



OCTOBER 3-5

2025 NATIONAL CONFERENCE FOR WOMEN

**EMPOWERMENT, EDUCATION, POLICY:
SEE ME. HEAR ME. BELIEVE ME.**

DEAR FRIENDS,

We are so honored to gather with you for this powerful and deeply meaningful weekend. Whether this is your first time attending or you've joined us before, your presence here is a vital part of a growing and resilient community of women who refuse to be overlooked.

Our theme this year, coined by our Fairy Godmother, Dr. Roshni Kulkarni — **See Me. Hear Me. Believe Me.** — is more than a tagline. It's a declaration. A call to action. A reminder that every woman in this space has a voice worth listening to, a story worth sharing, and a truth that matters.

We want you to know that we see you, hear you, and believe you and we hope you feel this across the connections and programs available at this year's conference. We read every evaluation. We listened. And we responded. This year, you'll find **more time dedicated to Leaders in Action (LIA) small groups**, giving you more space to connect deeply, reflect, and grow with one another. You'll also see an **expanded lineup of sessions focused on rare factor deficiencies**, created specifically to support and reflect the unique experiences within this community.

Together, we will shine a light on the lived experiences of women navigating bleeding disorders—often rare, frequently misunderstood, and too long underrepresented. Through education, connection, and community, we hope this conference gives you the tools, strength, and confidence to advocate not only for your health, but for your worth.

We see you! We hear you! We believe you!

Thank you for showing up—for yourself and for each other.

With gratitude and hope,



Susan Fenters Lerch
Executive Director, Hemophilia
Foundation of Michigan;
Regional Director, Great Lakes
Federal HTC Network



Shari Luckey, MA
Education and Program
Services Director, Hemophilia
Foundation of Michigan

CONFERENCE GUIDELINES

We are so glad you're here. This conference is designed to be a space where your voice and your experiences matter. We encourage **respectful dialogue**, recognizing that each person brings a unique perspective, and that there are many valid paths to self-care, treatment, and community engagement. This weekend is your opportunity to explore, discover, and engage with information in the way that feels right for you.

To help you navigate the event, we use an app to share schedules, session materials, and evaluations. We recommend logging into the app a few days before the conference to set up your profile and get familiar with the platform.

We recognize there may be community member attendees who also work for bleeding disorders companies, including homecare and industry. If this applies to you, your participation this weekend is expected to be solely as a **community member and consumer**. **Solicitation of other attendees for services or future programs is not permitted, and industry-affiliated individuals are not allowed to ask for or collect personal health or contact information from other participants.** If you are interested in representing your company at future events, please speak with an HFM staff member about sponsorship opportunities.

We are grateful to our industry partners for their generous support, which helps make this event possible. Some representatives may join us in the main ballroom sessions, and we encourage you to stop by their tables during breaks to collect educational resources. Your privacy is important to us, and you are always in control of how much personal information you share. **Industry representatives will not ask about your diagnosis, treatment, or medical history, and they cannot offer medical advice.** These conversations should remain between you and your healthcare provider. If you wish to continue discussions after the conference, you may voluntarily share your contact information—but please know that doing so is entirely your choice. If at any time you feel uncomfortable or pressured, please notify a member of the HFM staff immediately.

Lastly, this is a casual and come as you are space. Feel free to dress comfortably throughout the weekend. For Saturday's active sessions, clothing suitable for movement or light exercise is recommended.

This is your space, your story, and your time.





See hemophilia in a new light.

What could life with hemophilia look like? Our dedicated support and on-demand resources help keep the answer to that question simple: Full of potential.



Explore a new outlook.

RedefiningHemophilia.com

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AGENDA

ALL SESSIONS HELD IN THE LINDBERGH BALLROOM WILL BE TRANSLATED INTO SPANISH.
SPEAKER PHOTOS AND BIOS CAN BE FOUND VIA THE NUNIFY APP.

 Spanish translation available

Friday, October 3

3:00-8:00pm

Registration and Exhibitor Space Open

Pre-function Lindbergh Ballroom

Check in at the registration table and receive your small group assignment.

While you're here, be sure to visit our sponsor tables and connect with the organizations that help make this event possible.

4:00-5:00pm

Welcome Reception

Pre-function Lindbergh Ballroom

Light appetizers and refreshments

Genentech embraces
the increasingly diverse
world around us.



[GENE.COM/DIVERSITY-INCLUSION](https://www.gene.com/diversity-inclusion)

Genentech
A Member of the Roche Group

5:00-5:50pm

Connecting Faces: Small Group Meet and Greet

Breakout Rooms

Begin your conference journey by connecting with the group you were assigned based on your preferences. You received your group information when you checked in at registration. You'll connect with these individuals throughout the weekend. In this first gathering, you'll have a chance to introduce yourselves, share experiences, and set the tone for meaningful conversations ahead. This is your space to be seen, heard, and supported as you build community together.

