hfm©

2022 HFM WOMEN AND TEEN GIRLS CONFERENCE

FOR THOSE LIVING WITH HEMOPHILIA AND RARE FACTOR DEFICIENCIES

October 7 – 9


Left, Susan Fenters Lerch and right, Patrice Thomas

Dear Friends,

We are thrilled to have so many extraordinary women participate with the Hemophilia Foundation of Michigan's (HFM) fifth annual National Conference for Women and Teens with Hemophilia and Rare Factor Deficiencies. We understand that COVID still affects the health of our communities and may be a barrier to attendance. We have provided two paths for participation this year: virtual and in-person. While we expect the majority of us will be physically together, we will not forget those joining virtually, and will include our virtual participants in the proceedings as much as possible.

We are overjoyed to provide this specialized conference for women to reconnect with past acquaintances, while welcoming and embracing new participants. As always, we expect to offer exceptional learning, connection, celebration, and support.

We appreciate each person's flexibility during this 2022 hybrid conference experience as we utilize our online platform to bring together attendees and speakers in new and unique ways.

We ask everyone to keep in mind the importance of kindness and patience as well as curiosity and participation. We remain grateful to our medical, psychosocial, and organizational colleagues who are generously donating their expertise and time to come together for this important conference. Our HFM team is meeting many challenges this year and will continue our ongoing commitment to bring to you an engaging and educational conference. Together, we are making every effort to assure that participants, speakers, sponsors, and supporters have an authentic and uplifting experience. Please know we remain committed to each of you; those who live in our beautiful home state of Michigan, our region, across the country, as well as those from other countries.

Thank you to conference participants, HFM colleagues, presenters, sponsors, and supporters. It is our sincere desire that each of us will find HFM's 2022 National Conference for Women and Teen Girls empowering and a time of true community.

With admiration,

Susan Fenters Lerch
HFM Executive Director
Great Lakes Region V-E HTC
Network Regional Director

Patrice Thomas

Patrice Thomas, MSW, MS
HFM Program Services Director

PS Virtual attendees – Your link to enter our virtual platform will be emailed to you by **Wednesday, October 5.**

CONFERENCE GUIDELINES

Welcome to the fifth annual National Conference for Women and Teens with Hemophilia and Rare Factor Deficiencies. HFM staff and our ad hoc conference planning group hope for a weekend filled with constructive social interaction, education, and camaraderie. In this spirit, we appreciate everyone participating in activities to demonstrate respect for different opinions and methods of self-care. Due to national public health issues related to COVID-19, we have chosen to put on a hybrid conference this year. Since some of our attendees and speakers will be at home in front of their computers, we cannot guarantee confidentiality of the conversations that take place during the conference. We do hope that everyone is mindful of screen and audio sharing with others while they are engaged in the conference. Please keep this in mind when sharing personal information with others verbally or written.

We recognize that there may be some attendees this weekend who work with a home care company or with a related industry company. If this is the case for you, your participation this weekend is expected to be solely as a consumer. Attendees may not solicit the involvement of other attendees in future programs or services.

If you would like to have your company represented as a sponsor in a future women's conference, please talk with a member of the HFM staff.

We invite you to visit our industry sponsors throughout the conference. It is thanks to their generous support that we are able to host this event.

During the conference, attendees have the right to determine whether to share personal information in large group sessions where industry partners may be present as well as how they share their name in the attendee section. If you wish to continue the conversation with any of our industry sponsors after the weekend, you are free to share your contact information, however you are under no obligation to do so. We honor your right to privacy. While you may choose to share whatever information you are comfortable with, industry reps will not specifically ask you about your personal medical history, treatment, or bleeding disorder. Industry reps will not offer medical advice as this is a conversation that should take place between you and your healthcare team. If at any time you feel unduly pressured to provide personal information, please inform a member of the HFM staff immediately.

We believe that this weekend is an opportunity to share and receive information and education in the way that is most beneficial and comfortable for you.

IN-PERSON COVID POLICY

Women's Conference in-person activities require proof of COVID vaccinations. HFM reserves the right to require mandatory face masks for all attendees.

