaders
- Fosters collaboration and generates knowledge among core disciplines

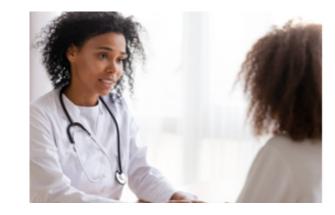
### **Our Work**

Undiagnosed, untreated blood disorders in women and girls have medical consequences at every life stage. Menstruation, pregnancy, childbirth and menopause present unique challenges in women and girls with blood disorders. The Foundation for Women & Girls with Blood Disorders (FWGBD) was founded in 2010 as a nonprofit 501(c)3 organization to serve as a single site, single source of information for physicians and healthcare professionals.

# **Questions?**

Visit <u>www.fwgbd.org/membership</u> or email <u>membership@fwgbd.org</u>. We would be glad to assist!





# Your Membership

Thank you for joining FWGBD! Your generous membership support enables us to provide healthcare professionals with continuing education opportunities, offer engaging and informative webinars on timely topics, translate and disseminate provider information and research, and support the development of designated combined clinics of excellence for young women/women. In exchange, you will join a national network of dedicated healthcare providers that values connections, collaborations, and optimal patient care.

## Membership Benefits Include:

•Professional Affiliation & Recognition – Take pride in belonging to the premier association for professionals caring for women and girls with blood disorders

- •Members receive a Lapel Pin, Digital Member Logo, and Membership Card
- Free participation in FWGBD Virtual Conference
- Opportunity to join FWGBD's Learning Action Networks (providers only):
  - $\circ$  Women & Girls with Bleeding Disorders LAN
  - $\circ$  Women & Girls with Sickle Cell Disease LAN
- •Access to Research Fellowship Award Opportunities
- •Access to library of key journal articles, Ask the Experts Video series and Quarterly E-Newsletter
- •Advance notice about upcoming programs and events



# EDUCATING PROVIDERS. CHANGING LIVES.

#### In 2019, FWGBD ... **EDUCATED** 32 EXPERT FACULTY EDUCATIONAL PROGRAMS and WORKSHOPS 700 +at major medical or interdisciplinary meetings led our programs and webinars on: Healthcare Caring for Transgender Youth AT: Professionals in live Connective Tissue Disorders - EDS programs Reproductive Life Challenges Faced by I IVF WFBINARS Women and Girls with Sickle Cell Disease making our total 17 archived on fwgbd.org Preconception Planning and Fertility Preservation Uterine Hemostasis RESULTS: Webinar: Connective Tissue Disorders: 112 Attendees / 211 Registrants 100% of participants rated the webinar as Excellent/Good of program participants 85% reported that what they 100% of participants reported the webinar INCREASED their knowledge about the topics learned will change their practice behaviors vis-à-vis 96% of participants reported the webinar INCREASED their competence women and girls with blood disorders 20% knowledge INCREASE between pre and posttest scores **RESULTS: EXPANDED** 50 our WGBD LAN to **100%** felt quality of educational process was ATTENDEES satisfactory and appropriate 190 +at WGSCD LAN meeting 24 institutions, 15 states members representing 6 expert speakers 61 institutions located in 28 states 1 in Ontario, Canada 1 in Utrecht, Netherlands felt format was relevant and enhanced 100% 104 their understanding of the subject ATTENDEES 27 Designated Clinics started by LAN members since 2013 at WGBD LAN meeting said will change management and/or 96% 59 institutions, 27 states treatment of patients because of 45 WGBD Clinics at HTCs (22 in 2015) 12 expert speakers participation in the meeting **AWARDED** REACHED 1097 FOLLOWERS on Facebook \$ 85,000\* Promoting XXcellence in Women's \$235,000 Health: Optimal Management of Women and Girls 495 FOLLOWERS on Twitter awarded to 9 Recipients with Blood Disorders awards (\*35k to be awarded since 2016 in 12/19) 70 FOLLOWERS on LinkedIn 4194 RECIPIENTS of our Newsletter HONORED 106 SUBSCRIBERS on YouTube (A 50% increase from 2018) Dr. Peter Kouides with FWGBD's inaugural Ann Marie Nazzaro Award 2.8 k views of Red Cell Alloimmunization 1k views of Ask the Experts: Tranexamic Acid Use for HMB

### fwgbd.org



# FWGBD 2020 September 24-25, 2020: 11 am - 4:30 pm ET

Join FWGBD virtually for its inaugural educational conference for healthcare professionals dedicated to the care and support of women and girls with blood disorders.

