

Who is in the room today...

South Carolina Wisconsin
Illinois Washington
California Pennsylvania
Tennessee
Connecticut
Virginia Texas Ohio Canada Minnesota
Vermont Michigan Georgia
Indiana Florida Alaska
Utah Alabama New York Massachusetts
Delaware Colorado
Maine Missouri North Carolina Rhode Island
New Jersey Oregon Louisiana
Maryland District of Columbia



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 7th 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)



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

Faculty: Kristin Paulyson Nuñez, MS, CGC and Andra H. James, MD, MPH

115 Live Event Attendees

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

for Women and Girls with Blood Disorders

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."

Nefertiti Harmon Durant, MD, MPH



"Excellent meeting!"

"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 speakers

100% satisfied with the quality of the sessions

95% 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

Plenary 2: Barriers to Clinical Trial Participation and Research for Women and People of Color

Plenary 3: Thrombosis and Hemostasis in the Gender Non-Conforming Populations

Plenary 4: 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 Sorkary, MD
- Patricia S. Huguelet, MD
- Roshni Kulkarni, MD
- Stacey Missmer, ScD
- Susan Kahn, MD, MSc
- Ware Branch, MD

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.



WGBD LAN

258 Members
83 Centers
35 States

WGSCD LAN

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.

WGBD and WGSCD Interdisciplinary Designated Young Women's / Women's Blood Disorder Clinics of Excellence



IN 2013, WE STARTED OUR WGBD LAN WITH ONLY 7 MEMBERS. TODAY, IT HAS GROWN TO INCLUDE 258 MEMBERS, FROM 83 CENTERS LOCATED IN 35 STATES, CANADA, AND THE NETHERLANDS.

La Anemia Por Deficiencia de Hierro

La anemia es una condición en la que tu sangre no tiene suficientes glóbulos rojos sanos. Los glóbulos rojos son importantes porque transportan oxígeno por todo el cuerpo.

La anemia por deficiencia de hierro (ADH) es cuando tu cuerpo no tiene suficiente hierro para producir hemoglobina.

La hemoglobina (Hgb) es una proteína dentro de los glóbulos rojos que ayuda a transportar oxígeno desde los pulmones al resto del cuerpo.

Si no obtienes suficiente hierro de los alimentos que comes o si tienes sangrado menstrual abundante (sangrado en exceso durante su periodo), es posible que tu cuerpo no pueda producir suficiente hemoglobina. Si no tienes suficiente hemoglobina, puedes desarrollar ADH.

La anemia a menudo se trata fácilmente. El tratamiento que elija tu proveedor de atención médica dependerá del tipo de anemia que tengas, su causa y su gravedad.

¿Cómo se diagnostica la anemia por deficiencia de hierro (ADH)?

- Tu proveedor de atención médica puede diagnosticar la anemia al:
 - analizar tus síntomas y hacer un examen físico
 - preguntar sobre tu dieta
 - hacer ciertos análisis de sangre como hemoglobina (Hgb) que son los glóbulos rojos que transportan oxígeno
 - hacer ciertos otros análisis de sangre como los niveles de hierro
 - determinar si un familiar ha tenido la misma condición

Síntomas de Anemia/ADH

- Sensación de cansancio y/o debilidad
- Piel pálida o amarilla
- Aumento de sed
- Mal humor
- Pica (sueño por comer productos no alimenticios como hielo o tierra)
- Aceleración de los latidos cardiacos
- Dificultad para respirar
- Mareos y pies fríos
- Uñas que se astillan o rompen con facilidad
- Poco apetito

Tratamiento de la ADH

- Tomar pastillas de hierro (siempre por vía oral o multivitamínicos)
- Comer alimentos ricos en hierro y vitamina C
- Tomar hierro con jugo de naranja o un suplemento de vitamina C
- Seguimiento de cuánto sangre durante su periodo
- Controlar a menudo sus niveles de hierro y hemoglobina con el médico
- Recibir transfusiones de sangre (solo en casos graves)
- Tratamiento para reducir la pérdida de sangre durante el periodo

Alimentos ricos en hierro

Frijoles, pollo, huevos, nueces, carne roja, cerdo, pescado, guisantes, espinacas, lentejas, brócoli, frijoles secos, zanahoria y remolacha, fortificados con hierro.

