

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



www.fwgbd.org

Our Membership

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 research, and support the development of designated combined clinics of excellence for young women and women. You will join a national network of dedicated healthcare providers that values connections, collaborations, and optimal patient care.



FWGBD membership types include:

- Core Membership (North America or International)
- Lifetime Membership
- Resident, Fellow, Graduate, and Medical Student Membership (North America or International)
- Core Nonprofit Professional Membership
- Honorary Membership (North America or International)
- Individual Industry Membership

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 and FWGBD membership card
- Discounted registration to FWGBD 2022, September 24-25, 2022, in Arlington, VA
- Opportunity to join FWGBD's Learning Action Networks (*for providers*):
 - * Women & Girls with Bleeding Disorders LAN
 - * 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 Newsletter
- Advance notice about upcoming programs and events

FWGBD & HTRS Joint Membership - FWGBD and the Hemostasis & Thrombosis Research Society (HTRS) offer a joint annual membership, available for Core and Associate members. Additional benefits include:

- Discounted registration to HTRS Scientific Symposia
- Eligibility to serve as HTRS committee member
- Access to members-only sections of the HTRS website, newsletters, and journals *Haemophilia* and *Thrombosis Research* online
- Advance notice of grant opportunities



FOUNDATION FOR
Women & Girls
with Blood Disorders

2021 YEAR-END IMPACT REPORT

LOOKING BACK, MOVING FORWARD

WITH GRATITUDE

LOOKING BACK

This past year, the pandemic continued to cause disruptions and prevented many of us from seeing one another in person. But while that may be true, our commitment to our mission never wavered, and we are delighted to celebrate several achievements.

In 2021, we:

- Continued to educate healthcare professionals through our live Webinars
- Helped drive the conversation regarding hemostatic disorders in women and girls
- Stood for high-quality reproductive healthcare for women and girls with SCD alongside a broad group of stakeholders
- Launched our new Case Conversations Journal Club Series
- Scaled up and expanded our WGBD Learning Action Network (LAN) membership to include 246 members representing 81 institutions located in 35 states
- Increased the membership of our WGSCD LAN to include 91 members from 44 centers in 25 states
- Promoted research excellence by granting three new research fellowship awards, and
- Continued to publish original stories to share the work being done in women's blood disorders and highlighted the providers behind this work to inspire action

LOOKING AHEAD

FWGBD is continuing the vision of our founders, Dr. James, Dr. Konkle, and Dr. Kulkarni, who were driven by the need to raise awareness, expand knowledge, increase engagement and inspire action so women and girls with blood disorders receive comprehensive, informed care. We are excited to host our second national conference on September 24-25, 2022, in Arlington, VA. And we will continue to offer education of excellence, expand our learning action networks, and support young investigators as they focus on the needs of women and girls.

Thank you for the critical role you have played in our continued success and for your valued support. We look forward to the wonderful opportunities that await all of us in this new year.

Thank you!

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OUR MISSION

TO ENSURE THAT ALL WOMEN AND GIRLS WITH BLOOD DISORDERS ARE CORRECTLY DIAGNOSED AND OPTIMALLY MANAGED AT EVERY LIFE STAGE

2021 *In Numbers*

1,035+

TOTAL ANNUAL ATTENDANCE

155+

ATTENDEES IN OUR FIRST THREE JOURNAL CLUB PROGRAM

\$85,000

GRANTED IN 3 NEW RESEARCH FELLOWSHIP AWARDS (MAKING OUR TOTAL SINCE 2016: 12 AWARDS = \$320,000)

16

LIVE PROGRAMS OFFERED

206

CME CERTIFICATES PROVIDED

81

NEW MEMBERS JOINED OUR FWGBD FAMILY

2,169

VIEWS OF OUR ARCHIVED WEBINAR ON VACCINE INDUCED THROMBOTIC THROMBOCYTOPENIA: WHAT WE KNOW & DON'T KNOW

NEW 2021 PROGRAM: Case Conversations Journal Club Series

The FWGBD Case Conversation Journal Club Series is an open forum that features case-based presentations and discussion by leading experts in the areas of hematology and reproductive health on the diagnosis, treatment and management of blood disorders affecting women and girls across the lifespan.

This virtual series offers a special emphasis on the ways in which collaboration between key specialists (i.e., hematology and reproductive health) augments management. Each session features key, recent articles to support the discussion and all registrants for the live program receive a copy of the selected journal articles in advance.

3 CONVERSATIONS ON:

- New Developments in Fetal and Neonatal Alloimmune Thrombocytopenia (FNAIT)
- Contraceptive Preferences in Females with SCD
- Sex Dimorphism in Trauma-Induced Coagulopathy

7 FACULTY

155 ATTENDEES

121 VIEWS OF ARCHIVED PROGRAM

2021 Highlights

March 9, 2021

Live Colloquium: Hemostasis Colloquium III: Hemostatic Disorders in Women and Girls (Virtual) Preceding HTRS Annual Meeting

Faculty: Gowthami Arepally, MD, Andra H. James, MD, MPH, Sarah O'Brien, MD, MSc, and Naomi Tepper, MD, MPH, FAAP
155 professionals attended (compared to 132 in 2019)

March 18-20, 2021

Live Program: Fertility Preservation North American Society for Pediatric and Adolescent Gynecology (NASPAG) (Virtual)
FWGBD member Kelly Acharya, MD, was our faculty.
80 professionals attended

April 29, 2021

Live Webinar: Vaccine Induced Thrombotic Thrombocytopenia: What We Know and Don't Know
Dr. Gow Arepally reviewed the diagnosis and management of vaccine-induced immune thrombotic thrombocytopenia (VITT) post-vaccination. This leading expert in heparin-induced thrombocytopenia (HIT) also shared recent information regarding its background, diagnosis, and clinical management.

116 professionals attended

May 12, 2021

Live Webinar: A Case-Based Discussion on Fetal and Neonatal Thrombocytopenia (FNAIT)
Dr. James Bussel, a leading expert in the area of immune thrombocytopenia, shared detailed information related to the diagnosis and management of FNAIT with special attention to the necessary diagnostic testing when FNAIT is suspected, as well as recent recommendations for FNAIT management and treatment.

70 professionals attended

June 28, 2021

Live Webinar: Inherited Thrombocytopenia: What Is It, Whom To Test, and How to Test?

This program was provided in partnership with *Run X7* Research Program and PDSA. Faculty included Michelle Lambert, MD, Katie Bergstrom, CSGC, Joy Anderson, and Christina Timleck
168 professionals attended

August 17, 2021

Symposium: NHLBI SCD Clinical Research Meeting (Virtual)
FWGBD's WGSCD LAN members Lydia H. Pecker, MD, MPH, and Deva Sharma, MD, MS, provided a comprehensive review of research gaps in sickle cell disease and issues related to the reproductive health of women and girls with SCD.
143 professionals attended

August 25, 2021

National Hemophilia Foundation (NHF) - Women's Health Issues session (Virtual)
FWGBD took part in NHF's third public health conference on women's health issues. At this year's meeting, FWGBD Founding President, Andra H. James, MD, MPH, gave a talk on maternal mortality and blood disorders and FWGBD Executive Director Kerry Funkhouser, EdD, gave a talk on workforce development.