AGENDA

ALL TIMES ARE EASTERN TIME. ALL SESSIONS HELD IN THE LINDBERGH BALLROOM WILL BE BROADCASTED TO OUR VIRTUAL ATTENDEES THROUGH WEBEX AND TRANSLATED IN SPANISH. WE INVITE YOU TO VISIT OUR INDUSTRY SPONSORS FOR INFORMATION AND RESOURCES THROUGHOUT THE DAY, INCLUDING BREAKS BETWEEN SESSIONS.

ES Spanish translation available
🖥 Accessible virtually

Friday, October 7

3:00pm
Registration Begins and Exhibitor Space Opens
Pre-function Lindbergh Ballroom

4:00-6:00pm
Welcome Reception with light appetizers and beverages
Pre-function Lindbergh Ballroom

6:00-7:00pm
Buffet Dinner
Lindbergh Ballroom

6:40-6:55pm
Welcome
Lindbergh Ballroom ES 🖥
Opening Speaker: Susan Fenters Lerch, Executive Director, Hemophilia Foundation of Michigan; Regional Director, Great Lakes Federal HTC Network

6:55-7:00pm

Sponsor Notes

Lindbergh Ballroom ES 💻

7:00-8:00pm

Conference Kickoff

Lindbergh Ballroom ES 💻

The group will be led through fun activities so we can get to know each other a little better and set the tone of inclusivity for the weekend.

Facilitators: Haelynne Barron, Program Director, GutMonkey

Margaret Bridges, Program Manager, GutMonkey

Session sponsored by Pfizer

8:00-9:00pm

Soul Broken: A Guidebook for Your Journey Through Ambiguous Grief

Lindbergh Ballroom ES 💻

Ms. Sarazin will speak about the concepts of ambiguous grief and how this relates to many aspects of our everyday lives.

Speaker: Stephanie Sarazin, Author

9:00–10:00pm

Mix & Mingle and Desserts

Lindbergh Ballroom and Pre-function Lindbergh Ballroom

Saturday, October 8

7:30am

Exhibitor Space Opens

Pre-function Lindbergh Ballroom

7:30-9:00am

Breakfast Buffet

Pre-function Lindbergh Ballroom and Lindbergh Ballroom

8:15-8:55am

GutMonkey Check-In

Lindbergh Ballroom ES 💻

Facilitators: Haelynne Barron, Program Director, GutMonkey

Margaret Bridges, Program Manager, GutMonkey

9:00-10:30am

Health Equity and Access to Care for Women and Girls with Hemophilia

Lindbergh Ballroom ES 💻

There are many healthcare providers and people in the bleeding disorders community who are concerned about how access to health care will change given the recent Supreme Court decision on abortion. This session will explore what we mean by access to care and how barriers to care intersect with health equity.

Speakers: Miriam Goldstein, JD, Policy Director and Principal Legal Counsel, Hemophilia Federation of America, Washington, D.C.

Magdelena Lewandowska, MD, Adult Hematologist, Indiana Hemophilia and Thrombosis Center, Indianapolis, IN

Shaveta Malik, MD, Obstetrics and Gynecology, Buffalo, NY

Keri Norris, PhD, MPH, MCHES, Director of Diversity, National Hemophilia Foundation, Atlanta, GA

Moderator: Ann-Marie Nazzaro, PhD, Director Emeritus, Foundation for Women and Girls with Blood Disorders, New Jersey

10:30-10:45am

Break

10:45-11:45am

Educational Breakout Sessions

1 Aging with a Bleeding Disorder

Lindbergh Ballroom ES 💻

As we age our bodies and our medical needs change. Individuals with a bleeding disorder are presented with unique aging challenges. This workshop will explore common medical challenges that accompany the aging process related to cardiovascular and bone health, and bleeding risk.

Speaker: Angela Lambing, MSN, ANP, GNP, Independent Consultant

Session sponsored by the Hemophilia Federation of America

2

Joint Health and Hypermobility

Earhart A

The diagnosis and treatment of joint hypermobility has been expanding in the past decade. Some women with hemophilia and other rare bleeding disorders may also have hypermobility. For many people it can be enlightening to realize that abnormalities in their connective tissue can help to explain some of their seemingly unique symptoms.