# Why Attend?

- **Inspiring Speakers:** Expand and enhance your knowledge with innovative and current best practice strategies by leading experts, memorable experiences, and collaborative sessions
- Free Continuing Medical Education (CME) credits
- **Dedicated Sessions:** Look forward to sessions built around multidisciplinary care and designed to inspire and challenge your thinking regarding the diagnosis, management, and care of women and girls with blood disorders
- **Engaged Community:** Connect and interact with healthcare leaders and professionals, and leave with new relationships, knowledge, inspiration, and resources

FWGBD 2020 Conference is complimentary for all paid FWGBD members, and core membership begins at just \$75. Join now at <u>fwgbd.org/membership</u>!

# Educating Providers. Changing Lives.

# fwgbd.org/conference



# **Ask the Experts**

**Ask-the-Experts** is a resource for healthcare providers that enables users to submit a question to the Foundation's Board and Medical Advisory Committee. These are researchers and educators at the top of their respective fields. Members include specialists in hemostasis, thrombosis, sickle cell disease, obstetrics/gynecology, and genetic counseling.





Visit fwgbd.org/ask-the-experts for the latest resources.



# Upcoming 2020 Sector Educational Programs

All events will be held virtually.



July 12-14, 2020: International Society for Thrombosis and Hemostasis (ISTH) Virtual Congress: <u>www.isth2020.org</u>

August 1-8, 2020: National Hemophilia Foundation's Bleeding Disorders Conference: <u>www.hemophilia.org</u>



August 10-13, 2020: NHLBI Sickle Cell Disease Research Meeting: www.nhlbi.nih.gov/events

August 24-29, 2020: Hemophilia Foundation of America's Virtual Summit: www.hemophiliafed.org



September 24-25, 2020: FWGBD 2020 Virtual Conference: <u>www.fwgbd.org/conference</u>

October 13-17, 2020: SCDAA National Virtual Convention: www.sicklecelldisease.org



# Our Vision: "All women and girls with blood disorders are correctly diagnosed and optimally managed at every life stage."

## **EDUCATION – Archived Webinars, Symposia and Workshops**

FWGBD provides a variety of educational programs to enhance healthcare providers' knowledge and expertise in the diagnosis, management, and treatment of blood disorders among women and girls. These include in-person Symposia and Workshops, as well as regularly hosted Webinars.

Each program features presentations by leading experts in the field, and covers up-to-date information on how to best diagnose and care for your patients. They also provide time for speakers and participants to discuss relevant issues during a question-and-answer period.

Recordings of FWGBD's educational programs are available for viewing at no charge on FWGBD's Website: <u>http://www.fwgbd.org/education/archived-webinars</u>

**Connective Tissue Disorders and Ehlers-Danlos Syndrome** 

This is a recorded version of the webinar *Connective Tissue Disorders and Ehlers-Danlos Syndrome.* This program was presented by Dr. Pamela Trapane and Dr. Sarah O'Brien and moderated by Kimberly Roque. It took place on October 15, 2019.

**Caring for Transgender Individuals at Risk of Thrombosis** 

This is a recorded version of the webinar *Caring for Transgender Individuals at Risk of Thrombosis*. This program was presented by Dr. Joshua Safer and Dr. Barbara Konkle and moderated by Kimberly Roque. It took place on July 31, 2019.

#### Uterine Hemostasis Colloquium II

On May 8 and 9, 2019, the Foundation for Women & Girls with Blood Disorders held its second national colloquium on Uterine Hemostasis preceding HTRS/NASTH 2019 Scientific Symposium in New Orleans, LA. The meeting convened several leading faculty/researchers/clinicians to review our current understanding of the science as well as current evidence-based practice related to the diagnosis and clinical management of uterine hemostasis.

