# Welcome, FWGBD Member!

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 girls. You have joined a national network of dedicated healthcare providers that values connections, collaborations, and optimal patient care.

This document will provide you with an overview of the impact of FWGBD, in addition to our activities that we offer throughout the year. We share many opportunities to engage in webinars, collaborative projects, and research via email. Please be sure to keep us updated with your preferred email address to keep up-to-date on our many resources and activities for providers.

Thank you. We are thrilled to have you here.

2023



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# FWGBD 2022 Year-End Report

Thank you for your continued support!



# INTRODUCTION

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## Thank you for another year of great partnership!

As we ring in this New Year, it's time to reflect on the past and look forward to the future. We wanted to take this opportunity to mark what brought us joy in 2022. Your support. The success and support from our community. And the shared commitment to our mission.

We began the year by introducing new members to our team (Board & Staff), and by welcoming more and more members to our growing FWGBD Membership family, to our WGBD LAN and to our WGSCD LAN.

In our 7<sup>th</sup> year of offering research fellowship awards, we added three more recipients to our research grant award portfolio, which now includes 18 awards being given since 2016.

Then, in September, we were lucky to be able to meet with you and 176 of your colleagues in-person for our second national conference, *FWGBD 2022*. This great turnout showed us that professionals want – *NEED* – continued education about women's unique needs, and that we continue to head on the right path.

In 2023, we intend to keep the momentum going. We remain committed to educating and engaging with others about the unique issues and solutions women with blood disorders face so that more of them can thrive in our society. We will continue to increase awareness and create opportunities that inspire professionals to act. The more professionals who know about our mission and join our community, the greater impact we will have.

To date, our programs have impacted over 10,000 healthcare professionals, but we have so much more to do. But for now, we hope that you will take a moment to review some of our accomplishments and milestones from this past year.

We are grateful to you, our generous community, our many partners, and colleagues for making our work possible.

## Thank you for your support!

# WHO WE ARE

## Our Mission:

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

Undiagnosed, untreated blood disorders in women have *medical consequences and unique issues at every life stage*, creating the need for a foundation dedicated to education and awareness.

In 2010, the Foundation for Women & Girls with Blood Disorders (FWGBD), a non-profit 501(c)3 organization, was launched to serve as a single site, single source where physicians and healthcare providers can obtain information. Provider education, across disciplines, is the focus of the Foundation. We benefit women and girls by educating their providers.



# **OUR WORK IN 2022**

By The Numbers



## 1016 PROFESSIONALS

Received education through our live programs

# **12 LIVE PROGRAMS**

Were offered through Conferences, Webinars, Journal Clubs, and Society Presentations

## 94 CE CERTIFICATES

Were given to program attendees



## \$475,000 AWARDED

To 18 Research Fellowship Awardees since 2016

## **106 NEW MEMBERS**

Joined FWGBD this year, making our total membership 444

## 93 WGSCD LAN 258 WGBD LAN

Members of our Learning Action Networks (LANs) Find Field Creat to see you all at #FWGBD2022! Thank you!

Christy Bemrich-Stolz @pedshemen... · 9/25/22
 So much learning. So much inspiration.
 #FWGBD2022 is the best.



# **INSPIRING CHANGE**

April 4, 2022 Live Webinar: Thromboembolism in Females *ISTH Academy* Faculty: Lakshmi Srivaths, MD and Bethany Samuelson Bannow, MD 100+ Live Event Attendees

#### April 8, 2022 Presentation: Code Red: Heavy Menstrual Bleeding

North American Society for Pediatric and Adolescent Gynecologists (NASPAG) – Chicago, IL Faculty: Gylynthia Trotman, MD 25 Live Event Attendees

#### April 14, 2022

Live Webinar: Reproductive Options and Prenatal Testing for Women with SCD for Women and Girls with Blood Disorders Faculty: Kristin Paulyson Nuñez, MS, CGC and Andra H. James, MD, MPH 115 Live Event Attendees Session – Houston, TX