Leaders in Action (LIA) Lead:

Kaite Scott, LLMSW, Program Social Worker, Hemophilia Foundation of Michigan

Hemophilia A

Wright A

Facilitator:

Edith Mejia

Hemophilia A

Wright B

Facilitator:

Erica McLeod

Hemophilia B

Earhart A

Facilitator:

Pam Migliore

Hemophilia B

Earhart B

Facilitator:

Marcelle Williams, PhD

Primetime (55+)

Armstrong

Facilitator:

Shellye Horowitz, MA, PPS

Midlife (35-55)

Balboa

Facilitator:

Mayra Cantu, MSW

Midlife (35-55)

Cook

Facilitator:

Lisa Swaney

Rare Factor Deficiencies

Cortez

Facilitator:

Allie McComber, MPA

Young Adult (Ages 18-34)

Magellan

Facilitator:

Amar Haidar

Grupo de Mujeres de Habla Española

Coronado

Facilitator:

Frances Rivera-Pacheco

Family Planning

Columbus

Facilitator:

Genny Moore

6:00-7:00pm

Dinner/Welcome

Lindbergh Ballroom 

Dessert will be served at your table during the documentary.

7:00-7:30pm

Welcome from Hemophilia Foundation of Michigan Executive Director

Lindbergh Ballroom 

Speaker: Susan Fenters Lerch, Executive Director, Hemophilia Foundation of Michigan; Regional Director, Great Lakes Federal HTC Network

7:30-8:30pm

Dismissed Screening: Five women. One misunderstood disorder. Generations of being ignored.

Lindbergh Ballroom 

Enjoy dessert while watching a film by **Believe Limited**. *Dismissed* is a film that tells the stories of women with hemophilia who have been ignored, misdiagnosed, or left untreated for generations. At its center is 15-year-old Isabelle, a rare case who received early care and now advocates for others. Alongside her are a pregnant mother without a treatment plan, a woman confronting symptoms she's long hidden, and another left partially paralyzed after being dismissed by doctors. The film is a call to action for recognition, advocacy, and change.

Supported by Sanofi

8:40-9:30pm

Dismissed Documentary Dialogue: Insights and Reflections

Join your group (see left column) for a guided conversation following the screening of *Dismissed*. Together, we'll reflect on the stories shared in the film, explore how they resonate with our own experiences, and discuss the impact of being seen, heard, and believed within the bleeding disorders community.

Saturday, October 4

7:30am-6:00pm

Exhibitor Space Open

Pre-function Lindbergh Ballroom

7:30am-12:00pm

Registration Open

Pre-function Lindbergh Ballroom

7:30-8:00am

Breakfast

Lindbergh Ballroom and Pre-function

Lindbergh Ballroom

8:00-8:10am

Morning Welcome

Lindbergh Ballroom 

Speaker: Shari Luckey, MA, Education and Program Services Director, Hemophilia Foundation of Michigan

8:10-9:00am

Washington Update: How to Prepare for Coming Health Insurance Changes

Lindbergh Ballroom 

Johanna Gray, Federal Policy Advisor to the National Bleeding Disorders Foundation and the Hemophilia Alliance, will give an update about policy changes coming out of Washington that will impact the community. She'll share what you need to know and give actionable tips for how you can prepare for and respond to coming changes to health insurance.

Speaker: Johanna Gray, MPA, Principle, Artemis Policy Group

9:00-9:15am

Break

9:15-10:45am

Patient Panel: The Personal and Shared Journey to Diagnosis and Treatment

Lindbergh Ballroom 

Every diagnosis has a story—and every story matters. In this engaging panel discussion, individuals with bleeding disorders will share their personal paths to diagnosis, the challenges

they faced along the way, and the strategies that helped them navigate treatment decisions. Attendees will gain insight into the emotional, medical, familial, and practical realities of living with a bleeding disorder, as well as the resilience, advocacy, and community support that make a difference. This session offers a unique opportunity to learn directly from patients' lived experiences and to better understand the journey from symptoms to solutions.

Facilitator: Ann-Marie Nazzaro, PhD,

Executive Director Emerita, Foundation for Women and Girls with Blood Disorders

Panel Participants: Amar Haidar, Leader in Action Member, Lived Experience Expert

Tracye Hamler, Lived Experience Expert

Shellye Horowitz, MA, PPS, Leader in

Action Member, Lived Experience Expert

Edith Mejia, Leader in Action Member, Lived Experience Expert

Medical Advisor: Jennifer Girard, MD,

MSE Bio, Clinical Assistant Professor,

Hemophilia and Coagulation Disorders,

University of Michigan

10:45-11:00am

Break

11:00-11:50am

Educational Breakout Sessions

1 FLOW Live Recording: Chicken Soup for the FLOW: Stories of Medical Gaslighting, Extreme Bleeds, and HTCs

For Young Adult Women age 18-30
Armstrong

Join us for communal nourishment and podcast recording! FLOWsters Sarah and Jessica from FLOW: straight talk about extreme periods will host a roundtable conversation on **menstruation**. Topics will cover many of the issues facing menstruators with bleeds—such as, the question “...is the menstrual cycle ‘a bleed’?” and of course, our favorite question: @howyourflow

FLOWsters: Jessica Richmond, Believe Limited / Bloodstream Media

Sarah Watson, LPC, CST, & Sexuality Educator

Space available to those first to arrive.