In this breakout session, we will present a brief review of the diagnosis of joint hypermobility, how to recognize it, and the role of a physical therapist in identifying and managing this condition. We will discuss the general structure of an effective exercise program for widespread joint hypermobility and some helpful concepts related to a gradual return to exercise and activity. Join Dave—who has many years of experience working with people with hypermobility and Sherry—a specialist in bleeding disorders as they share a bit of their background and facilitate a lively and interactive discussion with participants

Speakers: Sherry Herman-Hilker, PT, MS, Physical Therapist, Hemophilia Treatment Center, University of Michigan, Ann Arbor, Michigan

David Johnson, PT, MS, Physical Therapist, Michigan Medicine MedRehab, Ann Arbor, Michigan

3

Community Counts Project: Why it matters to the bleeding disorders community

Earhart B

Community Counts (CC) is a public health monitoring program funded by CDC's Division of Blood Disorders. The purpose of this project is to gather and share information about common health issues, medical complications, and causes of death that affect people with bleeding disorders cared for in US hemophilia treatment centers (HTCs).

This session will review how information is gathered for the project and discuss what has been learned. The audience will be invited to share their ideas and give input on how to improve participation and provide feedback on what would make the project more impactful to women in the bleeding disorder community.

Speaker: Skye Peltier, MPH, PA-C, Director, Public Health Programs and Surveillance - Community Counts, American Thrombosis and Hemostasis Network

4

Q & A: Reproductive Health Discussion for Teens and Young Adults

Wright A

Have questions or concerns about menstruation and heavy bleeding? Not sure what the various options are for addressing heavy bleeding? Will taking hormonal therapy cause delays with conception later on? This session is the place to have those conversations plus more!

Speakers: Cynthia Sabo, CPNP, Nurse Practitioner, Detroit Medical Center

Charity Stadler, RN, BSN, Nurse Coordinator, Detroit Medical Center

5

Expect the Unexpected: Prepare for Anything

Wright B

Emergency room staff, including physicians, may have little experience in the management of patients with bleeding disorders because they are rare conditions. This presentation will help you avoid and prepare for a possible trip to the ER, anytime, anywhere—even when traveling or during a natural disaster.

Speaker: Lisa Horstman, RN, BSN, Takeda

Session sponsored by Takeda

11:45-12:00pm

Break

12:00-1:10pm

Lunch Buffet with Topical Tables

Pre-function Lindbergh Ballroom and Lindbergh Ballroom

Enjoy sharing your lunch with new friends or family members; you are also welcome to join industry sponsor representatives at their reserved tables in the ballroom to discuss relevant topics to women with hemophilia and rare factor deficiencies. Topics for these tables will be shared ahead of time so you can participate in the discussion and learn from others.

1:15–3:30pm

Young Adult Session with Corner Health Youth Leaders

Armstrong Room

This afternoon session is open to teens and young adults (ages 24 and under). The Youth Leadership Council and staff from the Corner Health Center in Ypsilanti, MI will join us for an afternoon of engaging activities and conversation while we explore the challenges of growing up with a bleeding disorder. Attendees will have the opportunity to connect with peers who may share similar experiences, discuss how isolation can impact our mental health, and learn new skills for coping with life's challenges.

Speakers: Corner Health Youth Leaders and Staff

1:10-1:15pm

Sponsor Notes

Lindbergh Ballroom ES 👤

1:15–2:15pm

Barriers to Diagnosis: Women and X-Linked Disorders

Lindbergh Ballroom ES 👤

This presentation is designed for women with X-linked genetic disorders, healthcare providers, and caregivers. We will discuss challenges and barriers to care as well as provide an explanation of women and manifestation of symptoms of X-linked disorders. There will also be time for Q&A at the end.

Speaker: Dr. Rebecca Spencer, MD, PhD, Anesthesiologist, Concord Hospital, Concord, New Hampshire

2:15-2:30pm

Break

2:30-3:30pm

Educational Breakout Sessions

1

Rare Factor Deficiencies Update

Lindbergh Ballroom ES 👤

Dr. Davis will discuss best practices related to diagnosis and treatment of rare factor deficiencies and answer attendee questions.

Speaker: Joanna Davis, MD, Medical Director, Pediatric Comprehensive Hemophilia Treatment Center, University of Miami, Miami, FL

2

Pelvic Health: More than "Bikini Medicine"

Earhart A

We often talk about heavy menstruation and reproductive issues in people with bleeding disorders, but we seldomly discuss the impact on the musculoskeletal system. This session will take a deeper dive into the topic of pelvic health through the physical therapy lens. We will explore the anatomy and functionality of the female pelvic region as well as discuss pelvic floor dysfunctions, while highlighting the innovative ways physical therapy can improve your quality of life.