Si la ADH no se trata, puede causar complicaciones como:

- Dificultad de atención
- Cansancio
- Depresión
- Mayor riesgo de infecciones
- Retraso en el crecimiento y desarrollo
- Agrandamiento del corazón
- Cálculos más bajos en matemáticas

Sobre el hierro por vía oral (o pastillas de hierro)

Lo más importante que debes saber acerca de tomar hierro por vía oral (o hierro por la boca) es cuánto hierro elemental hay en el suplemento que tomas. A menudo se recomienda tomar hierro por vía oral una vez al día, e incluso una vez cada dos días. Tomarlo más de una vez al día no aumenta la cantidad que tu cuerpo absorbe. Debes evitar tomar hierro 1 hora ANTES o 2 horas DESPUÉS de las comidas o comer alimentos con alto contenido de calcio (como leche o yogur).

Asegúrate de seguir las instrucciones de tu proveedor de atención médica si te recetan pastillas. Si las pastillas te causan malestar estomacal, es difícil tragarlas o si te provocan estreñimiento, intenta tomarlas hasta que puedas hablar con tu proveedor. Si dejas de tomarlas, tu ADH podría empeorar. Tu proveedor puede pedirte que tomes una dosis más pequeña o que tomes las pastillas con alimentos o vitamina C para aumentar la absorción. Para la mayoría de las personas, tomar hierro por vía oral funciona bien y debería mejorar sus niveles de hemoglobina en aproximadamente un (1) mes. A veces, es posible que sea necesario administrar hierro a través de una vena.

Un agradecimiento especial a Penny Kung'u, RN (MS), y Cheryl Stadler, RN, y al Subcomité de Enfermería de WGBD LAN por su ayuda en la creación de este recurso.

Gynecologic Work-Up for Heavy Menstrual Bleeding (HMB) in Adolescents and Young Adults

Anovulatory Menstrual Pattern	Ovulatory Menstrual Pattern [‡]	Treatment of HMB [§]
CBC	CBC/Retic	Hormone Therapy
Ferritin	Ferritin/TIBC	
TSH, reflex free T4	Ferritin/HCG*	Tranexamic acid (preferred) or Aminocaproic acid
Proctolin	Urine HCG*	
Hematology Labs*	Hematology Labs*	
Hormonal Labs**		
Urine HCG*		

* If heavy menses, other bleeding symptoms, prior hemorrhage, surgical bleeding, or family history of bleeding symptoms. See "Hematology Work-up for HMB" section.

** PCOS work-up if clinical hyperandrogenism or > 3 years from menarche; free and total testosterone, sex hormone binding globulin, DHEA-S, 17-OHP, estradiol.

‡ Consider urine testing for gonorrhea if sexually active.

§ Berulsky C, Jeffrey J. Diagnosis and Management of Heavy Menstrual Bleeding and Bleeding Disorders in Adolescents. JAMA Pediatr. 2020; 174(2):198-194.

Our thanks to the WGBD LAN's Clinical Care Subcommittee for the development of this resource.

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.