Supported by Takeda

2 Coping with Anxiety and Depression

Wright A

This session provides an overview of anxiety and depression in hemophilia and strategies for coping with those issues.

Speaker: Brittany Savage, MSN,
AGPCNP-BC, Indiana Hemophilia &
Thrombosis Center

Sponsored by Novo Nordisk

3 Pre-Menopause and Menopause with Bleeding Disorders

Wright B

People with bleeding disorders face unique challenges during the transition through pre-menopause and menopause. This session provides an opportunity to discuss these experiences, share strategies and successes, and explore potential solutions.

Speaker: Jennifer Girard, MD, MSE Bio,
Clinical Assistant Professor, Hemophilia and
Coagulation Disorders, University of Michigan

4 Rare but Relevant: Living with Factor VII and XI Deficiencies

Earhart A

Factor VII and XI deficiencies may be uncommon, but for those living with them, the impact is significant. This session will feature two physicians with expertise in rare bleeding disorders, offering an in-depth look at treatment options and the unique challenges women face. Attendees will gain up-to-date medical insights along with practical strategies for advocating for their needs in healthcare settings.

Speakers: Suchitra Acharya, MD, MBBS,
Director Lifespan Hemostasis and Thrombosis
Center, Northwell Health

Meera Chitlur, MD, Director, Hemophilia
Treatment Center, Children's Hospital of
Michigan

5 Educate, Advocate and Prepare for Action

Earhart B

This is an interactive session about sharing your healthcare journey in a 3-5 minute synopsis with CONFIDENCE and then learning to state what you need from your healthcare providers. Groups of 4-5 persons will strategize solutions to scenarios on each

table topic before the instrumental music ends. Lastly, each table will compete in a dance-off game of Name That Tune!

Speaker: Connie L. Montgomery, Ret.
OTR/L, Global Patient Advocate

12:10-1:15pm

Luncheon Buffet with Topical Tables

Lindbergh Ballroom and Pre-function

Lindbergh Ballroom

Enjoy lunch while connecting with new friends or family, or, if you're interested, take a seat at the reserved tables hosted by Sanofi or Novo Nordisk. These tables feature topics especially relevant to women with hemophilia and rare factor deficiencies: "Speaking Your Truth and Why it Matters" and "Meeting the Educational Needs of Women and Girls with Hemophilia" (available in English and Spanish). Join the conversations that matter most to you—spaces where your voice is heard, your experiences are seen, and your story is believed. Look for the signs marking the designated tables and discover conversations that inspire and empower.

1:15 – 1:30pm

Lack of Data Collection for Women and Girls with Bleeding Disorders—What Can We Do?

Lindbergh Ballroom 

Dr. Kulkarni will explore the current gaps in data collection for women and girls with bleeding disorders, highlighting where women and girls are represented, where they are missing, and why these gaps matter.

Speaker: Roshni Kulkarni, MD, Professor
Emerita of Pediatrics and Human
Development, and former Director for
the Michigan State University Center for
Bleeding and Clotting Disorders

1:30-2:30pm

Iron Deficient Anemia through the Lifespan

Lindbergh Ballroom 

Iron deficiency with or without anemia is common among all women, and even more likely to affect women with bleeding disorders. In this session, Dr. Weyand will talk about why iron is important, what symptoms iron deficiency can cause, and how to diagnose and treat iron deficiency appropriately.

Speaker: Angela Weyand, MD, Associate Professor of Pediatric Hematology, Pediatric Medical Director, Hemophilia and Coagulation Disorders, University of Michigan

2:40-3:30pm

Body and Mind Breakout Sessions

located on the lower conference level, unless noted otherwise

1 Aqua Work-It-Out: Water Aerobics

Hotel Pool – 2nd Floor

Walk past the Fitness Center doors; the pool entrance is tucked just ahead.

Swimming is not required.

A fun, intense workout to improve cardio condition and toning. Improve flexibility and strength without impact. *Limited to 25 participants. Space available to those first to arrive.*

Facilitator: Cathy Thorburn, Assistant Manager, Rutherford Pool, Power Wellness

2 Restorative Yoga: Intentionality for Breath, Body, and Mind

Balboa

Join us for a yoga class that offers a gentle and accessible way for individuals of all ages and abilities to experience the benefits of yoga while staying on or near the floor while utilizing props for support. Practitioners will engage in a series of poses and movements that focus on breath and body awareness. We'll cultivate an empowering atmosphere of inner calm and relaxation with others in our bleeding disorders community.