#### May 17, 2022 Live Webinar: Health Equity for Women with Bleeding Disorders Hemophilia Federation of America (HFA) Faculty: Roshni Kulkarni, MD and Kerry Funkhouser, EdD 116 Live Event Attendees

#### May 24, 2022 Journal Club: An Update on Pediatric Immune Thrombocytopenia (ITP): Differentiating Primary ITP, IPD, and PID Faculty: Michele Lambert, MD, MSTR and Rachael Grace, MD, MMSC 70 Live Event Attendees

#### June 14, 2022 Live Webinar: Rare Bleeding Disorders During Pregnancy Faculty: David Abel, MD and Annabel Frank, MD 110 Live Event Attendees

## August 25, 2022 Presentation: Making Strides Towards Advancing Care

National Hemophilia Federation (NHF) Women's Health Session - Houston, TX Faculty: Meera Chitlur, MD 100 Live Event Attendees

September 23, 2022 Live Program: WGBD & WGSCD LAN Workshop Arlington, VA 80 Live Event Attendees

#### September 24-25, 2022 Live Program: FWGBD 2022 Arlington, VA 176 Live Event Attendees

October 14, 2022 Presentation: Aging with Sickle Cell Disease: Is Aging Just a Number? Sickle Cell Disease Association of America (SCDAA) Faculty: Charity Oyedeji, MD 45 Virtual Attendees

November 9, 2022 Case Conversation: Safety and Efficacy of Classical Complement Pathway Inhibition with Sutimlimab in Chronic Immune Thrombocytopenia Faculty: Catherine Broome, MD and James Bussel, MD 36 Live Event Attendees

December 11, 2022 Live Program: Blood Disorders in Women and Girls: Pathway to a Powerful Career ASH in New Orleans, LA Faculty: Russell Ware, MD, PhD, Leslie Skeith, MD, FRCPC, MHPE, Jill Johnson, MD, and Homa Ahmadzia, MD, MPH 43 Live Event Attendees

"In coming to the conferences and my consistent participation in the organization, I constantly receive updates from my colleagues throughout the nation. I receive up-to-date information about treatments, therapies, national guidelines, and even international guidelines, so that our patients can receive the best care."

FWGBD 2022 Year-End Report

Nefertiti Harmon Durant, MD, MPH

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#### September 24-25 | Arlington, VA

"Excellent meeting!"

**FWGBD** "This was one of the best conferences I've attended!"

"Engaging speakers, relevant topics, exceptional dinner speaker on Saturday!"

"Workshops were excellent. So many great sessions but the one on transgender care was a highlight."

"The plenaries were truly excellent."

Over 176 attendees were able to listen to and engage with 28 international experts speak on topics related to bleeding and clotting disorders for people with the potential to menstruate across the lifespan. The dynamic group of hematologists, obstetricians, gynecologists, and other specialties had an opportunity to highlight their specific areas to further the collaboration needed to better support their patients.

Post-conference highlights include the awareness of disease processes and treatment, especially TXA and DOACs, the most updated recommendations and evidence-based approaches to care, and ways to be more inclusive to all patients. We were also excited to host a special session related to advocacy for reproductive rights.

#### Online Survey Results:

100% satisfied with the speakers100% satisfied with the quality of the sessions95% satisfied with the number of sessions



#### Plenary 1: Management of Pain

- Endometriosis-Related Pain
- Post-Thrombotic Pain
- Managing Pain During Menstruation for Women/Girls with Sickle Cell Disease

<u>Plenary 2</u>: Barriers to Clinical Trial Participation and Research for Women and People of Color

<u>Plenary 3</u>: Thrombosis and Hemostasis in the Gender Non-Conforming Populations

<u>Plenary 4</u>: Addressing Key Issues in the Management of Pregnancy for Women with Bleeding and Clotting Disorders