100+ professionals attended

August 25, 2021

Live Program: Case Conversation: New Developments in Fetal and Neonatal Alloimmune Thrombocytopenia (FNAIT) (Virtual)
This journal club offered case-based insight related to the diagnosis and management of FNAIT and had a special focus on the maternal and fetal considerations professionals must address in making evidence-based decisions.
58 participants

September 19, 2021

Live Program: WGSCD LAN Annual Workshop IV (Virtual)
63 professionals attended

September 20, 2021

Live Program: WGBD LAN Annual Workshop VII (Virtual)
162 professionals attended

October 28, 2021

Live Program: Congressional Briefing on Women with SCD
300+ professionals attended

October 29, 2021

Live Program: Case Conversation: Contraceptive Preferences in Females with Sickle Cell Disease (Virtual)
This journal club offered information regarding the limitations in providing optimal patient care due to need for research on contraception usage and decision making and provided strategies to discussing contraception that will lead to improved health.
78 participants

November 17, 2021

Live Webinar: Iron Deficiency Anemia in Pregnancy
Dr. Andra H. James reviewed the consequences of iron deficiency anemia in pregnancy, and detailed information regarding the screening for, diagnosis of and new thoughts about its treatment.
66 professionals attended.

November 24, 2021

Live Webinar: NHF's Chapter Resources Series
Kerry Funkhouser, EdD, described available resources through FWGBD that may be useful to NHF's chapters.

December 1, 2021

Live Webinar: NHF Wednesday Webinar Series: Spots, Dots and Clots Clinic: A designated combined clinic at OHSU
Drs. Kristina Haley and Maureen Baldwin gave an overview of their designated combined clinic at OHSU.
67 participants

December 17, 2021

Live Program: Case Conversation: Sex Dimorphism in Trauma-Induced Coagulopathy (Virtual)
This journal club offered case-based insight related to sex-specific coagulation differences and their impact on clinical treatment and outcomes.
19 participants

***Also...FWGBD Hosted Virtual Booths at:**

March 18-20, 2021: NASPAG
July 8-10, 2021: WFH Global Summit (no booth but online materials shared)
October 8-9, 2021: Hear Our Voices: Women with Hemophilia Conference
October 12-16, 2021: Sickle Cell Disease Association of America (SCDAA)

Educating providers. Changing lives.

Hemostasis Colloquium III:

Hemostatic Disorders in Women and Girls

March 9, 2021
Preceding HTRS Annual Meeting

Abnormal uterine bleeding presents unique management challenges and serious medical and quality-of-life consequences for women of childbearing age, especially for women with bleeding and clotting disorders. Understanding uterine hemostasis is critical to aid healthcare professionals in proper diagnosis and management to improve maternal and fetal outcomes.

To provide education on uterine hemostasis, FWGBD convened 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 abnormal uterine hemostasis.

155 PARTICIPANTS OF LIVE PROGRAM

645+ VIEWS OF ARCHIVED LECTURES

100% AGREED THE FORMAT OF THE DISCUSSION WAS RELEVANT AND ENHANCED THEIR KNOWLEDGE OF THE SUBJECT

“One of the best virtual meetings I’ve attended this academic year! Great speakers and fantastic topics!”

“Outstanding faculty and very interesting topics”

FEATURED SPEAKERS/LECTURES:

Welcome/Introduction	Andra H. James, MD, MPH Chair, Activity Director and Faculty
Uterine Hemostasis Overview – Abnormal Uterine Bleeding – Bleeding and Clotting Disorders	Andra H. James, MD, MPH
Women and Girls with Hemophilia – Epidemiology and Variability in Phenotype	Sarah H. O’Brien, MD, MSc
Management of Delivery in Women with Hemophilia – Maternal & Fetal Issues	Andra H. James, MD, MPH
Thrombosis and Exogenous Hormones	Naomi K. Tepper, MD, MPH, FACOG
Is It HELLP Syndrome? Is It TTP? Is It Atypical HUS? Does It Matter? Thrombotic Microangiopathies	Gowthami M. Arepally, MD
Panel Discussion and Continued Q & A	All Faculty and Chairs

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Webinar Highlights

ARCHIVING OUR LIVE SYMPOSIA AND WEBINARS ENABLES US TO SHARE THE INSPIRING AND NECESSARY INFORMATION HEALTHCARE PROFESSIONALS NEED TO EFFECTIVELY CARE FOR WOMEN AND GIRLS WITH BLOOD DISORDERS.

April 29, 2021

Live Webinar: Vaccine Induced Thrombotic Thrombocytopenia: What We Know and Don't Know

Faculty: Gowthami Arepally, MD and Roshni Kulkarni, MD (Moderator)

Pre-registrations: 210

Attendees of Live Event: 116

Overall rating: 4.9/5

Views of Archived Program since Live Date: 2,169

Provider Comments from the evaluations:

- Answer patient questions more confidently
- As a nurse, increased my understanding of VITT, and better answer questions regarding COVID vaccines from my patients
- Awareness of potential dx and need for early consultation!
- Be aware of signs of csvt in patients reporting potential symptoms who has received the COVID19 vaccines in question
- Help with identifying early and treatment plan. Overall, improved my knowledge
- Better prepared to counsel patients about the risks of thrombosis from COVID19 vaccines
- In suspected cases avoid initial heparin anticoagulation while completing workup
- More knowledgeable about pathophys, work up and therapy
- Now I know how to recognize and treat VITT. Woohoo!
- Am prepared to consult on new patients presenting with suspected VITT

May 12, 2021

Live Webinar: A Case-Based Discussion on Fetal and Neonatal Thrombocytopenia (FNAIT)

Faculty: James Bussel, MD, Jerome Federspiel, MD, PhD, Kateena Addae-Konadu, MD, PhD, and Andra H. James, MD, MPH (Moderator)

Learning Objectives:

- Understand the importance of, and apply to practice, assessing and monitoring patients for the identification of FNAIT
- Discuss and describe the potential maternal and fetal consequences of FNAIT and the considerations professionals must address in making decisions regarding management
- Describe new, effective approaches to diagnosis, testing, assessment in order to improve fetal, neonatal and maternal outcomes
- Describe the ways intersection of obstetrics and hematology augments management

Pre-registrations: 112

Attendees of Live Event: 70

CE Certificates Awarded: 22

Program Evaluation completed: 59

Overall rating: 4.6/5

Average pre-test scores: 47%

Average post-test scores: 68%

Knowledge gain: 45%

Our Faculty



Gowthami M. Arepally, MD
Professor of Medicine
Vice Chief of Research, Division of Hematology
Duke University Medical Center
Durham, NC



Roshni Kulkarni, MD
Professor Emerita
Former Director of MSU Center for Bleeding and Clotting Disorders, Division of Pediatric Hematology/Oncology
Michigan State University
Lansing, MI

2,169

Views of the Archived VITT Webinar since its live date

November 17, 2021

Live Webinar: Iron Deficiency Anemia in Pregnancy

Faculty: Andra H. James, MD, MPH and Bethany Samuelson Bannow, MD (Moderator)

Learning Objectives:

- Understand the importance of, and apply to practice, assessing and monitoring patients for the identification of FNAIT
- Discuss and describe the potential maternal and fetal consequences of FNAIT and the considerations professionals must address in making decisions regarding management
- Describe new, effective approaches to diagnosis, testing, assessment in order to improve fetal, neonatal and maternal outcomes
- Describe the ways intersection of obstetrics and hematology augments management

Pre-registrations: 123

Attendees of Live Event: 66

CE Certificates Awarded: 24

Views of Archived Program since Live Date: 111

Program Evaluation completed: 39

Overall rating: 4.5/5

Average pre-test scores: 52%

Average post-test scores: 81%

Knowledge gain: 56%

Educating providers. Changing lives.
Journal Club Series Highlights

THIS SERIES IS DESIGNED TO BRING TOGETHER LEADING EXPERTS IN THE AREAS OF HEMATOLOGY AND REPRODUCTIVE HEALTH DISCUSSING CHALLENGING CASES, SHARING INSIGHTS, AND REVIEWING RECENT JOURNAL ARTICLES REGARDING THE DIAGNOSIS, TREATMENT AND MANAGEMENT OF BLOOD DISORDERS AFFECTING WOMEN AND GIRLS ACROSS THE LIFESPAN.