Facilitator: Saydi Davis, LLMSW, Regional Program Manager, Hemophilia Foundation of Michigan

3 Music, Imagery, and Self Compassion

Cook

Take time for yourself in a guided music imagery session with Dr. Terra Merrill. Through sound, silence, and compassionate imagery, you'll connect with body, mind, and spirit while supporting nervous system renewal.

Facilitator: Theresa Merrill, PhD, MT-BC, Sound Living Therapy, LLC

4 Balance, Strength, and Stretch

Cortez

A full-body workout that develops strong, lean and flexible muscles through a dynamic and fluid combination of stretching and strengthening. Following a gentle pace with intentional movement, this class rebalances the body, improves posture, and unlocks tight joints leaving you feeling energized, youthful and healthy. Wonderful for those living with autoimmune diseases or joint pain and stiffness.

Facilitator: Kim Boyce, CPT, The Mix Studios

5 Reflections in Watercolor

Magellan

Step into a creative space where color, movement, and expression come together. In this watercolor session, you'll explore how art can capture feelings, stories, and perspectives that words sometimes cannot. No prior experience is needed, just an openness to experiment and let your creativity flow. This is a chance to pause, reflect, and allow your inner voice to be seen and heard through brush and water. *Limited to 36 participants. Space available to those first to arrive.*

Facilitator: Elizabeth Wilson Fischer, K-12 Art Educator, BFA Art Education and Hospitality Business

6 Speak for Yourself: Your Voice and Your Power

Coronado

A session of improvisation games and exercises to help you tell your story in an assertive, empowering, and inspiring way. *Limited to 30 participants. Space available to those first to arrive.*

Facilitator: Frances Rivera-Pacheco, Leader in Action

7 Latin Dance Cardio

Columbus

A fusion of Latin dance moves, cardio, strength, and the best Latin dance beats! No dance background needed. Work out at your own pace and have fun moving! All levels welcome, no dance background needed. *Limited to 30 participants. Space available to those first to arrive.*

Facilitator: Brooke Nimmer, LMT, PTA, CLT, CPT, The Mix Studios

3:30-4:00pm

Afternoon Snack

Lindbergh Ballroom and Pre-function

Lindbergh Ballroom

Take a moment to refresh and recharge before the afternoon sessions continue.

4:00-4:50pm

Educational Breakout Sessions

1 Hemophilia A and B: What We Know (and want to know) for Females At-Risk

Lindbergh Ballroom **2.5**

Any female who inherits a DNA change that causes hemophilia is at-risk to have low factor levels and/or excessive bleeding. Dr. Johnsen will highlight points from the scientific literature, talk about ongoing research, and present unpublished findings from ongoing research in the My Life, Our Future (MLOF) repository, followed by interactive discussion on bridging the information gap between textbooks and real-world female experiences.

Facilitator: Jill Johnsen, MD, Associate Professor, University of Washington, Washington Center for Bleeding Disorders

2 Flow Live Recording: Chicken Soup for the FLOW: Stories of Medical Gaslighting, Extreme Bleeds, and HTC's

For Adult Women age 30+

Armstrong

Join us for communal nourishment and podcast recording! FLOWsters Sarah and Jessica from FLOW: straight talk about extreme periods will host a roundtable conversation on **peri/menopause**. Topics will cover many of the issues facing menstruators with bleeds—such as the question “...is the menstrual cycle ‘a bleed’?” and of course, our favorite question: @howyourflow

FLOWsters: Jessica Richmond, Believe Limited / Bloodstream Media

Sarah Watson, LPC, CST, & Sexuality Educator

Supported by Takeda

3 Peaks, Troughs, and Everything in Between

Wright A

Join us for an educational presentation, led by a Community Relations and Education

(CoRe) Manager, designed to help you better understand and manage hemophilia A. Through this program, you will learn about the balance of hemostasis, the importance of factor activity levels, available treatment types, and the significance of pharmacokinetics (PK).

Speaker: Ashley Smith, MA, Community Relations and Education Manager (CoRe), Rare Blood Disorders, Sanofi

Sponsored by Sanofi

4 OB-GYN Care for Women with Bleeding Disorders including periods and pregnancy

Wright B

People with bleeding disorders experience unique challenges related to menstrual cycles and pregnancy. This session is an opportunity to discuss these challenges, share successes, and discuss solutions.

Speaker: Jennifer Girard, MD, MSE Bio, Clinical Assistant Professor, Hemophilia and Coagulation Disorders, University of Michigan

5 The Rare Reality: Living with Fibrinogen and Factor XIII Deficiencies

Earhart A

Fibrinogen and Factor XIII deficiencies are among the rarest bleeding disorders, yet their effects on daily life can be profound. This session will shed light on treatment approaches and the specific challenges women face. Attendees will gain up-to-date clinical insights and practical strategies for self-advocacy, helping to bridge the gap between rare condition awareness and effective care.