Conference Co-Chairs: Kristina Haley, DO and Ware Branch, MD

## Faculty:

Allison P. Wheeler, MD Andra H. James, MD, MPH Andrea H. Roe, MD, MPH Angela Weyand, MD Arthur Vaught, MD Bethany Samuelson Bannow, MD Biree Andemariam, MD Claudia Borzutzky, MD Deva Sharma, MD, MS Elisabeth Quint, MD Eric Mullins, MD Homa Ahmadzia, MD, MPH James Curtis, Jr., DMD Janice Bacon, MD Jean Connors, MD Jerome Federspiel, MD, PhD Kristyn Brandi, MD, MPH, FACOG Maureen K. Baldwin, MD, MPH Meera Chitlur, MD Melissa Creary, PhD, MPH Nancy Sokkary, MD Patricia S. Huguelet, MD Roshni Kulkarni, MD Stacey Missmer, ScD Susan Kahn, MD, MSc 8 Ware Branch, MD

FWGBD 2022 Year-End Report

# **CREATING ACTION**

## FWGBD's Learning Action Networks (LANs)

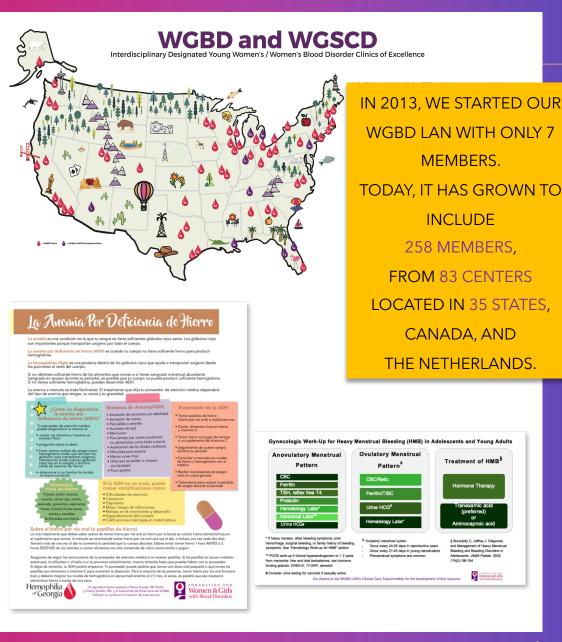
The Learning Action Network is a network that brings together healthcare professionals around a specific agenda to harness the power of collaboration, spread practical implementation of best practices, and connect participants to national initiative activities and resources. This network brings together 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 services for women/girls.



<u>WGSCD LAN</u>
93 members
44 Centers
23 States

# FOSTERING COMMUNICATION, COLLABORATION, AND ACTION

In addition to the establishment and implementation of designated interdisciplinary clinics for women and girls, our LAN members worked hard this year to develop and publish a series of tools to be used by providers in the care of their patients. These included a Period Pocket Guide, an Iron Supplement Table, and four informational sheets (made available in both English and Spanish) covering the topics of menstruation, heavy menstrual bleeding, iron deficiency anemia, and period products.



# **CULTIVATING THE NEXT GENERATION**

In 2022, we awarded \$85,000 in research fellowship awards to three impressive recipients.



Bethany Samuelson Bannow, MD

Project: Bleeding in Carriers of Hemophilia A: the Role of von Willebrand Factor, Platelet Function and Endometrial Tissue Expression of FVIII



Emilie Vander Haar, MD

Project: The Natural History of Anti-HPA-Alloimmunization in a Diverse Patient Population



Zachary Ramsay, MD

Project: The Influence of Sex Hormones and Menses on Sickle Cell Pain in Women

To learn more about these awards, and read about our past recipients, please visit: https://www.fwgbd.org/about/research-fellowship-awards Travel Awards Made Available to FWGBD 2022 for North American FWGBD Student Members

As part of our mission to build the next generation of researchers and providers for women and girls with blood disorders, FWGBD was pleased to present \$1,000 Travel Awards in honor of Jeanette Doner Mann as a travel stipend to attend the FWGBD biennial conference. Congratulations to our awardees!! And a BIG thank you to Dr. Ken Mann!!