Role of Selectins and Adhesion in the Pathophysiology of Acute Vaso-occlusive Crisis in Sickle Cell Disease

This is a recorded version of the webinar *Role of Selectins and Adhesion in the Pathophysiology of Acute Vaso-occlusive Crisis in Sickle Cell Disease*. This program was presented by Dr. Marilyn Telen and moderated by Dr. Andra James. It took place on March 7, 2019. The production and archiving of this program were made possible in part by an educational grant from **Pfizer**.

Addressing the Prevention, Treatment, and Management of VTE in Pregnancy: 2018 ASH VTE 01/29/19 Clinical Practice Guidelines

This is a recorded version of the webinar *Addressing the Prevention, Treatment, and Management of VTE in Pregnancy: 2018 ASH VTE Clinical Practice Guidelines* This program was presented by Dr. Shannon Bates and moderated by Dr. Anita Rajasekhar. It took place on January 29, 2019. The production and archiving of this program were made possible in part by an educational grant from **Grifols**.

#### 07/31/19

10/15/19

#### 05/08-09/19

03/07/19

### fwgbd.org

Evaluation and Management of Postpartum Hemorrhage	12/11/2018
This is a recorded version of the webinar <i>Evaluation and Management of Postpartum Hemorrhage.</i> This program was presented Grotegut and Dr. Cathleen Peterson-Layne, and moderated by Dr. Ravi Sarode. It took place on December 11, 2018. The product of this program were made possible in part by an educational grant from <b>Aptevo</b> .	
Evaluation and Treatment of Complement-Mediated Blood Disorders in Women of Childbearing Age	11/30/2018
This is a recorded version of the <i>Friday Satellite Symposium preceding the 60th American Society of Hematology (ASH) Annual Me</i> November 30, 2018. There are seven presentations, including an Introduction. This program was jointly provided by CineMed a Foundation for Women & Girls with Blood Disorders.	
Iron Deficiency Anemia and Heavy Menstrual Bleeding: Prevalence, Impact, Management	07/26/18
This program was presented by Dr. Lakshmi Srivaths and Dr. Jacqueline Powers, and moderated by Marissa Clifford, MPH, CHE was jointly sponsored by Creighton University and the Foundation for Women & Girls with Blood Disorders.	S. This webinar
Morbidity Challenges and Treatment Advances for Hemophilia Carriers: Focus on FIX/FVIII and Management of Both Types	12/19/17
This program was presented by Dr. Robert Sidonio, Jr. and moderated by Dr. Roshni Kulkarni. It took place on December 19, 20 production and archiving of this program were made possible in part by an educational grant from <b>Aptevo</b> .	17. The
Bleeding Disorders in Women and Girls: Pathway to a Powerful Career	12/10/17
On December 10, 2017, FWGBD held its next-generation program: <i>Bleeding Disorders in Women and Girls: Pathway to a Powerfu Career.</i> Pathways is a unique program that combines education in bleeding disorders, and their particular impact on women and career pathways education and guidance. Three experts in bleeding disorders in women and girls presented at this year's program. Dis. Diane Nugent, Michael Recht, and Ayesha Zia. The production and archiving of this program were made possible in part by grant from <b>Shire</b> .	ld girls, with ram. They were
Achieving Hemostasis in Women with Bleeding Disorders: Challenges and Therapies in VWD	11/13/17
This program was presented by Dr. Andra H. James and Dr. Margaret Ragni, and moderated by Kerry Funkhouser, EdD. This we sponsored by Creighton University and the Foundation for Women & Girls with Blood Disorders. The production and archiving were made possible in part by an educational grant from <b>Shire</b> .	
Rare Bleeding Disorder Manifestations in Women and Girls	10/10/14
This program was presented by Dr. Sweta Gupta and Dr. Suchitra Acharya and moderated by Dr. Amy Shapiro.	
The Management Challenges of Antithrombin Deficiency in Pregnancy	06/27/17
This program was presented by Dr. Andra H. James and Dr. Barbara A. Konkle and moderated by Dr. Evelyn Lockhart. This web sponsored by Creighton University and the Foundation for Women & Girls with Blood Disorders. The production and archiving were made possible in part by an educational grant from <b>Grifols</b> .	
Uterine Hemostasis Colloquium: The Challenges of Obstetric and Gynecologic Bleeding in the	04/4-5/17
Reproductive Years	
FWGBD held a national colloquium on uterine hemostasis preceding HTRS 2017 10th Scientific Symposium in Scottsdale, AZ. T convened several leading faculty/researchers/clinicians to review our current understanding of the science as well as current of practice related to the diagnosis and clinical management of abnormal uterine hemostasis.	
A Continued Conversation on the Maternal and Fetal Consequences of Rare Bleeding Disorders	02/03/17
This program was presented by Dr. Meera Chitlur and Dr. Madhvi Rajpurkar and moderated by Kerry Funkhouser, EdD. This was sponsored by Creighton University and the Foundation for Women & Girls with Blood Disorders. The production and archiving were made possible in part by an educational grant from <b>Novo Nordisk Inc</b> .	