Speaker: Suchitra Acharya, MD, MBBS, Director Lifespan Hemostasis and Thrombosis Center, Northwell Health

6 So Much to Do, So Little Time: Reclaiming Self-Care

Earhart B

Women often carry the weight of multiple roles—professionals, caregivers, partners, and more—leaving little time for themselves. This session offers a supportive space to explore the challenges of balancing responsibilities and to share strategies for reclaiming time and energy for self-care.

Speakers: Karen Boyd, LMSW, Clinical Social Worker, Michigan State University Center for Bleeding and Clotting Disorders
Ellen Kachalsky, LMSW, ACSW, Clinical Social Worker, Hemophilia and Thrombosis Center, Henry Ford Health System
David Rushlow, LMSW, Clinical Social Worker, Northern Regional Bleeding Disorder Center, Munson Medical Center

5:00–5:50pm

Reflections: Saturday Debrief

Gather with your group to pause, reflect, and share thoughts from the day. This conversation offers a chance to process what stood out, voice personal insights, and strengthen the connections built throughout your conference experience.

Leaders in Action (LIA) Lead: Kaite Scott, LLMSW, Program Social Worker, HFM

Hemophilia A

Wright A

Facilitator:

Edith Mejia

Hemophilia A

Wright B

Facilitator:

Erica McLeod

Hemophilia B

Earhart A

Facilitator:

Pam Migliore

Hemophilia B

Earhart B

Facilitator:

Marcelle Williams,
PhD

Primetime (55+)

Armstrong

Facilitator:

Shellye Horowitz,
MA, PPS

Midlife (35-55)

Balboa

Facilitator:

Mayra Cantu, MSW

Midlife (35-55)

Cook

Facilitator:

Lisa Swaney

**Rare Factor
Deficiencies**

Cortez

Facilitator:

Allie McComber,
MPA

**Young Adult
(Ages 18–34)**

Magellan

Facilitator:

Amar Haidar

**Grupo de
Mujeres de
Habla Española**

Coronado

Facilitator:

Frances Rivera-
Pacheco

Family Planning

Columbus

Facilitator:

Genny Moore

6:00–7:00pm

Dinner Buffet

Lindbergh Ballroom and Pre-function

Lindbergh Ballroom

Dessert will be served during evening activities.

7:15–9:30pm

Evening Creative & Social Activities

The evening activities were designed and will be facilitated by the 2025 Leaders in Action Cohort.

1

Arts, Crafts, & Fun

Lindbergh Ballroom

- **Karaoke** – Want to be heard? Now is your chance! Sing by yourself or grab a friend.
- **Yarn and Yammer** – Have you always wanted to learn to crochet or knit? Join the yarn and yammer group—you are more than welcome to bring a project from home you're working on or grab an extra skein from us (limited skeins available).
- **Create Your Vision** – The Women's Conference is a fantastic environment to think about what you want your next year to look like. Make a vision board of how you see your future.
- **Hair Tinsel** – Care to have a little dazzle in your hair? Find Haley and get your sparkle on.
- **Bracelet Making** – We're in our Women's Conference Era! Make a bracelet for yourself or someone else.
- **Frame Your Memories** – Would you like a special frame to hold a photo from the conference? Come design your own and hang it up when you get home.
- **Words to Live By: Fabric Marker Craft** – Craft a design with fabric markers with a word that inspires you from the conference that you can keep throughout the year.
- **Heartfelt Messages** – Share a special message with someone from the conference—either hand it to them directly or put it in their mailbox.
- **Step and Repeat Photos** – Capture the magic of the evening with fun photos in our step-and-repeat area.

2 Social Lounge

Pre-function Lindbergh Ballroom

Relax and chat with fellow attendees in a welcoming atmosphere.

3 Relaxation & Mindful Moments

Wright A and B

- **Henna** – Amar will be using her creativity to apply unique Henna designs on a hand of your choice.
- **Self-Care Masks** – Single use face masks and hand masks available for a spa moment - treat yourself!
- **Hand Spa** – Connect with your body at the self-hand massage table—instructions and lotion provided.
- **Journaling** – Grab a journal and design the cover. Keep it for your notes from upcoming conference sessions, your overall health, or even your daily thoughts and musings.
- **Color and Connect** – Looking to zone out and connect with people at your table? Pick a page to color and join the conversation.

Sunday, October 5

7:00-8:30am

Breakfast Buffet

Lindbergh Ballroom and Pre-function
Lindbergh Ballroom

7:30-8:00am

Informational Session for Leaders in Action

Wright B

Are you eager to develop your leadership skills and serve women in the bleeding disorders community both at the conference and within your chapter? Join us for breakfast to learn about the expectations, time commitment, and support provided by HFM staff. You'll also hear insights from current committee members. Bring your questions and ideas—we're excited to connect with you!

Note: Attendance of one of the information sessions is required to apply to the 2026 cohort. If you cannot attend this in-person session, the virtual session will be October 14th at 8:00 pm EST.