Since 2016, FWGBD has awarded \$475,000 in research awards to 18 recipients. Three more awards are set to be assigned in early 2023.

FWGBD 2022 Year-End Report

# **OUR COMMUNITY**

## Web Traffic - fwgbd.org

11% growth rate over 2021

In 2022, our Website had 21,233 unique users at *fwgbd.org*, who visited us a total of 28,884 times. Compared with 19,182 / 24,230 last year, we've grown our Website reach by 11% and our visits by 19%. Our users reside in 159 countries across the globe.

57.4% of Website visitors went directly to *fwgbd.org*, 34.5% searched for us online and navigated to our Website via a search engine (Google.com, Bing.com, etc.).

Aside from our homepage, these pages had high traffic in 2022: https://www.fwgbd.org/education/conference

https://www.fwgbd.org/education/conference/program

https://www.fwgbd.org/education/conference/fwgbd-2022-program-agenda

<u>https://www.fwgbd.org/clinics</u>

https://www.fwgbd.org/patient

https://www.fwgbd.org/questions/using-birth-control-in-patients-with-itp

Our social media channels are the main entry point to reach new audiences and interact with our community daily. **Great growth** everywhere!



**845 46% increase** since 2021

40,643 views (up 14% since 2021)



1.315 14% growth rate over 2021

1.2k

158 joined us 2022



629 9% increase over 2021 52 new in 2022



**196** 87% increase from 2021

Top YouTube Video Ask the Experts: Tranexamic Acid Use for Heavy Menstrual Bleeding 13,779k views in 2022

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

# FINANCIALS

## Total Operating Expenses: \$595,222 (Programs & Activities = \$491,965)

# Contributions and Grants = 82% Gifts/memberships and donations = 13% Program Revenue = 3% Interest = 0% Miscellaneous Income = 2%

83¢ of every dollar was invested in our educational programs.

These financials are the latest figures from our independent audit of our last fiscal year (July 1, 2021, to June 30, 2022).

# **SOME VERY SPECIAL PARTNERS**



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.



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 has been the proud recipient of several annual grants from The Hemophilia Alliance Foundation which contribute to the strengthening of the organization.



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. Beginning in 2020, FWGBD and HTRS created a joint FWGBD/HTRS membership between the two organizations.



A new partner to FWGBD in 2022, The Alliance Pharmacy gifted \$25,000 to the Foundation in support of our educational programs and initiatives.

# with **GRATITUDE**

#### FWGBD Board of Directors

Andra H. James, MD, MPH Founding President Barbara A. Konkle, MD Founding Board Member Roshni Kulkarni, MD Founding Board Member Leslie J. Graham, MSHA Treasurer Sarah Luke, ID Secretary Kenneth Mann. PhD Michael Recht, MD, PhD, MBA Russell Ware, MD, PhD lanice Bacon, MD Ravi Sarode, MD Sarah O'Brien, MD, MSc

#### Foundation Staff

Kerry Funkhouser, EdD Executive Director Katherine Cantu Anguiano, MPH Manager of Education Elizabeth Kearns Program Coordinator Jennifer Longo Database and Membership Services Manager Rachel Moehl, MA Manager, Digital Communications/Social Media 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. Our Lifetime Members are:

Janice Bacon, MD Obstetrics/Gynecology FWGBD Board Member

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

Jennifer Domm, MD Hematology/Oncology Nashville, TN

Katherine Hassel, MD Hematology University of Colorado, Anschutz Medical Campus

Biree Andemariam, MD Gowthami Arepally, MD Maureen Baldwin, MD, MPH Shannon Bates, MDCM, MSc, FRCP(C) Leo Brancazio, MD David Ware Branch, MD James Bussel, MD Meera Chitlur, MD Alice Cohen, MD, FACP James W. Curtis, Jr., DMD Mary Cushman, MD, MSc Jennifer Dietrich, MD, MSc, FACOG 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

#### Medical Advisory Committee (MAC)

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 Ann-Marie Nazzaro, PhD FWGBD Executive Director Emeritus

Michael Recht, MD, PhD, MBA Hematology FWGBD Board Member

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

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

Luis Pacheco, MD Michael Paidas, 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

Thank you!