AFTER THE PRESENTATION AND ARTICLE REVIEW, DISCUSSION AMONGST THE FACULTY IS FOLLOWED BY A Q & A SESSION WITH PARTICIPANTS. ALL REGISTRANTS RECEIVE A COPY OF THE SELECTED JOURNAL ARTICLE IN ADVANCE OF THE PROGRAM.

August 25, 2021

Live Program: Case Conversation: New Developments in Fetal and Neonatal Alloimmune Thrombocytopenia (FNAIT)

Faculty: James Bussel, MD and Emilie Vander Haar, MD, MPH; Andra H. James, MD, MPH (Moderator)

Pre-registrations: 134

Attendees of Live Event: 58

CE Certificates Awarded: 14

Views of Archived Program since Live Date: 91

Program Evaluation completed: 21

Overall rating: 4.6/5

Average pre-test scores: 51%

Average post-test scores: 82%

Knowledge gain: 61%

October 29, 2021

Live Program: Case Conversation: Contraceptive Preferences in Females with Sickle Cell Disease

Faculty: Andrea Roe, MD, MPH and Tammy Singleton, MD, (Moderator)

Pre-registrations: 91

Attendees of Live Event: 78

CE Certificates Awarded: 14

Program Evaluation completed: 53

Overall rating: 4.69/5

Average pre-test scores: 67%

Average post-test scores: 85%

Knowledge gain: 27%

December 17, 2021

Live Program: Case Conversation: Sex Dimorphism in Trauma-Induced Coagulopathy

Faculty: Julia R. Coleman, MD, MPH, Eugene "Gene" Moore, MD, and Kenneth Mann, PhD (Moderator)

Pre-registrations: 51

Attendees of Live Event: 19

CE Certificates Awarded: 6

Views of Archived Program since Live Date: 30

Overall rating: 4.7

Educating providers. Changing lives.

Learning Action Networks:

Annual Meeting Highlights

SEPTEMBER 19, 2021 WGSCD LAN Virtual Workshop IV

65 participants representing
35 institutions from 22 states

Educational Topics Covered:

- Keynote Presentation: *Sickle Cell Disease and the Incidence and Etiology of Preterm Birth*
- Keynote Presentation: *New Options vs. Old Opinions: Disparities in Care and Sparking Change*
- WGBD and WGSCD LANs - Opportunities for Collaboration
- WGSCD LAN Collaborative Research Projects - Planning Work, Discussion
- WGSCD Subcommittee Planning and Breakout Work
- Introduction to the SCD Center at Children's Hospital of Michigan/Wayne State Medical University
- What are the Key Items of a SCD Program for Women/Young Women

Participant Comments:

- Increased awareness of the SS associated morbidities
- Will speak to females with sickle cell about pain and menses
- Improved ideas for research
- Will add neurocog testing as part of 5-6 years evaluation
- Will explore possibility of incorporating PBAC in SCD adolescent girls' annual visits
- More collaboration and communication with other specialties

100% of participants felt

- the program met their learning needs,
- speakers were knowledgeable, and
- Information gained from this conference will result in making a change in my practice

IN 2016, FWGBD LAUNCHED ITS LEARNING ACTION NETWORK (LAN) INITIATIVE TO BRING TOGETHER HEALTHCARE PROFESSIONALS TO HARNESS THE POWER OF COLLABORATION, SPREAD PRACTICAL IMPLEMENTATION OF BEST PRACTICES, AND CONNECT PARTICIPANTS ACROSS DISCIPLINES TO IMPROVE QUALITY OF CARE FOR WOMEN AND GIRLS WITH BLOOD DISORDERS.

FWGBD FELT THAT CREATING THE OPPORTUNITY FOR LAN MEMBERS TO CONVENE IN-PERSON AT THE SITE OF ESTABLISHED CENTERS WITH DEDICATED SERVICES FOR WOMEN AND/OR GIRLS WOULD HELP FOSTER THE COLLABORATION BETWEEN OB-GYNS AND HEMATOLOGISTS IN THE CARE OF THESE WOMEN AND GIRLS.

SEPTEMBER 20, 2021 WGBD LAN Virtual Workshop IV

162 participants representing
69 unique institutions from 32 states

Educational Topics Covered:

- Keynote Presentation: *Women and Girls with Hemophilia*
- Keynote Presentation: *Iron Deficiency Anemia: Practical Applications v. Clinical Directives*
- WGBD and WGSCD LANs - Opportunities for Collaboration
- WGBD LAN Collaborative Research Projects - Planning Work, Discussion
- WGBD LAN Member-Initiatives Research Projects
- WGBD Subcommittee Planning and Breakout Work and Reports
- Ask-the-Experts Panel Case Review

Participant Comments:

- Ability to perform an adequate assessment of patient's bleeding experience
- Learning how/why standardized treatments are utilized across the country is very helpful
- The workshop continues to allow me to network with other providers who I share resources with that inform the practices of our female adolescent bleeding clinic. The workshop provides me with updated resources and research that we incorporate into our clinic.

Evaluation Results:

Met learning objectives:	4.89/5.0
Knowledge before activity:	3.5/5.0
Knowledge after activity:	4.1/5.0
Provided new ideas:	94% Yes
Will Improve Patient Outcomes:	91% Yes