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>

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

<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

158 joined us 2022

1.2k



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

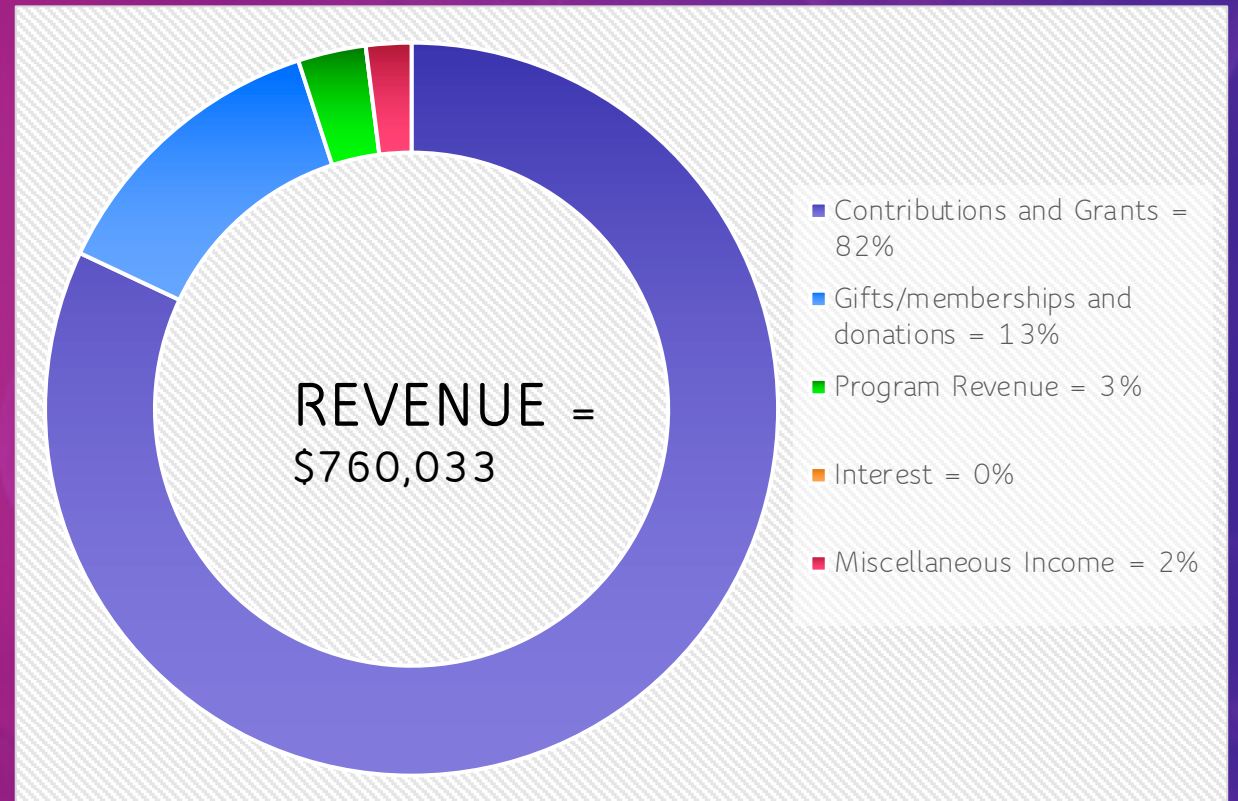
<https://www.youtube.com/watch?v=ZWvO7nDHLzM>

FINANCIALS

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

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



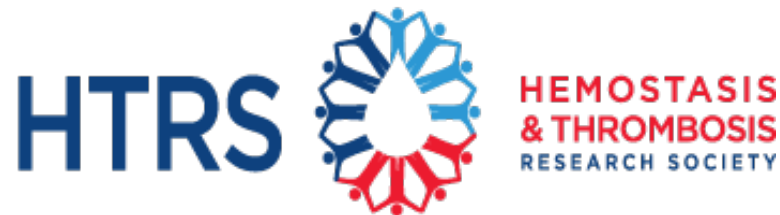
In 2020, the HTC partnered with us once again by granting us a financial matching grant of \$135,000. They continue to be one of our biggest supporters.



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
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Michael Recht, MD, PhD, MBA
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Janice Bacon, MD
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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

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
FWGBD Board Member

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

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

Medical Advisory Committee (MAC)

Biree Andemariam, MD
Gowthami Arepally, MD
Maureen Baldwin, MD, MPH
Shannon Bates, MDCM, MSc, FRCPC(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

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Diane Nugent, MD
Kristin Paulyson Nuñez, MS, CGC

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



*Educating Providers.
Changing Lives.*

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