#### Adolescent Thrombosis Etiology, Prophylaxis and the Role of Hormonal Therapy

This program was presented by Dr. Lakshmi Srivaths and Dr. Jennifer E. Dietrich, and was moderated by Kerry Funkhouser, EdD. This webinar was jointly sponsored by Creighton University and the Foundation for Women & Girls with Blood Disorders.

#### 12/04/15 An In-Depth Look at Emerging Science and Technology to Improve the lives of Women with Blood **Disorders**

This is a recorded version of the Friday Satellite Symposium preceding the 57th American Society of Hematology (ASH) Annual Meeting on December 4, 2015. There are nine 10- to 42-minute presentations, including an Introduction, final Closing Remarks, and Q&A. This webinar was jointly sponsored by the Duke University Health System Department of Clinical Education and Professional Development and FWGBD.

#### **Reproductive Issues for Women with Sickle Cell Disease**

This program was presented by Dr. Kim Smith-Whitley and moderated by Dr. Evelyn Lockhart. This webinar was jointly sponsored by Creighton University and the Foundation for Women & Girls with Blood Disorders.

#### Women and Bleeding: Challenges of Hemophilia Carriage, VWD and Other Rare Bleeding **Disorders**

This program was co-presented by Dr. Roshni Kulkarni and Dr. Robert Sidonio, Jr., and moderated by Dr. Evelyn Lockhart. This webinar was jointly sponsored by the Duke University School of Medicine and the Foundation for Women & Girls with Blood Disorders. It was made possible in part by an education grant from Bayer Healthcare Pharmaceuticals.

#### **Reproductive Issues in Women with Bleeding Disorders**

This is a .pdf file of the slides and audio file of the webinar provided by the CDC. The webinar was presented by Andra H. James, MD, MPH, who is a consulting professor at Duke University and the current board president of the Foundation for Women & Girls with Blood Disorders.

#### The Global Impact of Anemia on Women and Girls: SCD, Malaria, Obstetric Hemorrhage, Inherited 12/05/14 **Bleeding Disorders**

This is a recorded version of the Friday Satellite Symposium preceding the 56th American Society of Hematology (ASH) Annual Meeting on December 5, 2014. There are five 18- to 42-minute presentations, followed by an International Forum Q&A. This webinar was jointly sponsored by the Duke University School of Medicine and the Foundation for Women & Girls with Blood Disorders.

#### Diagnosis and Treatment of Acquired Hemophilia in Women During the Reproductive and Late **Menopausal Life Stages**

This program was co-presented by Dr. Barbara Konkle and Dr. Rebecca Kruse-Jarres from the University of Washington, and was moderated by Dr. Evelyn Lockhart. This webinar was jointly sponsored by the Duke University School of Medicine and the Foundation for Women & Girls with Blood Disorders. It was made possible in part through an educational grant from Baxter Healthcare Corporation.

#### **Dental Management of Female Patients with Bleeding Disorders**

This webinar was co-presented by Andrew Brewer, B.SC, B.Ch.D, MFDS and Karen Ridley, RDH, MS. It was moderated by Dr. Evelyn Lockhart.

#### Across the Lifespan of Women and Girls with Blood Disorders: Adolescence through Menopause

This is a recorded version of the Friday Satellite Symposium preceding the 55th American Society of Hematology (ASH) Annual Meeting on December 6, 2013. There are six 25- to 35-minute presentations, followed by Q&A after each main topic area. This webinar was jointly sponsored by the Duke University School of Medicine and the Foundation for Women & Girls with Blood Disorders.