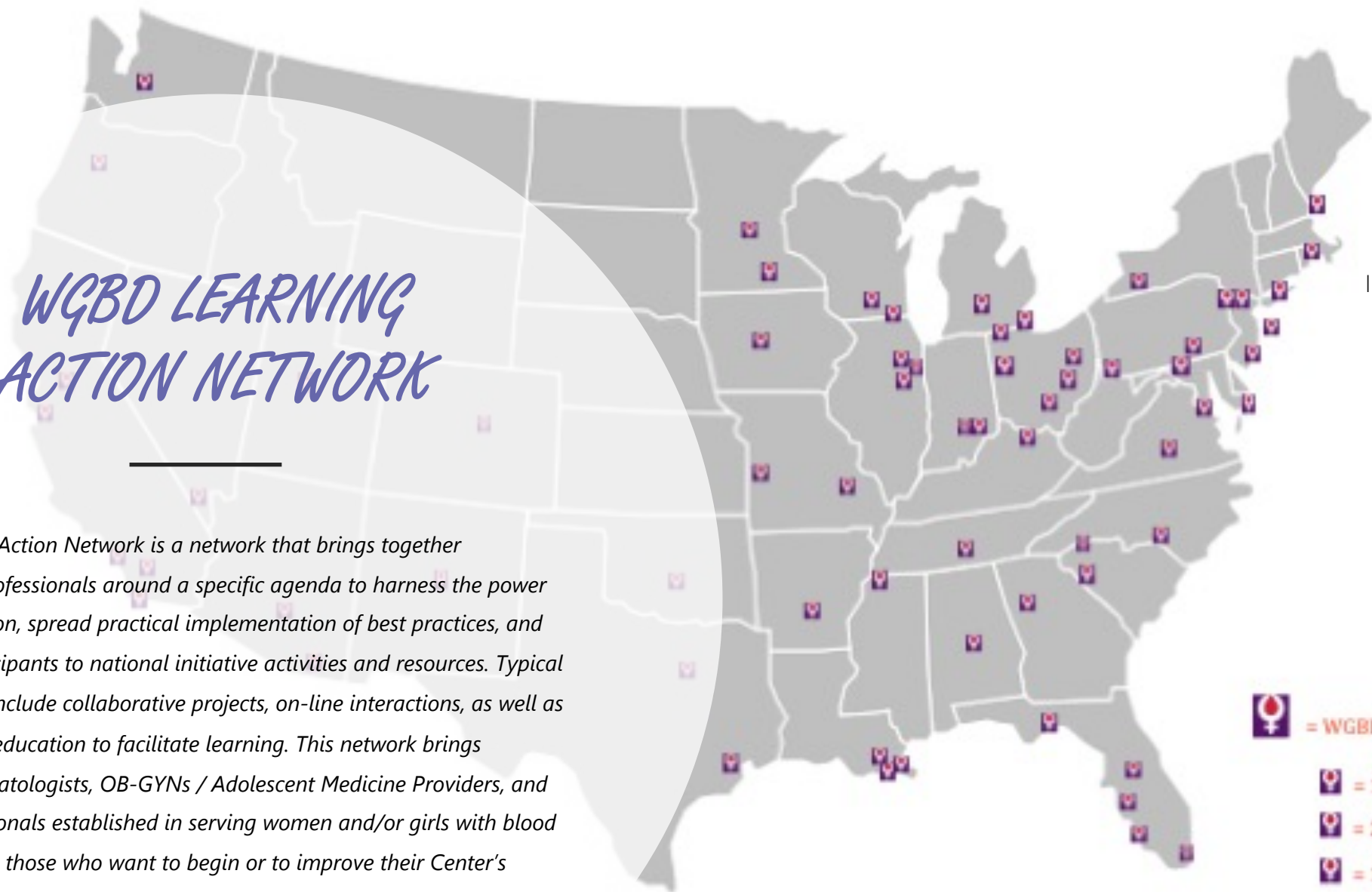
WGBD LEARNING ACTION NETWORK

The Learning Action Network is a network that brings together healthcare professionals around a specific agenda to harness the power of collaboration, spread practical implementation of best practices, and connect participants to national initiative activities and resources. Typical LAN models include collaborative projects, on-line interactions, as well as peer-to-peer education to facilitate learning. This network brings together Hematologists, OB-GYNs / Adolescent Medicine Providers, and other professionals established in serving women and/or girls with blood disorders with those who want to begin or to improve their Center's services for women/girls.

246

IN 2013, WE STARTED OUR WGBD LAN WITH ONLY 7 MEMBERS. TODAY, IT HAS GROWN TO INCLUDE 246 MEMBERS, FROM 81 CENTERS LOCATED IN 35 STATES, CANADA, AND THE NETHERLANDS.

-  = WGBD LAN Member Location
-  = 1 in Alaska
-  = 2 in Canada
-  = 1 in Utrecht, Netherlands



A FOCUS ON SCD AND WOMEN'S REPRODUCTIVE HEALTHCARE

On October 28, 2021, FWGBD alongside the American Society of Hematology, American College of Obstetricians and Gynecologists, Association of Maternal & Child Health Programs, and the Sickle Cell Disease Association of America, was a proud co-sponsor of a sickle cell disease and reproductive health virtual congressional briefing.

Their Lives Depend On US: Rising to the Challenge of Providing High Quality, Evidence-Based Reproductive Health Care for Women and with Sickle Cell Disease was inspired by the meeting that FWGBD held in conjunction with the CDC, the work of our WGSCD LAN members, and with ASH's working group on the reproductive needs of women with SCD of which FWGBD is a member. Close to 300 people registered for the briefing, including congressional staff, representatives from SCD community groups, members of the co-sponsoring organizations, and the 100+ organizations in the SCD Coalition.

Dr. Lydia Pecker gave an excellent overview of the current state of reproductive healthcare for women with SCD and proposed several suggested strategies to improve the outcomes.



Congressional Briefing:
Their Lives Depend on Us: Rising to the Challenge of Providing High Quality, Evidence-Based Reproductive Health Care for Women with Sickle Cell Disease

Thursday, October 28, 2021
2:00 p.m. – 3:00 p.m. ET
[REGISTER HERE](#)

Barriers to receiving high quality, comprehensive care for sickle cell disease (SCD) are a significant problem in the United States, resulting in health care disparities and inequities. This is especially true for women with SCD who are pregnant: they are ten times more likely to die in childbirth than non-Hispanic Black women without SCD. This disparity is compounded by the fact that the maternal mortality rate for all non-Hispanic Black women is already more than double the U.S. maternal mortality rate. Women with SCD require high-quality, multidisciplinary reproductive health care; their deaths are not inevitable. Comprehensive care is proven to decrease the risk of adverse pregnancy outcomes, including maternal mortality.

This briefing will present an overview about the current state of reproductive health care for women with SCD, a personal story of a mother's pregnancy journey with the disease; and a presentation of proposed policy strategies to improve the outcomes. Join us to learn how you can help improve SCD care and outcomes for women with SCD.

Program:

- **Welcome, Introductions, and Overview of Sickle Cell Disease**
Chancellor Donald, MD, Chair, American Society of Hematology Committee on Practice, Tulane University
- **Impact of SCD on Reproductive and Maternal Health**
Lydia H. Pecker, MD, Johns Hopkins University
- **A Mother's Story**
Ejfa Ahmed-Williams, SCD Advocate
- **Presentation of Potential Policy Strategies**
Dr. Chancellor Donald

Please click [here](#) to register.

Cosponsored by: American Society of Hematology, American College of Obstetricians and Gynecologists, Association of Maternal & Child Health Programs, Foundation for Women & Girls With Blood Disorders, Sickle Cell Disease Association of America, and Sickle Cell Reproductive Health Education Directive

(This is a widely attended event.)



Since 2016, FWGBD
has awarded
\$320,000 in research
awards to 12
recipients.

(And three (3) more awards
are set to be assigned in early
2022)

RESEARCH AWARDS

The objectives of the *Promoting XXcellence in Women's Health: Optimal Management of Women and Girls with Blood Disorders (WGBD)* awards are to:

1. Foster and sustain interest/knowledge of the next-generation of healthcare providers working in blood or bleeding disorders affecting women/girls.
2. Foster collaboration between two core disciplines for WGBD - the Hematologist and the OB-GYN (or Women's Reproductive Health Specialist).
3. Support an opportunity for junior faculty or fellows to conduct research in these important areas.

DR. ANDREW'S STORY



*AWARD FOCUS AREA: BLOOD DISORDERS - ALL BLOOD DISORDERS
(\$15,000)*

Lauren Andrew, MD is currently an obstetrics and gynecology resident with the University of Calgary in Canada, researching clinical trial design for postpartum women with risk of venous thromboembolism (VTE). She is also on target to begin a master's degree program on women's health and VTE prevention.

"There has been a call from the research community to include and encourage participation of pregnant and postpartum women in well-designed clinical trials to provide high-quality data," explains Dr. Andrew, adding that this participation can result in critical learnings around childbirth.

However, it's not always easy to enroll pregnant women in clinical studies that evaluate health in the period immediately following labor and delivery. The postpartum period can be a stressful time with unique challenges for women, particularly those with blood and bleeding disorders. "We must better understand patient factors that contribute to or hinder research participation during the postpartum period to guide clinical practice and improve women's lives," she says.