# **THANK YOU!**

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



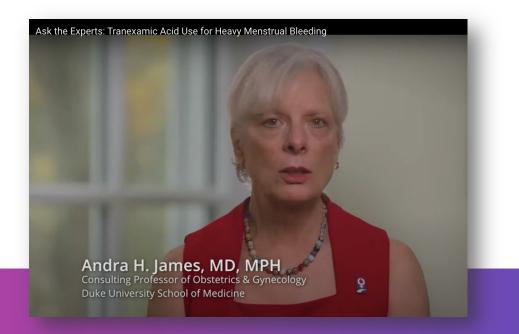
# **Ask the Experts**

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.

You can find our video archive and submit a question on our Website:

www.fwgbd.org/resources/ask-the-experts-video-archive





# **FWGBD 2023 Planned Meetings**

Dates	Conference/Event	Location	2023
3/9-3/10	FWGBD Colloquium on Uterine Hemostasis Preceding HTRS	Orlando, FL	
	(https://www.htrs.org/home/EventsEducation/Scientific-		
	Symposium/Registration#precon)		
3/10-3/12	HTRS 2023 Scientific Symposium (HTRS.org)	Orlando, FL	
3/25-3/27	North American Society for Pediatric and Adolescent Gynecology (ACRM)	Nashville, TN	
	(NASPAG) (naspag.org)		
6/19	World Sickle Cell Day	Virtual	
6/24-28	ISTH 2023 Congress (isth2023.org)	Montreal, Quebec, Canada	
August TBD	NHLBI SCD Clinical Research Meeting	Hybrid	
8/17-8/19	NHF 's Virtual Annual Bleeding Disorders Conference (hemophilia.org)	Washington D.C. and Virtual	
9/30-10/3	WGBD and WGSCD LAN Meetings	Detroit, MI	
October TBD	National Conference for Women & Teens with Hemophilia & Rare Factor Deficiencies (HFM)	TBD	
10/13	World Thrombosis Day (ISTH)	Virtual	
October TBD	Sickle Cell Disease Association of America (SCDAA) (sicklecelldisease.org)	TBD	
10/18-10/20	ATHN Data Summit (athn.org)	Atlanta, GA	
12/9-12/12	American Society of Hematology Annual Meeting and Exposition (ASH) (hematology.org)	San Diego, CA	18

# Meetings of Note

Dates	Conference/Event	Location	2023
5/10-5/12	World Federation of Hemophilia (wfh.org)	Buenos Aires, Argentina	
5/10-5/13	2023 ASPHO Conference (aspho.org)	Fort Worth, TX	
5/19-5/21	2023 Annual Clinical & Scientific Meeting (ACSM) ACOG (acog.org)	Baltimore, MD	
6/8-6/11	EHA2023 Congress (EHA) (ehaweb.org)	Frankfurt, Germany	
6/14-6/16	EHA2O23 Virtual Days (EHA) (ehaweb.org)	Virtual	
7/17-7/19	World Gynecology & Obstetrics Congress (WGOC 2023)	Madrid, Spain	
9/21-23	Association of Pediatric Hematology/Oncology Nurses (APHON) (Aphon.org)	Cleveland, OH	
10/9-10/12	ACEP23 Scientific Assembly (American College of Emergency Physicians) (Acep.org)	Philadelphia, PA	
10/14-10/17	Advancement of Blood & Biotherapies (AABB) (aabb.org)	Nashville, TN and virtual	



Educating Providers. Changing Lives.