#### Menorrhagia in the Adolescent

This program was presented by Dr. Jennifer Dietrich, Chief of Pediatric and Adolescent Gynecology at Texas Children's Hospital in Houston, Texas and Division Director of Pediatric and Adolescent Gynecology at Baylor College of Medicine. The webinar was jointly sponsored by the Duke University School of Medicine and the Foundation for Women & Girls with Blood Disorders.

# 06/27/13

3

### 01/22/15

05/08/14

12/06/13

11/20/14

06/16/15

02/11/15

05/02/16

#### Complex Cases in Pregnant Women with Blood Disorders: Hemostasis and Thrombosis Issues

This is a recorded version of the Friday Satellite Symposium preceding the *54th American Society of Hematology (ASH) Annual Meeting* on December 7, 2012. There are six 25-minute presentations, followed by Q&A after each main topic area. This webinar was jointly sponsored by the Duke University School of Medicine and the Foundation for Women & Girls with Blood Disorders.

#### Thrombophilia, Thromboembolism and Pregnancy: Incorporating New ACCP 9 Guidelines

This program was presented by Dr. Shannon Bates, a leader in developing these Guidelines. The webinar was jointly sponsored by the Duke University School of Medicine and the Foundation for Women & Girls with Blood Disorders.

Gynecologic Challenges for Hematologists: Tools for Optimal Management of Women and Adolescent12/09/11Girls with Blood Disorders12/09/11

This is a recorded version of the Friday Satellite Symposium preceding the *53rd American Society of Hematology (ASH) Annual Meeting* on December 9, 2011. There are five 25-minute presentations, followed by Q&A after each main topic area. This webinar was jointly sponsored by the Duke University School of Medicine and the Foundation for Women & Girls with Blood Disorders.

#### Women and Bleeding Disorders

This program was presented by Dr. Andra James and Dr. Barbara Konkle. The webinar was jointly sponsored by the Duke University School of Medicine and the Foundation for Women & Girls with Blood Disorders.

Managing Pregnancy in Women with Bleeding Disorders: Obstetric and Hematologic Issues

This program was presented by Dr. Andra James and Dr. Barbara Konkle on April 10, 2011 for the Region II Hemophilia Treatment Centers. The meeting was held in New Jersey.

12/07/12

10/24/12

#### 12/01/11

04/10/11

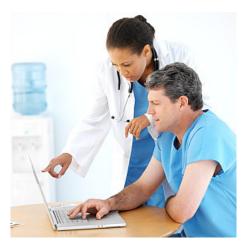


## Fall 2019 - Learn, Integrate, Collaborate

Educating Providers. Changing Lives.

#### Live Webinar: Connective Tissue Disorders and Ehlers-Danlos Syndrome

When:November 15, 2019Time:12:00 - 1:00 PM EDTFaculty: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** 

#### 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 Acti on Networks (LANs) for <u>Women/Girls with Bleeding Disorders and Sickle Cell Disease</u> 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 Networks, please contact Kimberly Roque at <a href="https://www.kroque@fwgbd.org">kroque@fwgbd.org</a>.

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



#### **New Resources**

#### **Recorded Presentations**

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

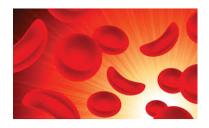
#### On Demand Webinars

• Caring for Transgender Individuals at Risk of Thrombosis

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

#### 2019 SCDAA National Convention Fertility Preservation for 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 provide insight on fertility preservation for 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!

#### **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 cho ose 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: 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: MOTHERS: https://is.gd/HELPFULPregnancySurvey

#### 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.; Russell Ware, M.D., Ph.D.; Bimpe Adesina, M.D.; Kelly Acharya, M.D.; and Kristin Paulyson Nunez, M.S., CGC. A special thanks to our terrific faculty. Thanks to their efforts, FWGBD has already been invited to develop another program for the 2020 meeting.



Contact

#### Our Vision:

info@fwgbd.org

FWGBD.org

Stay Connected

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