Dr. Andrew's FWGBD funding will support her qualitative interview study, offering a unique opportunity to explore:

- Randomized trial participation from the patient perspective
- VTE and bleeding risk
- Shared decision making
- Informed consent
- Patient perceptions of their postpartum VTE risk
- Physician perspectives on postpartum VTE prevention

This study will enhance another pilot trial by a broader team of researchers: Postpartum Aspirin to Reduce Thromboembolism Undue Morbidity (PARTUM), which weighs the feasibility of a larger international randomized trial evaluating aspirin versus placebo in postpartum women at risk of developing venous thromboembolism.

DR. OVED'S STORY



*SPECIAL AWARD FOCUS AREA: BLEEDING DISORDERS
(\$35,000)*

Joseph Oved, MD is currently an instructor in the Division of Hematology at the Children's Hospital of Pennsylvania (CHOP) in Bala Cynwyd, Pennsylvania.

Dr. Oved's FWGBD funding will support his study which is to examine the downstream effects of this gut microbiome dysbiosis and the shifts in the metabolomic signatures and immunoglobulin-pathogen coating that results from these microbe alterations. The data from these studies will inform a predictive modeling algorithm to help determine which patients are not only at risk for developing disease but those who are at risk for progressing to chronic/refractory disease.

The second aim of this study will be to expand the gut microbiome sequencing of their ITP cohort to allow for sub-population analyses focusing on adolescent females with bleeding symptoms in the setting of newly diagnosed ITP.

Ultimately, they will use the results from this pilot as the basis for future longitudinal studies of gut microbial dysbiosis throughout the course of disease and resolution as well as metabolomic studies to elucidate shifts in relative concentrations of biochemical molecules resulting from microbial perturbations. These results will be important for defining new targetable pathways involved in ITP pathogenesis.

DR. LIM'S STORY



*SPECIAL AWARD FOCUS AREA: BLEEDING DISORDERS
(\$35,000)*

Ming Y. Lim, MBBChir, MSCR is currently medical director of the Utah Center for Bleeding & Clotting Disorders at University of Utah Health. She earned her medical degree at Cambridge University, England and completed her residency in internal medicine at the Mayo Clinic Rochester and her fellowship training in hematology and oncology at the University of North Carolina at Chapel Hill.

Dr. Lim specializes in the field of hemostasis and thrombosis. The focus of Dr. Lim's research with this funding is "to determine pregnancy outcomes and postpartum contraception in women with von Willebrand disease using a unique, statewide, population-based cohort that is linked to electronic health records, the Utah Population Database." Von Willebrand disease (VWD) is a common bleeding disorder, which affects approximately one in 100 individuals. People with VWD experience delayed or abnormal blood clotting. For pregnant women with VWD, there can be heavy, hard-to-stop bleeding after childbirth.

"It is well-recognized that women with bleeding disorders are underrecognized and underdiagnosed," explains Dr. Lim. "There is a critical need to raise awareness for both healthcare providers and patients to improve the care of women with von Willebrand disease. My project is a first step in identifying the magnitude of the problem in the contemporary era."

Dr. Lim believes the successful completion of her project will have a positive impact on the VWD community by providing the necessary evidence to inform institutional, local and regional service providers, insurance payers and state policymakers to enhance clinical services, tailor educational programs and track outcomes on the needs of women with VWD.

"This will strengthen the care of women with von Willebrand locally and regionally, leading to a reduction in pregnancy-related morbidity and mortality," she says. Next up, Dr. Lim plans to conduct a needs assessment for women with VWD in Utah to examine trends in acute care utilization across all ages and identify factors associated with increased acute care utilization. She also plans to engage patients and providers in a qualitative study to understand the barriers and facilitators to a timely diagnosis of inherited bleeding disorders.

OUR REACH IN 2021

The FWGBD Community

FWGBD is continuing to build a community of people who learn about the unique needs of women and girls with blood disorders through our programs, our Website, and our social media channels. These individuals are consciously opting to be a part of our mission. They are signing up to receive regular information, attend events, donate resources, or engage in other ways with and on behalf of FWGBD. We want to continue to build and energize these individuals with regular contact and interaction.

Web Traffic – fwgbd.org

In 2021, our Website had 19,182 unique users at fwgbd.org, who visited us a total of 24,230 times. Compared with 14,646 / 19,338 last year, we've grown our Website reach by 31% and our visits by 25%. Our users reside in 163 countries across the globe, up from 146 in 2020.

In 2021, 54.5% of Website visitors went directly to fwgbd.org, 39.1% searched for us online and navigated to our Website via a search engine (Google.com, Bing.com, etc.). 4.4% landed at fwgbd.org from other links on other Websites, and 2% came directly from social medial links.

Aside from our homepage, these pages had high traffic in 2021:

<http://www.fwgbd.org/questions/using-birth-control-in-patients-with-itp>

<http://www.fwgbd.org/education/archived-webinars>

<http://www.fwgbd.org/membership>

<http://www.fwgbd.org/patient>

Newsletter

In 2021, our number of newsletter subscribers **grew by 9%**, with an average open rate of 20% across all campaigns.*

**From Constant Contact analytics.*

Facebook

The FWGBD Facebook community is comprised of 1,156 individuals. Forty-five (45) individuals joined us in 2021, generating a **4% growth rate**. Two of our top posts by reach and engagement in the order they were published were...



Twitter

The FWGBD Twitter community is comprised of 577 followers. Of these individuals, 36 were new in 2021, showing a **7% increase** over 2020.

LinkedIn

Our LinkedIn channel has 105 followers, **up 21 (25%)** from 84 last year.

YouTube

FWGBD has a total of 577 subscribers, which is a **110% increase** since 2020.

- 35.4k views (24.6k in 2020, 6.2k in 2019, 2.9k in 2018) - **up 44%** since 2020

- 2.4k watch hours (1.4k in 2020, 436.2 in 2019, 247.2 in 2018) - **up 71%** since 2020

Top Video:

Ask the Experts: Tranexamic Acid Use for Heavy Menstrual Bleeding
10k views in 2021

<https://www.youtube.com/watch?v=ZWvO7nDHLzM>



THREE SPECIAL PARTNERS



The Hemophilia Center of Western Pennsylvania (HCWP)

In 2020, the HTC partnered with us once again by granting us a financial matching grant of \$135,000. They continue to be one of our biggest supporters.

Hemostasis Thrombosis Research Society (HTRS)

In 2021, FWGBD held its third educational session focusing on hemostatic disorders impacting women and girls preceding the HTRS Scientific Symposium. They are a supportive and valued partner.

Also, in 2020, FWGBD and HTRS created a joint FWGBD/HTRS membership between the two organizations. Today, we have **61** joint members.

Hemophilia of Georgia (HOG)

Since 2016, HOG has partnered with FWGBD by granting us an award for our HCWP matching grant. Together, we continue to create educational opportunities and materials that benefit both providers and patients.

FWGBD Board of Directors

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Social Media

WITH GRATITUDE

Thank you!

Our sincere thanks to our Lifetime Members—thank you for your dedication to the field and to FWGBD. We appreciate your commitment to the health and sustainability of the organization. As a Lifetime Member, you ensure that FWGBD will always be able to provide quality programming to enhance knowledge and increase awareness about the unique needs of women and girls with blood disorders.