Speaker: Kaite Scott, LLMSW, Program Social Worker, Hemophilia Foundation of Michigan

8:00am-12:30pm

Exhibitor Space Open

Pre-function Lindbergh Ballroom

8:20-8:30am

Morning Welcome

Lindbergh Ballroom 

Speaker: Carrie McCulloch, Development Director, Hemophilia Foundation of Michigan

8:30-9:00am

National Spotlight: Updates from NBDF, HFA, and FWGBD

Lindbergh Ballroom 

Stay in the loop with the latest news and initiatives from our national bleeding disorders organizations—National Bleeding Disorders Foundation (NBDF), Hemophilia Federation of America (HFA), and Foundation for Women and Girls with Blood Disorders (FWGBD). Learn about current programs, advocacy efforts, and upcoming opportunities to get involved, and discover how these updates can make a difference in your community.

Speakers: Meera Chitlur, MD, Director, Hemophilia Treatment Center, Children's Hospital of Michigan, Foundation for Women and Girls with Blood Disorders Board of Directors

Marc Pangilinan, Director, Health Equity & Community Engagement, Hemophilia Federation of America

Phil Gattone, MEd, President and Chief Executive Officer, National Bleeding Disorders Foundation

9:10-10:00am

Educational Breakout Sessions

1

Unlocking the Power of Genetics in a Hemophilia Treatment Center

Lindbergh Ballroom 

Uncover the strength of family history, discover how genetic testing can help guide care, and explore new genetic technology. Join Samantha as we outline our own family trees and discuss when genetic testing is most helpful throughout a patient's journey.

Additionally, we will learn about the current landscape of gene therapy and what the future may hold.

Speaker: Samantha L. Cassisi, MS, LCGC, Licensed and Certified Genetic Counselor, Michigan State University Center for Bleeding and Clotting Disorders

2 **For Young Adult Women (20s–30s): Girl, Ask Away: Unfiltered Talk on Sex, Love, and Everything in Between**

Armstrong

A candid, no-judgment session for real questions about intimacy, sex, communication, and relationships. Submit your questions anonymously and stay curious.

Speakers: Mina Nguyen-Driver, Psy.D, Arkansas Center for Bleeding Disorders
Sarah Watson, LPC, CST, & Sexuality Educator

3 **Es su turno: cómo hacer que el seguro médico funcione para usted**

Wright A

Cuando se trata de seguros de salud, hay que saber jugar bien las cartas para aprovechar al máximo su plan. En este programa, los participantes explorarán diferentes tipos de planes de seguro de salud, aprenderán a determinar la cobertura para el cuidado y tratamiento de trastornos hemorrágicos, y recibirán consejos y estrategias sobre cómo hacer que sus planes de seguro trabajen mejor para ellos. Todos se irán con un conocimiento transformador sobre seguros médicos y la confianza para navegar exitosamente sus planes.

Speaker: Amalia “Amy” Vega, DrPH, MPH, CHES, Community Relations and Education (CoRe) Manager, Sanofi

Sponsored by Sanofi

4 **Rare, Real, and Often Overlooked: Exploring Platelet Function Disorders in Women**

Wright B

Platelet function disorders including Glanzmann's Thrombasthenia, PAI-1 deficiency, and other platelet-related bleeding conditions are rare but very real—especially

for women who often experience symptoms that go unrecognized or misdiagnosed. This session will provide an overview of how platelets work, what happens when they don't function properly, and how these disorders uniquely affect women's bleeding experiences.

Speaker: Meera Chitlur, MD, Director, Hemophilia Treatment Center, Children's Hospital of Michigan

5 **Your Voice, Your Impact: Partnering in Research**

Earhart A

Your experiences matter—and by joining Community Voices in Research (CVR), you can help shape the future of the bleeding disorders community. CVR is a community-powered registry that makes it easy for you to share your story and make a real difference. In this interactive workshop, you'll learn how CVR simplifies research, connects you with useful resources, and turns your experiences into meaningful change. Plus, as a participant, you'll have access to the data collected and any presentations or publications that come from it—so you can see the impact of your voice. Together, we can improve care and create solutions that truly meet the needs of our community. Join us and be part of the change your community needs. Your voice matters!

Speaker: Maria Santaella, PhD(c), MSN, RN-BC, CPHON, Vice-President of Research Strategy, National Bleeding Disorders Foundation

6 **Pelvic Health Myths: It's Not Just Part of Being a Woman!**

Earhart B

This session will address common pelvic health concerns experienced by women from early childhood through late menopause. Too often, these issues are dismissed as simply part of being female, when in reality most can be effectively managed. Through knowledge, lifestyle modifications, and proper muscle training, participants will learn strategies that are safe and beneficial—even for those with bleeding disorders.

Speaker: Amanda Kilgore, PT, DPT, Athletic

10:10-11:00am
Educational Breakout Sessions

**1 For More Mature Women (40s+):
Still Got IT: Real Talk on Desire,
Intimacy, and Owning Your Voice**
Armstrong

Unfiltered, unapologetic, and full of heart. This is your space to ask your anonymous questions about sex, intimacy, and relationships that no one talks about (but everyone wonders) because curiosity and connection don't expire.