## **FWGBD 2022**

FWGBD 2022 brought together nearly 200 physicians, researchers, nurses, social workers, and advocates who focus on the care and treatment of blood and clotting disorders for people with the potential to menstruate. The sessions included expert faculty addressing the management of pain, barriers to clinical research participation, management of pregnancy, gender affirming care, and a special highlight on provider advocacy for reproductive healthcare.

The dynamic group of hematologists, obstetricians, gynecologists, and other specialties had an opportunity to highlight their specific areas to further the collaboration needed to better support their patients. Post-conference highlights include the awareness of disease processes and treatment, especially TXA and DOACs, the most updated recommendations and evidence based approaches to care, and ways to be more inclusive to all patients. These sessions are not the start nor the end of important conversations to be had – please see below for upcoming events hosted by FWGBD.

## New Ask-the-Experts Video

## Borderline Dosage Considerations

Q: As providers, we struggle with the changing recommendations for dosage, especially when patients are on the (age or weight) border. What guidance do you suggest following?

#### Answered by:

Jacquelyn Powers, MD, MSc, Director, Iron Disorders and Nutritional Anemias Program, Co-Director, Young Women's Bleeding Disorders Clinic, Assistant Professor, Department of Pediatrics, Section of Hematology/Oncology, Baylor College of Medicine, Texas Children's Hospital *Ask-the-Experts* is a resource for healthcare providers to ask questions of the Foundation's Board and Medical Advisory Committee. These expert practitioners have recorded a set of Ask-the-Experts videos to answer the most pressing questions.



## **Upcoming Events**



Case Conversation Sutimlimab in Chronic Immune Thrombocytopenia

Wednesday, November 9, 2022 12:00 – 1:00 PM ET

Dr. Catherine Broome will guide us through her recent publication, Safety and Efficacy of Classical Complement Pathway Inhibition with Sutimlimab in Chronic Immune Thrombocytopenia. Dr. Broome will highlight the findings of this study, including how sutimlimab administration was associated with a rapid increase in mean platelet count, that treatment with sutimlimab effectively inhibited Weislab-CP activity and CH50 with a decrease from baseline sustained through the treatment period and return to baseline following treatment discontinuation. The case presentation and discussion will be followed by an interactive Q&A session with participants.

**REGISTER TODAY!** 

## **Blood Disorders in Women and Girls**: Pathway to a Powerful Career

December 11, 2022 | 8:00 PM Renaissance New Orleans Arts Warehouse District Hotel



The Foundation for Women & Girls with Blood Disorders is pleased to host,*Blood Disorders in Women and Girls: Pathway to a Powerful Career.* This unique program that will combine education in bleeding disorders and the impact on women and girls with experts in the field of blood disorders. During this dinner and discussion, experts will share their own career pathway and attendees will have an opportunity to talk informally at the dinner table with a leading expert.

We invite fellows, new faculty, and residents in hematology who are attending the**64th ASH** Annual Meeting and Exposition in New Orleans, Louisiana. FWGBD's Pathways will be held at the

Renaissance New Orleans Arts Warehouse District Hotel on Sunday, December 11<sup>th</sup>, 2022, at 8:00 PM.

**Register for Pathways** 

## **Education and Recent Research**

Fashakin V, Weber JM, Truong T, Craig A, Wheeler SM, James AH. Sickle cell disease and the incidence and etiology of preterm birth. *Am J Obstet Gynecol MFM* 2022;4:100723.

Konkle, BA. The burden of heavy menstrual bleeding. Blood. 20 October 2022.

Marshall AL, Sharma D, Hsu G, Pecker LH, Cushman M. Abortion access and the US medical workforce: A looming crisis for haematology. *The Lancet*. 13 October 2022.

#### Learn more about membership to FWGBD HERE.

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



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