Our Lifetime Members are:

Janice Bacon, MD, Obstetrics/Gynecology
FWGBD Board Member

Richard Burwick, MD, MPH, Obstetrics/Gynecology
Cedars-Sinai Medical Center

Andra H. James, MD, MPH, Obstetrics/Gynecology
FWGBD Co-Founder and Founding President of FWGBD's Board of Directors

Barbara A. Konkle, MD, Hematology
FWGBD Co-Founder and member of FWGBD's Board of Directors

Roshni Kulkarni, MD, Hematology
FWGBD Co-Founder and member of FWGBD's Board of Directors

Ann-Marie Nazzaro, PhD
FWGBD Executive Director Emeritus

Michael Recht, MD, PhD, MBA, Hematology
The Hemophilia Center, OHSU FWGBD Board Member

Margo Rollins, MD, Hematology/Oncology, Transfusion Medicine
WGSCD LAN Member

Ravi Sarode, MD, Pathology/Clinical Laboratory Services
FWGBD Board Member

FWGBD is a top-rated non-profit
organization.



Medical Advisory Committee (MAC)

Biree Andemariam, MD (joined in 2021)
Gowthami Arepally, MD
Maureen Baldwin, MD, MPH
Shannon Bates, MDCM, MSc, FRCP(C)
Leo Brancazio, MD
David Ware Branch, MD, PhD
Julia E. Brittain, PhD
James Bussel, MD
Meera Chitlur, MD
Alice Cohen, MD, FACP
James W. Curtis, Jr., DMD (joined in 2021)
Mary Cushman, MD, MSc
Jennifer Dietrich, MD, MSc, FACOG
Terry Gernsheimer, MD
Chad Grotegut, MD, MBA, MHS
Sweta Gupta, MD
Kristina Haley, DO, MCR
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Peter Kouides, MD
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James Munn, BSN, MS
Alecia Nero, MD, MSCS, FACP
Diane Nugent, MD
Kristin Paulyson Nuñez, MS, CGC
Luis Pacheco, MD (joined in 2021)
Michael Pidas, MD
Claire Philipp, MD
Margaret Ragni, MD, MPH
Karen Ridley, RDH, MS
Sandra Schneider, MD
Robert Sidonio, Jr., MD, MSc
Leslie Skeith, MD (joined in 2021)
Lakshmi Srivaths, MD
Alexis Thompson, MD, MPH
Arthur J. Vaught, MD
Adrianna Vlachos, MD

YOUR SUPPORT CHANGES LIVES

Thank you for donating to FWGBD. Your support helps us continue to provide education of excellence which is critical to improving the lives of women and girls with blood disorders. Every gift builds our resources and expands our reach.

Thank you for giving generously to
our mission:

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

PO Box 1358
Montclair, NJ 07042
fwgbd.org
Our Tax ID # is 27-2456813





FOUNDATION FOR
Women & Girls
with Blood Disorders

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.



FWGBD 2022

September 24-25, 2022 | Arlington, VA

Join FWGBD for our biennial 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

The FWGBD 2022 Conference is discounted for all paid FWGBD members, and core membership begins at just \$75. Join now at fwgbd.org/membership!

Foundation for Women & Girls with Blood Disorders 2022 Planned Meetings

As of 1.7.2022

Dates	Conference	Location
4/7-9/2022	North American Society for Pediatric and Adolescent Gynecology (ACRM) (NASPAG) (naspag.org)	Chicago, IL
5/8-11/2022	World Federation of Hemophilia (wfh.org)	Montreal, Quebec, Canada
7/9-13/2022	ISTH (isth2022.org)	London, England, UK
August 2022	NHLBI 2022 Annual SCD Clinical Research Meeting (nhlbi.nih.gov/events)	TBD
8/25-27/2022	NHF 's Virtual Annual Bleeding Disorders Conference (hemophilia.org)	Houston, TX
9/23/2022	WGBD and WGSCD LAN Meetings	Arlington, VA
9/24-25/2022	FWGBD 2022 Conference (fwgbd.org)	Arlington, VA
October 2022	National Conference for Women & Teens with Hemophilia & Rare Factor Deficiencies (HFM) (hfmich.org)	TBD
10/13/2022	World Thrombosis Day (ISTH) (worldthrombosisday.org)	Virtual
Late October 2022	Sickle Cell Disease Association of America (SCDAA) (sicklecelldisease.org)	TBD
Late October 2022	ATHN Data Summit (athn.org)	TBD
December 2022	American Society of Hematology (ASH) Annual Meeting & Exposition (hematology.org)	TBD
Other Sector Meetings of Note in 2022		
5/4-7/2022	American Society of Pediatric Hematology Oncology (ASPHO) (Aspho.org)	Pittsburgh, PA
5/6-8/2022	ACOG (Acog.org)	San Diego, CA
6/9-12/2022	26th European Congress of European Hematology Association (EHA) (ehaweb.org)	Vienna, Austria
8/25-8/27/2022	Thrombosis & Hemostasis Summit of North America (THSNA) (thsna.org)	Chicago, IL
9/15-17/2022	APHON (Aphon.org)	Palm Beach, FL
10/1-4/2022	AABB (aabb.org)	Virtual and Orlando, FL
October 2022	ACEP (Acep.org)	



FOUNDATION FOR
Women & Girls
with Blood Disorders

Our Vision: “All women and adolescent girls with blood disorders are optimally treated and 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:

<http://www.fwgbd.org/education/archived-webinars>

<i>Case Conversation: Sex Dimorphism in Trauma-Induced Coagulopathy</i>	12/17/21
This is a recorded version of the webinar <i>Case Conversation: Sex Dimorphism in Trauma-Induced Coagulopathy</i> . This webinar was presented by Dr. Julia Coleman, Dr. Gene Moore, and was moderated by Dr. Kenneth Mann.	
<i>Iron Deficiency Anemia in Pregnancy</i>	11/17/21
This is a recorded version of the webinar <i>Iron Deficiency Anemia in Pregnancy</i> . This webinar was presented by Dr. Andra H. James, and was moderated by Dr. Bethany Samuelson Bannow. It took place on November 17, 2021.	
<i>Case Conversation: New Developments in Fetal and Neonatal Alloimmune Thrombocytopenia (FNAIT)</i>	8/25/21
This is a recorded version of the Journal Club program <i>Case Conversation: New Developments in Fetal and Neonatal Alloimmune Thrombocytopenia (FNAIT)</i> . This program was presented by Dr. Jim Bussel and Dr. Emilie Vander Haar, and was moderated by Dr. Andra James and Kim Roque. It took place on August 25, 2021. The production and archiving of this program were made possible in part by an educational grant from Janssen .	
<i>Inherited Thrombocytopenia: What Is It, Whom to Test, and How to Test?</i>	6/28/21
This is a recorded version of the webinar <i>Inherited Thrombocytopenia: What Is It, Whom to Test, and How to Test?</i> . This program was produced in collaboration with The <i>RunX1</i> Research Program and the Platelet Disorder Support Association (PDSA), and was presented by Dr. Michelle Lambert, genetic counselor Katie Bergstrom, and patient advocates Joy Anderson and Christina Timleck. It took place on June 28, 2021.	
<i>A Case-Based Discussion on Fetal and Neonatal Thrombocytopenia (FNAIT)</i>	5/12/21
This is a recorded version of the webinar <i>A Case-Based Discussion on Fetal and Neonatal Thrombocytopenia (FNAIT)</i> . This program was presented by Dr. Jim Bussel, Dr. Jeff Federspiel, and Dr. Kateena Addae-Konadu and was moderated by Dr. Andra James. It took place on May 12, 2021.	
<i>Vaccine Induced Thrombotic Thrombocytopenia: What We Know & Don’t Know</i>	4/29/21

This is a recorded version of the webinar *Vaccine Induced Thrombotic Thrombocytopenia: What We Know & Don't Know*. This program was presented by Dr. Gowthami Arepally and was moderated by Dr. Roshni Kulkarni. It took place on April 29, 2021.