Speakers: Mina Nguyen-Driver, Psy.D, Arkansas Center for Bleeding Disorders
Sarah Watson, LPC, CST, & Sexuality Educator

**2 Unfiltered Me:
Collaging My Truth:
Young Women 18-34**
Wright A

Ever felt misunderstood related to your bleeding disorder? This hands-on session is your chance to take control of your story. Using collage, you'll create a powerful self-portrait that truly captures who you are, blending images and textures to represent your experiences with hemophilia or rare factor deficiencies and your life.

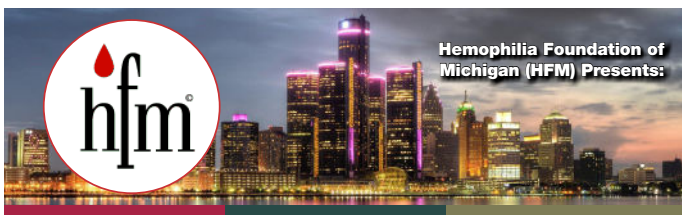
Come as you are, all materials provided—let's make some art that speaks volumes!

Speakers: Alice Cakebread, LMSW, Clinical Social Worker, Hemophilia and Coagulation Disorders, University of Michigan
Rachel Cain-Kellman, LMSW, Clinical Social Worker, Division of Hematology/ Oncology, Children's Hospital of Michigan

3 Shared Decision Making and the Shift to Person-Centered Care
Wright B

You are the lived experience expert of your bleeding disorder. And, as the lived experience expert, you are the center of your care network and a vital member of the shared decision-making process. This workshop will explore the shift towards person-centered care and outline the concepts of shared decision-making. In addition, you will gain advocacy and communications skills as well as important resources.

Speaker: Ryan Sarshuri, Education Specialist I, National Bleeding Disorders Foundation



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About Kedron Biopharma

At Kedron Biopharma, our mission is to enhance lives through our work in the field of rare and ultra-rare diseases. With a global community of 5,200 people, we are committed to collecting plasma and producing plasma-derived therapies that treat and prevent rare and debilitating conditions. In partnership with the medical and scientific community, institutions, patient advocacy groups, and research organizations, we drive sustainable innovation and improve patient care.

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4 La toma de decisiones compartida y el cambio a la atención centrada en la persona

Earhart A

Usted es el experto que ha vivido su trastorno hemorrágico o sanguíneo y/o el de su hijo/a. Y, como experto en la experiencia vivida, usted es el centro de su red asistencial y un miembro vital del proceso de la toma de decisiones compartida.

Este taller explorará el cambio hacia una atención centrada en la persona y esbozará los conceptos de la toma de decisiones compartida. Además, adquirirá habilidades de defensa y comunicación, así como importantes recursos.

Speaker: Maria Santaella, PhD(c), MSN, RN-BC, CPHON, Vice-President of Research Strategy, National Bleeding Disorders Foundation

5 More Than One Story: Exploring Joint Health in Hemophilia, Hypermobility, and Beyond

Earhart B

Sorting out the cause of joint pain can be challenging—especially when you have a bleeding disorder, hypermobility, or other conditions that impact joint health. Join this session for an interactive discussion about joint health and joint pain. A physical therapist and hematologist will facilitate this open conversation.

Speakers: Jennifer Girard, MD, MSE Bio, Clinical Assistant Professor, Hemophilia and Coagulation Disorders, University of Michigan

Sherry Herman-Hilker, PT, MS, Physical Therapist, Hemophilia and Coagulation Disorders, University of Michigan

11:10am-12:00pm

Closing Reflections: Looking Back, Moving Forward

As the weekend comes to a close, join your group one last time to reflect on your experience, share takeaways, and honor the connections made. This is a space to celebrate your voice, acknowledge growth, and carry the weekend's insights with you beyond the conference.

Leaders in Action (LIA) Lead: Kaite Scott, LLMSW, Program Social Worker, HFM

Hemophilia A

Wright A

Facilitator:

Edith Mejia

Midlife (35-55)

Cook

Facilitator:

Lisa Swaney

Hemophilia A

Wright B

Facilitator:

Erica McLeod

Rare Factor Deficiencies

Cortez

Facilitator:

Allie McComber, MPA

Hemophilia B

Earhart A

Facilitator:

Pam Migliore

Young Adult (Ages 18–34)

Magellan

Facilitator:

Amar Haidar

Hemophilia B

Earhart B

Facilitator:

Marcelle Williams, PhD

Grupo de Mujeres de Habla Española

Coronado

Facilitator:

Frances Rivera-Pacheco

Primetime (55+)

Armstrong

Facilitator:

Shellye Horowitz, MA, PPS

Family Planning

Columbus

Facilitator:

Genny Moore

Midlife (35-55)

Balboa

Facilitator:

Mayra Cantu, MSW

12:10-1:00pm

Celebration Lunch & Evaluations

Pre-function Lindbergh Ballroom and Lindbergh Ballroom 

Join us for a closing lunch buffet as we come together one last time to celebrate our time together and provide feedback to help shape future conferences.