Speaker: Lena Volland, DPT, Director of Education, National Hemophilia Foundation

3

Processing the Continued Impact of 3H (or HHH)

Earhart B

3H refers to those affected by hemophilia, hepatitis C and/or HIV due to the tainted blood crisis in the 1980s. This includes those living with hemophilia and hepatitis/HIV or relatives of those affected by hemophilia and hepatitis/HIV. This is a space to talk about loved ones and to process the impact of 3H on individuals, families, and the community.

Facilitator: Shellye Horowitz, MA, Associate Director of Education, Hemophilia Federation of America, Trinidad, CA

4

Pain Matters

Wright A

Pain can affect everyday life for people with hemophilia. Learn about pain management options and tools to help talk about pain with health care providers.

Speaker: Jonathan C. Roberts, MD, Associate Medical Director and Associate Research Director, Bleeding & Clotting Disorders Institute (BCDI); Assistant Professor of Pediatrics, University of Illinois College of Medicine at Peoria, Peoria, IL

Session sponsored by Novo Nordisk

3:30-3:45pm

Break

3:45-4:45pm

Uterine Challenges and Gynecological Care

Lindbergh Ballroom ES 👤

This session will provide an overview of uterine challenges, including endometriosis and fibroids. We will discuss the complexity of identifying and treating bleeding of the uterus in persons with bleeding disorders. The session will also discuss when to seek care from a gynecologist and how to coordinate care with your bleeding disorder provider.

Speakers: Laura Gusba, CNP, MSN, Nurse Practitioner, Hemophilia Treatment Center and Benign Hematology, Henry Ford Hospital, Detroit, MI

Andrea Lausman, MD, Maternal-Fetal Medicine Specialist, St. Michael's Hospital, Toronto, Canada

Michelle Sholzberg, MD, Division Head of Hematology-Oncology and Medical Director of the Coagulation Laboratory, St. Michael's Hospital, Toronto, Canada

4:45-5:30pm

Break

5:30–7:00pm

Dinner Buffet

Pre-function Lindbergh Ballroom

6:45-6:55pm

Introduction to Evening Activities

Lindbergh Ballroom ES 👤

6:55-7:00pm

Sponsor Notes

Lindbergh Ballroom ES 👤

7:00-9:00pm

Evening Activities

1 Intergenerational Storytelling Workshop

Lindbergh Ballroom ES 👤

This interactive workshop will bring together individuals of all ages and backgrounds for an opportunity to build community and collaboration across multiple generations. Participants will discover the power of storytelling and how sharing one's story can help raise awareness, challenge harmful stigmas, and advocate for resources and quality care. We'll work through how to select, develop, structure, tell and practice an impactful story. Participants will also explore the value of listening and the strength that is built by fostering connections with other individuals within the bleeding disorders community.

Speakers: Adela Nieves Martinez and Diana Seales

2 Game Night

Wright A and B

Relax with others while chatting and playing a variety of games: cards, board games or Pictionary—your choice!

Sunday, October 9

8:00am

Exhibitor Space Opens

Pre-function Lindbergh Ballroom

7:30-9:00am

Breakfast Buffet

Pre-function Lindbergh Ballroom and Lindbergh Ballroom

8:55-9:00am

Sponsor Notes

Lindbergh Ballroom ES 👤

9:00-10:00am

National Update: News about Women and Girls with Bleeding Disorders

Lindbergh Ballroom ES 👤

Our national bleeding disorders organizations, Hemophilia Federation of America (HFA) and the National Hemophilia Foundation (NHF), will present summaries of their recent outreach activities in a panel to women and girls and plans for future projects.

Speakers: Rose Bender, Patient Representative, Medical and Scientific Advisory Council (MASAC), NHF

Amy Dunn, MD, Director of Pediatric Hematology, Nationwide Children's Hospital, Columbus, Ohio, NHF MASAC Chair

Jeanette Jones, MEd, Program Manager, HFA

Natalia Winberry, MNLM, Manager of Education, NHF

10:00-10:15am

Break

10:15-11:15am

Educational Breakout Sessions

1

Wonder Woman: Debunking the Myth that Women Have to Take Care of Everything

Lindbergh Ballroom ES 👤

Are you the family's CEO, administrative assistant, social organizer, housekeeper, Uber driver, child referee, and caregiver? In the United States, women comprise nearly half of the workforce, yet a significant amount of household responsibilities are shouldered by women. Women do an amazing job at caring for others, but sometimes get so caught up caring for others that they have lost sight of themselves. Attend this session to discover strategies to take care of yourself, feel empowered, and renew your spirit.

