



# 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

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**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

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**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

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



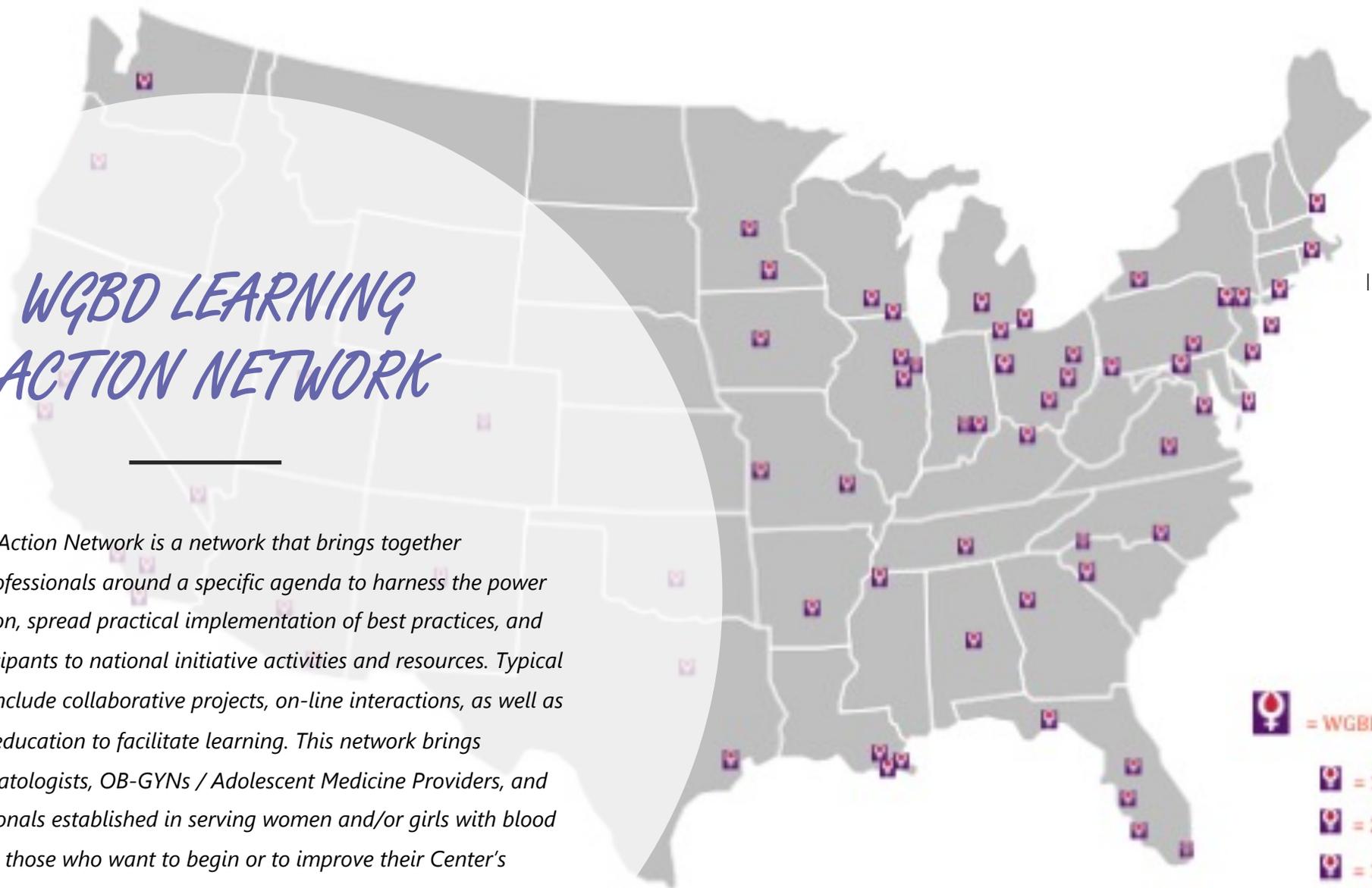
# WGBD LEARNING ACTION NETWORK

*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

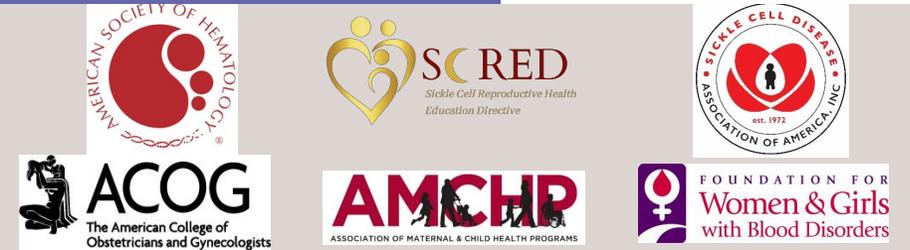


# A FOCUS ON SCD AND WOMEN'S REPRODUCTIVE HEALTHCARE

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](http://fwgbd.org)

In 2021, our Website had 19,182 unique users at [fwgbd.org](http://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](http://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](http://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>

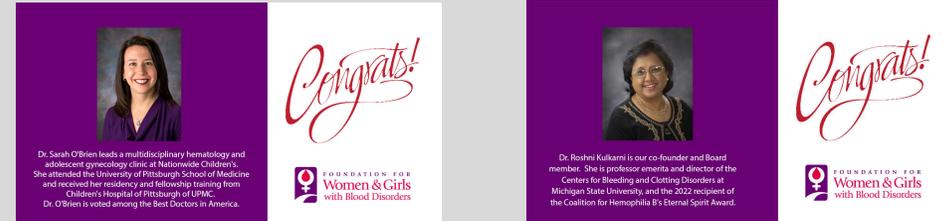
## Newsletter

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

Andra H. James, MD, MPH  
Founding President  
Barbara A. Konkle, MD  
Founding Board Member  
Roshni Kulkarni, MD  
Founding Board Member  
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Sarah Luke, JD  
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Russell Ware, MD, PhD  
Janice Bacon, MD  
Ravi Sarode, MD  
Sarah O'Brien, MD, MSc

Ann-Marie Nazzaro, PhD  
Executive Director Emeritus

## Foundation Staff

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Executive Director  
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Manager of Education  
Elizabeth Kearns  
Program Coordinator  
Ginny Schulze  
Operations Manager  
Jennifer Longo  
Database and Membership Services  
Manager  
Rachel Moehl, MA  
Manager, Digital Communications/  
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  
Paula James, MD, FRCPC  
Peter Kouides, MD  
Alice Ma, MD  
Marilyn Manco-Johnson, MD  
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

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## YOUR SUPPORT CHANGES LIVES

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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*

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Montclair, NJ 07042  
[fwgbd.org](http://fwgbd.org)  
Our Tax ID # is 27-2456813