Hemostatic Disorders in Women and Girls Colloquium (Uterine Hemostasis Colloquium III)

3/9/21

On March 9, 2021, the Foundation for Women & Girls with Blood Disorders held its third national colloquium on Uterine Hemostasis preceding the HTRS 2021 Scientific Symposium. The virtual meeting convened four 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. The presentations from each session are offered here. The recording and archiving of this program were made possible in part by an educational grant from **Grifols**.

Addressing the Use of Long-Acting Reversible Contraception (LARC), with Special Considerations for Use with Young Women and Women with Heavy Menstrual Bleeding

10/9/20

This is a recorded version of the webinar *Addressing the Use of Long-Acting Reversible Contraception (LARC), with Special Considerations for Use with Young Women and Women with Heavy Menstrual Bleeding*. This program was presented by Dr. Oluyemisi Adeyemi-Fowode and Dr. Allison Wheeler and was moderated by Dr. Claudia Borzutzky. It took place on October 9, 2020. The production and archiving of this program were made possible in part by an educational grant from **Bayer Pharmaceuticals**.

FWGBD Inaugural Conference and 10th Anniversary Celebration

9/24-25/20

This is a recorded version of the *FWGBD Inaugural Conference and 10th Anniversary Celebration* on September 24-25, 2020. There are seven presentations, including an Introduction. This program was jointly provided by Cine' Med and the Foundation for Women & Girls with Blood Disorders. Presentations include *Bleeding Across the Lifespan – What's Common and What's Not? Obstetrical, Gynecological and Hematological Perspectives*; *The Challenges of SCD for Women*; *Stopping the Clot: Etiology, Prophylaxis and the Role & Risks of Hormonal Therapy*; *Bleeding and Clotting Conundrums*; *COVID-19: Ask-the-Experts Panel Session: Late Breaking News*; *Your Guide to Acute Bleeding in a Patient with Heavy Menstrual Bleeding*; *When Bleeding Patients Clot*; *Females with Mild or Moderate Hemophilia*; *Ehlers-Danlos Syndrome in Women & Girls with Bleeding Disorders*; and *Caring for Special Populations: Transgender Youth*.

Addressing the Use of Long-Acting Reversible Contraception (LARC), with Special Considerations for Use with Young Women and Women with Heavy Menstrual Bleeding

10/15/20

This is a recorded version of the webinar *Addressing the Use of Long-Acting Reversible Contraception (LARC), with Special Considerations for Use with Young Women and Women with Heavy Menstrual Bleeding*. This program was presented by Dr. Oluyemisi Adeyemi-Fowode and Dr. Allison Wheeler and was moderated by Dr. Claudia Borzutzky. It took place on October 9, 2020. The production and archiving of this program were made possible in part by an educational grant from **Bayer Pharmaceuticals**.

Addressing the Management of ITP: An Introduction and Review of the Most Recent ASH 2019 Clinical Practice Guidelines for ITP

8/25/20

This is a recorded version of the webinar *Addressing the Management of ITP: An Introduction and Review of the Most Recent ASH 2019 Clinical Practice Guidelines for ITP*. This program was presented by Dr. Terry Gernsheimer and was moderated by Dr. Gowthami Arepally. It took place on August 25, 2020. The production and archiving of this program were made possible in part by an educational grant from **Dova Pharmaceuticals**.

Connective Tissue Disorders and Ehlers-Danlos Syndrome

10/15/19

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

07/31/19

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

05/08-09/19

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. The presentations from each session are offered here.

Role of Selectins and Adhesion in the Pathophysiology of Acute Vaso-occlusive Crisis in Sickle Cell Disease **03/07/19**

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 Clinical Practice Guidelines **01/29/19**

This is a recorded version of the webinar *Addressing the Prevention, Treatment, and Management of VTE in Pregnancy: 2018 ASH VTE Clinical Practice Guidelines* 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**.

Evaluation and Management of Postpartum Hemorrhage **12/11/18**

This is a recorded version of the webinar *Evaluation and Management of Postpartum Hemorrhage*. This program was presented by Dr. Chad Grotegut and Dr. Cathleen Peterson-Layne, and moderated by Dr. Ravi Sarode. It took place on December 11, 2018. The production and archiving of this program were made possible in part by an educational grant from **Aptevo**.

Evaluation and Treatment of Complement-Mediated Blood Disorders in Women of Childbearing Age **11/30/28**

This is a recorded version of the *Friday Satellite Symposium preceding the 60th American Society of Hematology (ASH) Annual Meeting* on November 30, 2018. There are seven presentations, including an Introduction. This program was jointly provided by Cine' Med and the Foundation for Women & Girls with Blood Disorders. Click on the link below to view the presentations.

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, CHES. This webinar was jointly sponsored by Creighton University and the Foundation for Women & Girls with Blood Disorders.

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, 2017. The production and archiving of this program were made possible in part by an educational grant from **Aptevo**.

Bleeding Disorders in Women and Girls: Pathway to a Powerful Career **12/10/17**

On December 10, 2017, FWGBD held its next-generation program: *Bleeding Disorders in Women and Girls: Pathway to a Powerful Career*. Pathways is a unique program that combines education in bleeding disorders, and their particular impact on women and girls, with career pathways education and guidance. Three experts in bleeding disorders in women and girls presented at this year's program. They were Drs. Diane Nugent, Michael Recht, and Ayesha Zia. The production and archiving of this program were made possible in part by an educational grant from **Shire**.

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 webinar was jointly sponsored by Creighton University and the Foundation for Women & Girls with Blood Disorders. The production and archiving of this program were made possible in part by an educational grant from **Shire**.

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 webinar was jointly sponsored by Creighton University and the Foundation for Women & Girls with Blood Disorders. The production and archiving of this program were made possible in part by an educational grant from **Grifols**.

Uterine Hemostasis Colloquium: The Challenges of Obstetric and Gynecologic Bleeding in the Reproductive Years

04/4-5/17

FWGBD held a national colloquium on uterine hemostasis preceding HTRS 2017 10th Scientific Symposium in Scottsdale, AZ. 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 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 webinar was jointly sponsored by Creighton University and the Foundation for Women & Girls with Blood Disorders. The production and archiving of this program were made possible in part by an educational grant from **Novo Nordisk Inc.**

Adolescent Thrombosis Etiology, Prophylaxis and the Role of Hormonal Therapy

05/02/16

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.

An In-Depth Look at Emerging Science and Technology to Improve the lives of Women with Blood Disorders

12/04/15

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

06/16/15

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

02/11/15

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

01/22/15

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 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 Bleeding Disorders

12/05/14

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

11/20/14

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

05/08/14

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

12/06/13

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

06/27/13

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.

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

12/07/12

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

10/24/12

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 Adolescent Girls with Blood Disorders

12/09/11

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

12/01/11

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

04/10/11

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.



Fall 2021 Quarterly Newsletter

Educating Providers. Changing Lives.