Speaker: Mina Nguyen-Driver, PsyD, Pediatric Psychologist, University of Arkansas for Medical Sciences, Fayetteville, AR

2

What Do We Do with Leftovers from Grief?

Earhart A

During this weekend we have learned we can experience grief on many levels in our lives. These experiences of grief can create lingering feelings and thoughts—some pleasant and some filled with pain and sorrow. For others it may awaken the impact of uncovered feelings and thoughts that came to light this weekend.

This highly interactive session will provide the opportunity to share your feelings and thoughts related to your experience with grief. We will share with each other in a supportive manner the experiences of this weekend as you now wonder, what do I do?

Two experienced hemophilia treatment center social workers will be on hand to facilitate this most important conversation.

Speakers: Karen Boyd, LMSW, Clinical Social Worker, Michigan State University Center for Bleeding and Clotting Disorders
Dave Rushlow, LMSW, Program Manager, Bleeding Disorder Center, Munson Medical Center, Traverse City, MI

3

CoRe Conversation: Parenting with a Chronic Condition

Wright A

Parenting is challenging. And it becomes even more complicated with a bleeding disorder in the mix. For parents with a bleeding disorder, there are unique challenges that can directly impact family life. You may have a lot of questions, such as: How do I talk to my kids about my condition? Is my partner feeling overwhelmed? What if a bleed interferes with our daily routine? We developed this program so that parents—and expecting parents—can talk about the issues they face in a supportive and encouraging environment.

Speaker: Rebecca Gorde, MSW, BSN, RN, Community Relations & Education Manager, MI & IN Rare Blood Disorders, Sanofi

Session sponsored by Sanofi

4

Gene Therapy in Hemophilia B

Wright B

This talk will review a brief overview of hemophilia and its history along with the evolution of treatment and treatment approaches. Focusing on the unmet needs of people with hemophilia (PwH), we will explore the potential of gene therapy and how it may advance the landscape of Hemophilia B treatment including research on a virus-mediated gene therapy that is being studied.

Speaker: Rhonda Fritz, MSN, CPNP, Medical Affairs, Coagulation, CSL Behring

Session sponsored by CSL Behring

11:15-11:30am

Break

11:30-12:00pm

Farewell to conference attendees, evaluation, and lunch to go

Pre-function Lindbergh Ballroom and Lindbergh Ballroom ES 👤

Biotherapies for Life®

CSL Behring

Proud to serve the bleeding disorders community with the latest technologies, innovative therapies and support.

For additional information please contact:
Lauren Hecht MA, LLP
Senior Manager Coagulation Products
248-310-0202
Lauren.Hecht@CSLBehring.com

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INDUSTRY SPONSORS

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 OR THE ONLINE SPONSOR PAGES, 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.

CSL Behring

Starting a century ago, CSL Behring made a promise to save lives and protect the health of people. Today, that same promise has never been stronger. A global leader in the biotherapeutics industry, CSL Behring is passionate about improving the quality of patients' lives and remains committed to the global bleeding disorders community. CSL Behring manufactures and makes a range of recombinant and plasma-derived products for the treatment of Hemophilia, von Willebrand Disease and other bleeding disorders. We are proud to be able to sponsor chapter programs such as HFM's National Conference for Women with Hemophilia and Rare Factor Deficiencies. For more information, please visit **www.cslbehring.com**.

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.

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 do everything we can 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 power to truly transform. To shift the trajectory. To change lives.

Takeda

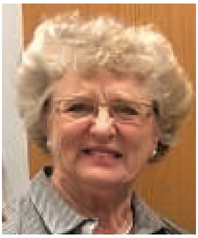
For over 70 years, Takeda has been committed to the bleeding disorders community. You have trusted us to provide support and education along your journey. As the road ahead evolves, we will continue to work with and for you, focusing on advancing treatments for today and innovating for tomorrow.