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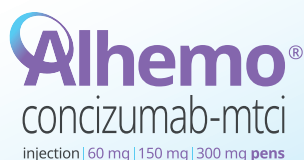


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February 2025

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We are very pleased to welcome our industry sponsors as true partners in this weekend's conference. Each sponsor is making a unique contribution to the success of the conference by setting a tone of support, respect, education, and understanding. We encourage you to visit each of the sponsor display tables and to take the many opportunities available this weekend to learn more about each company and their commitment to the hemophilia and rare factor deficiencies community. We invited our industry sponsors to share a few words with you about who they are.

Genentech

Genentech is committed to advancing all aspects of life with hemophilia A, starting with patient care. We strive to provide Treatment for All who need it, including underserved communities around the globe. We Support the Person through education, resources, and tools designed to help individuals thrive throughout their treatment journey. We Connect the Community through active engagements that help bring these individuals together to learn and grow.

Kedrion Biopharma

At Kedrion Biopharma, our mission is to enhance lives through our work in the field of rare and ultra-rare diseases. With a global community of 5,200 people, we are committed to collecting plasma and producing plasma-derived therapies that treat and prevent rare and debilitating conditions. In partnership with the medical and scientific community, institutions, patient advocacy groups, and research organizations, we drive sustainable innovation and improve patient care.

Novo Nordisk

Our Philosophy

At Novo Nordisk, with each new treatment we develop, and every new patient we meet, we are expanding our commitment to helping people live better lives. Together with patients and the people who care for them, we are working toward bigger goals and visions for our world, and with any new advancement comes the question, What's next? For more than three decades, one of our main focuses has been Changing Hemophilia®. We are changing how people with hemophilia A and B, acquired hemophilia, factor FXIII deficiency, Factor VII deficiency, Glanzmann thrombasthenia, and congenital hemophilia with inhibitors, live and how health care providers understand these conditions.

Pfizer

The Pfizer focus on rare disease builds on more than two decades of experience, a dedicated research unit focusing on rare disease, and a global portfolio of multiple medicines within a number of disease areas of focus, including rare hematologic, neurologic, cardiac and inherited metabolic disorders. Pfizer Rare Disease combines pioneering science and deep understanding of how diseases work with insights from innovative strategic collaborations with academic researchers, patients, and other companies to deliver transformative treatments and solutions.

Sanofi

At Sanofi, treating rare blood disorders isn't just what we do—it's who we are. Because rare is in our blood. It's why we strive to make a difference in the lives of patients, caregivers, and physicians. It's why we pursue the best possible therapies, services, and resources. Why we research, develop, and discover groundbreaking advancements. Why we use our global scale to create a true, lasting difference. From pipeline to patients, we know that our commitment has the potential to truly transform. To shift the trajectory. To change lives.

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WITH GRATITUDE

THANK YOU TO ALL OUR AMAZING SPEAKERS AND VOLUNTEERS FOR THEIR TIME AND ENERGY IN HELPING TO MAKE THIS A UNIQUE EXPERIENCE AND TO OUR SPONSORS FOR THEIR SUPPORT AND COMMITMENT TO THE COMMUNITY.

WE'D LIKE TO EXPRESS OUR APPRECIATION TO OUR EXCEPTIONAL CONTENT ADVISORS:

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Marcelle Williams, PhD

APPRECIATION TO THE HFM DREAM TEAM!

Heartfelt thanks to this incredible team. Your commitment, talent, and teamwork brought this event to life—thank you for everything!

Dana Brendecke-Carrier: Data Dynamo
Sharon Ceci: Chief Coin Commander
Meghan Mair Crosslin: Messaging Maestro
Saydi Davis: Zen Guide Extraordinaire
Ariana Herrera-Wilder: Right-Hand Rockstar
Gwyn Hulswit: Second-in-Command Superstar
Dave Kaumeyer: Guardian of the Green
Angellica “Gelli” Kelley: Young Adult Champion
Susan Fenters Lerch: Visionary-in-Chief
Shari Luckey: Madam Maestro
Carrie McCulloch: Connections Conductor
Travis Miller: Tech Sidekick Extraordinaire
Shawna Norris: Travel & Hospitality Legend
Zach Ryan: Signage & Support Superstar
Kaite Scott: Empowerment Enthusiast
Travis Tussing: Legal Eagle & Tech Assistant
Tim Wicks: Tech Titan

SPECIAL THANKS TO:

Angie Shaw of ASK Travel Services for coordinating all of our travel!



YOUR FEEDBACK MATTERS!

**PLEASE HELP US IMPROVE BY
EVALUATING OUR CONFERENCE,
SESSIONS, AND SPEAKERS.**

A link to the online conference evaluation will be
provided to all attendees on Sunday, October 5.



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The Hemophilia Foundation of Michigan (HFM) exists to enhance
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