**Join Us for Our Next
Case Conversation:
Contraceptive Use and Preferences
in Females with Sickle Cell Disease**
October 29, 2021
12:00-1:00 pm ET



In the second of FWGBD's *Case Conversation* series, our expert faculty, **Dr. Andrea Roe and Dr. Tami Chrisentery-Singleton**, will review the upcoming journal article, "*Contraceptive use and preferences among females with sickle cell disease.*"

In this study, patients with sickle cell disease were surveyed about their contraceptive usage and preferences; results identified that women with sickle cell disease are less likely to use contraception, and use different kinds of contraception, than the general US population. Our expert faculty will illustrate the limitations in providing optimal patient care due to the need for research on contraception usage and decision-making, and will provide strategies for discussing contraception with women with SCD that will lead to improved patient health. The discussion will be followed by an interactive Q&A session with participants.

CME credits will be provided.

REGISTER NOW

Archived Programs: Did You Miss Them?

**Journal Club Case Conversation: A Case-Based
Discussion on Fetal and Neonatal
Thrombocytopenia (FNAIT)**

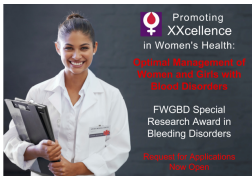


This program details information related to new advances in the diagnosis, treatment, and management of fetal and neonatal alloimmune thrombocytopenia (FNAIT) and features leading experts Dr. Jim Bussel, Dr. Emilie Vander Haar, and Dr. Andra James.

Webinar: Inherited Thrombocytopenia: What is It, Whom to Test, and How to Test?

This program on inherited thrombocytopenia is produced in collaboration with the RunX1 Research Program and the Platelet Disorder Support Association (PDSA), and features Dr. Michelle Lambert, genetic counselor Katie Bergstrom, and patient advocates Joy Anderson and Christina Timleck.

REVIEW ARCHIVED PROGRAMS NOW



Research Awards: Deadline Approaching Soon!

Application Due Date:
October 29, 2021, at 11:59 pm ET

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

Award Target: Junior Faculty or Fellows
Number of Awards to Be Given: 2
Amount of Each Award: \$35,000

To learn more, click [HERE](#)

2) FWGBD Annual Research Grant Award 2021 Focus Area: Blood Disorders Affecting Women and Girls

Award Target: Junior Faculty or Fellows
Number of Awards to be Given: 1
Amount of Award: \$15,000

To learn more, click [HERE](#)

** The offering of the Special Research Grant Award is made possible in part through an educational grant from Takeda.*

New Ask-the-Experts: Fallacies in Testing for von Willebrand Disease

In this new video, **Dr. Ravi Sarode, MD**, responds to the question, "What are the fallacies in testing for von Willebrand disease?"



Ravi Sarode, MD
Professor of Pathology, the Chief of Pathology, and the Medical Director of Clinical

Ask-the-Experts is a resource for healthcare providers to ask questions of the Foundation's Board and Medical Advisory Committee. These expert practitioners have recorded a set of Ask-the-Experts videos to answer the most pressing questions.

Laboratory Services
Medical Director of the Division of Transfusion
Medicine and Hemostasis
John H. Childers, MD, Professorship in
Pathology
University of Texas Southwestern Medical
Center in Dallas

VIEW THE VIDEO



Welcome to Our New MAC Member Dr. Luis Pacheco

We are proud to announce the recent appointment of our newest Medical Advisory Committee (MAC) member, **Luis Pacheco, MD**. Dr. Pacheco is Director of Maternal Critical Care Services, Professor of Obstetrics & Gynecology, and Professor of Anesthesiology at the University of Texas Medical Branch (UTMB).

We are thrilled to have him join us and are thankful for his leadership and ongoing commitment to ensuring that all women and girls with blood disorders are correctly diagnosed and optimally managed across the lifespan.



SUSAN SKINNER
MEMORIAL FUND
SCHOLARSHIP

Empowering women
to lead the bleeding
disorders community

Now Accepting Applications — Apply today!

Do you want to deepen your involvement with the bleeding disorders community and meet women who are going through similar experiences to your own? Now is your chance!

The Susan Skinner Memorial Fund Scholarship is looking for women from 18 to 60 years old who want to develop their leadership skills and boost their confidence.

Scholarship recipients are given a unique opportunity to:

- participate in skills development workshops alongside peers from the WFH's 147 member organizations
- learn about best practices in care
- meet and be inspired by female community leaders from around the world

in addition to attending the WFH 2022 World Congress, the largest gathering of the global bleeding disorders community!

The deadline to submit your application is **November 15th, 2021**

Click [here](#) to learn more about the application process



The experience I had through this scholarship gave me the motivation to go back to my country and deepen my engagement with the society. I was president of the Society for 8 years and at the moment I am a member of the Board of Directors.

Maria Nacheska, Macedonia (2008)
Board member, Civil Haemophilia Association of
Republic of Macedonia



WFH Launches Scholarship for Women with Inherited Bleeding Disorders

The World Federation Hemophilia (WFH) will soon be launching a scholarship opportunity for women with inherited bleeding disorders.

The *Susan Skinner Memorial Fund Scholarship* program aims to cultivate leadership and promote engagement of women in the global bleeding disorders community by providing opportunities for education, training and networking.

New Resources:

Journal Articles By FWGBD Members



A big congratulations to WGSCD LAN Research & Publications co-chairs Dr. Lydia Pecker and Dr. Deva Sharma, along with WGSCD LAN chair Dr. Alecia Nero, MAC member Dr. Michael Paidas, FWGBD Board Members Drs. Russell Ware and Andra James, and long-time supporter Dr. Kim Smith-Whitley, who recently authored a journal article in the *British Journal of Haematology* on **knowledge gaps in reproductive and sexual health in women and girls with sickle cell disease**. [Review the article here.](#)

Our congratulations also goes to WGSCD LAN member Dr. Andrea Roe and long-time FWGBD supporter Dr. Kim Smith-Whitley, as well as their co-authors, who have recently published an insightful journal article on **contraceptive use and preferences in females with sickle cell disease** in the journal *Contraception*. To register for the upcoming webinar on this article, [click here. View the article here.](#)

Dr. Julia Coleman, the 2018 FWGBD Promoting XXcellence in Women's Health award winner, recently co-authored a research paper, "Whole blood thrombin generation is depressed in severely injured patients requiring massive transfusion" that appeared in the *Journal of American College of Surgeons*. [Review the journal article here.](#)

Are You A Member?



Our FWGBD Membership Program has been steadily growing, and we are thrilled to report that we now have over 300 members. Current Members, keep an eye out for our Renewal Reminder Emails so you can keep your membership up to date! [Renew or Join Now!](#)

Have you signed up for FWGBD membership yet? You could be taking advantage of our many benefits, including:

- Advance invitation and discounted registration to [FWGBD's Biennial Conference](#) (next conference: September 2022)
- Advance notice about programs, events, and research award opportunities
- Receipt of our Quarterly Member Newsletter
- A FWGBD lapel pin, membership card, and more!

Resident, Fellow, Graduate & Medical Students are welcome to join and receive a complimentary membership!

We also have a great joint membership program in concert with HTRS. Take advantage and save money! To learn more, visit [HERE](#).

Questions? Contact Jennifer Longo, Database and Membership Services Manager, at 845-642-2925 or membership@fwgbd.org.



Sector-Wide Events

[Sickle Cell Disease Association of America's Annual Conference:](#)
October 12-16, 2021, Virtual

[American Thrombosis & Hemostasis Network's Data Summit:](#)
October 28-29, 2021, Virtual

American Society of Hematology Annual Meeting and Exposition (ASH):
December 11-14, 2021, Atlanta, GA, and Virtual



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