Haelynne Barron, Program Director, GutMonkey

Haelynne (they/she) believes that genuine human connection and play are catalysts for positive change. They are a committed practitioner of active fun and saying yes to a challenge. After earning a degree in elementary education from the University of Portland they spent eight years in the professional camping field, and seven years teaching yoga and movement practices. Haelynne is passionate about access and equity, especially in health care, and believes that experiential learning environments are an essential piece of this work. They are honored to be a part of the GutMonkey team and to share space with the bleeding disorders community.

Rose Bender, Patient Representative, Medical and Scientific Advisory Council (MASAC), National Hemophilia Foundation

Rose is a woman living with hemophilia A, who is very excited to join the women's conference this weekend! She graduated in 2019 from Yale with her bachelor's degree in biomedical engineering, and most recently, she graduated in 2022 from the University of Washington with a Master of Science in Health Metrics Sciences. She is one of the newest members of MASAC and is so excited to be representing women with hemophilia in the scientific decision-making arm of NHF. In her spare time, Rose enjoys hiking, biking, running, and cooking new recipes from many different cultures. Currently, she is a first year medical student at Yale University, looking forward to learning all about the best ways to care for patients.



Karen Boyd, LMSW, Clinical Social Worker, Michigan State University Center for Bleeding and Clotting Disorders

Karen Boyd is a licensed clinical social worker and has been privileged to work with the bleeding disorders community for over 17 years. She was instrumental in creating retreats for men, women, couples, and families to learn more about their disorder. Karen has conducted research focusing on children with chronic illness and its impact on the family. She has been involved in conducting research for the National Impact Quality of Life on Pain Study in conjunction with sponsoring treatment centers. As a therapist, she is privileged to work with families and adults who are impacted by a chronic health condition. Karen's priority in working with the bleeding disorder community is facilitating collaboration between consumers and providers and enhancing intimate relationships. When away from her busy professional life, Karen enjoys a delicious cup of coffee, ballroom dancing, gardening, entertaining, and travel.

Margaret Bridges, Program Manager, GutMonkey

Margaret (she/her) is a program manager with GutMonkey. She believes in exploring the intersection of creativity and people's connection with themselves, their communities, and our earth. She has facilitated programs globally in youth development, women's leadership, arts and community engagement, and experiential programming. After graduating from Carnegie Mellon University in Pittsburgh, she served with the Peace Corps in Morocco, earned her graduate degree from UT Austin, and has worked with organizations from Texas to Wisconsin and everywhere in between. She's excited to be a part of HFM's National Conference for Women and Teens to further explore equitable and innovative access to healthcare.

Joanna Davis, MD, Medical Director, Pediatric Comprehensive Hemophilia Treatment Center, University of Miami, Miami, FL

Dr. Joanna Davis received her undergraduate degree from Barnard College of Columbia University and attended the Albert Einstein College of Medicine in New York. Dr. Davis did her pediatric internship and residency at the Children's Hospital at Montefiore in the Bronx and completed her general training at Jackson Memorial Medical Center in Miami. She completed a fellowship in pediatric hematology/oncology at Jackson Memorial Hospital and joined the faculty of the University of Miami in

1984. Dr. Davis started the Pediatric Hemophilia Treatment Center (HTC) in 1987, at a time when there were only 6 patients enrolled. Today the UM HTC is the only federally-funded combined pediatric and adult HTC in South Florida, serving over 400 patients through the life spectrum who have been diagnosed with a variety of bleeding and clotting disorders. Patient and provider education and outreach have been a cornerstone of the mission for the HTC. Nationally recognized patient programs, publications, and research projects have been and continue to be developed. The HTC sponsors several projects utilizing point-of-care ultrasound. Robust personalized physical therapy initiatives as well as psychosocial counseling are unique aspects of our commitment to comprehensive care.

Amy Dunn, MD, Director of Pediatric Hematology, Nationwide Children's Hospital, Columbus, Ohio, NHF MASAC Chair

Amy Dunn, MD, received her medical degree from Wright State University School of Medicine and completed her pediatric hematology/oncology training at Emory University in Atlanta. She is an Associate Professor of Pediatrics at Nationwide Children's Hospital/Ohio State University where she serves as Director of Pediatric Hematology and directs the HTC. Dr. Dunn is involved with numerous professional associations, has published multiple articles, abstracts, and textbook chapters, as well as provided a myriad of presentations nationally and internationally. She was recently named Chair of NHF's Medical & Scientific Advisory Council. She and her husband enjoy travel and scuba diving.

Rhonda Fritz, MSN, CPNP, Medical Affairs, Coagulation, CSL Behring

Rhonda has over 30 years experience in the bleeding disorders community. Rhonda spent 23 years as a nurse at Boston Children's Hospital, 13 of those as a Hemophilia Nurse Practitioner at the Boston Hemophilia Center where, in addition to the hemophilia program, she was involved in educational initiatives on a local and national level. Rhonda has also served as Chair of the National Hemophilia Foundation Nursing Working Group. For the past 11 years Rhonda has worked in Medical Affairs in industry with a focus on bleeding disorders and gene therapy. She is presently a member of the Medical Affairs team at CSL Behring.

Miram Goldstein, JD, Policy Director and Principal Legal Counsel, Hemophilia Federation of America, Washington, DC

Miriam Goldstein is the policy director and principal legal counsel at the Hemophilia Federation of America. Miriam's work includes monitoring and analyzing federal legislation and policies impacting patient access to care; insurance, Medicaid, and Medicare issues; blood and pharmaceutical safety; and more. Miriam also works with HFA member organizations on state advocacy and policy initiatives. Miriam lives in Arlington, Virginia, and is the mother of two adult sons with hemophilia.

Rebecca Gorde, MSW, BSN, RN, Community Relations and Education (CoRe) Manager, Sanofi

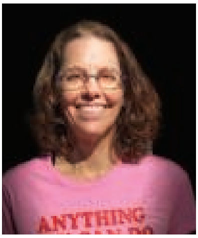
Throughout her career, Rebecca has dedicated herself to empowering individuals and families through challenging times and encouraging them to live their best lives. Whether she's traveling, volunteering, or learning a new skill, Rebecca loves experiencing other cultures, finding interesting adventures, and meeting new people.

Laura Gusba, CNP, MSN, Nurse Practitioner, Hemophilia Treatment Center and Benign Hematology, Henry Ford Hospital

Laura is a native of Michigan and has many nurses in her family. She married and moved to Windsor, Canada completing her BSN at the University of Windsor and then went on to earn her master's degree. She has been working at Henry Ford Hospital since 1994 and spent most of her career working in labor and delivery and women's health. In 2015, she took on the challenge of learning something new, and joined the team at the Henry Ford Hemophilia Treatment Center and the Hematology Division at Henry Ford. She really enjoys when she gets to combine her two career interests, women's care and bleeding disorders!

Sherry Herman-Hilker, PT, MS, Physical Therapist, Hemophilia Treatment Center, University of Michigan, Ann Arbor, MI

Sherry is a physical therapist at the University of Michigan Medical Center where she has worked since 1989 primarily in pediatrics. She began her role as the physical therapist in the University of Michigan Hemophilia Treatment Center 25 years ago. Sherry loves the challenge of the ever-changing world of care for people with bleeding disorders. Most recently she has developed an interest in the recognition and care of patients with hypermobility or connective tissue disorders in the context of the hemophilia treatment center. She is currently striving to understand their unique needs and to clarify her role in participating in their management and optimizing their care. Sherry provides physical therapy support to both pediatric and adult bleeding disorders clinics.

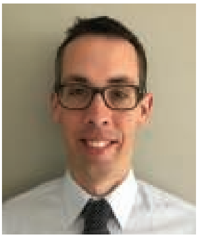


Shellye Horowitz, MA, Associate Director of Education, Hemophilia Federation of America

Shellye Horowitz was a high school counselor and teen workshop leader and has been in the field of education for over 25 years. During her career she has worked as a principal and as a school counselor at every level from preschool through high school. Shellye has strong ties to the bleeding disorders community with five traceable generations of hemophilia in her family.

Lisa Horstman, RN, BSN, Takeda

Lisa is a Community Education Specialist at Takeda Pharmaceuticals covering Ohio and Michigan. She has over 34 years' experience as a RN and 6 years' experience in the bleeding disorders community.

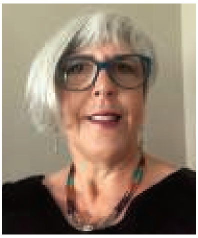


David Johnson, PT, MS, Physical Therapist, Michigan Medicine MedRehab, Ann Arbor, MI

Dave is a physical therapist working at the Michigan Medicine MedRehab Briarwood clinic. He treats general orthopedic patients with an emphasis on progressive strength training and targeted manual therapy. Specialty areas include the treatment of patients with hypermobility, chronic pain patients, and patients with hip and shoulder pathologies. He is a member of the clinical faculty for the Michigan Medicine Orthopedic Physical Therapy Residency. He instructs the residents in pain science and evaluation and treatment of hip and lumbopelvic diagnoses. He graduated from PT school at the University of Minnesota in 2001 and has been practicing as a PT since that time. Prior presentations on the state and national level have been on topics related to chronic pain and joint hypermobility.

Jeannette Jones, Program Manager, Hemophilia Federation of America

Jeanette lives in somewhat rural Oklahoma with her husband, two children, and two dogs. Jeanette has a rare bleeding disorder and has been involved with the community since 2011. She studied religious education and missions at Oklahoma Christian University. She has a master's degree from the University of Central Oklahoma in linguistic and English education which was the focus of her career. Jeanette worked with her local bleeding disorders chapter as communications director for more than two years and recently joined the HFA education team. She works closely with member organizations and leads the Blood Sisterhood Program.



Angela Lambing, MSN, ANP, GNP, Independent Consultant

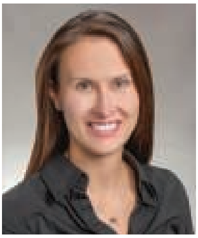
Angela Lambing has been a nurse practitioner for over 30 years, with certification in adult and geriatric care. She has spent more than 20 years in the bleeding disorders community where she was the coordinator for a hemophilia treatment center in Detroit Michigan for 15 years, followed by six years in pharma as a nurse educator. Her passion areas include pain and aging issues in bleeding disorders. She is widely published with multiple publications in these areas. Angela has given lectures locally, nationally, and internationally on a variety of topics specific to bleeding disorders.

Andrea Lausman, MD, Maternal-Fetal Medicine Specialist, St. Michael's Hospital, Toronto, Canada

Dr. Andrea Lausman is currently appointed as a Maternal-Fetal Medicine Specialist at St. Michael's Hospital, in Toronto, Canada, where she is also the Deputy Chief of Obstetrics. She is an Assistant Professor at the University of Toronto. Her current clinical practice includes a focus on medical complications of pregnancy, and their implications for both mother and baby. Her research interests are varied and include exploring diagnosis and treatment options for iron deficiency anemia in pregnancy. Her clinical practice is in high-risk obstetrics with a focus on maternal health including collaborating and coordinating care of pregnant patients with hereditary hemorrhagic telangectasia, multiple sclerosis, renal transplants and cystic fibrosis. From the fetal perspective, she continues to contribute to the literature on fetal growth restriction.

Susan Fenters Lerch, Executive Director, Hemophilia Foundation of Michigan; Director, Federal Great Lakes Region V-E HTC Network, Ypsilanti, MI

Susan Fenters Lerch is an accomplished leader who has served in the nonprofit sector for four decades. Sue joined HFM as the executive director in June 2014; however, she came to this role having previously served as the HFM associate director from 1982-1995. In 1996 Sue joined Make-A-Wish Foundation of Michigan as president and CEO until 2010 when she launched Autism Alliance of Michigan. Additionally, Sue has served as the lead consultant in implementing World AIDS Day Detroit, initiated the Hospice of Michigan Foundation and created Bring Joy consulting services. Currently, as the executive director at HFM, Susan is responsible for statewide patient educational programming and advocacy services and also serves as the Great Lakes and Region V-East Hemophilia Treatment Centers' regional director. She has an amazing, loving family including 4-year-old granddaughter Margeaux with hemophilia.

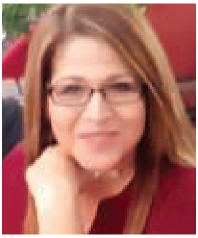


Magdalena Lewandowska, MD, Adult Hematologist, Indiana Hemophilia and Thrombosis Center, Indianapolis, IN

Dr. Magdalena Lewandowska serves as an adult hematologist at the Indiana Hemophilia and Thrombosis Center (IHTC) in Indianapolis, IN. She graduated from Jagiellonian University in Cracow, Poland and completed postgraduate medical education in internal medicine and hematology/oncology at St. Elizabeth's Medical Center in Boston, MA. She is involved in medical education and clinical research at IHTC, with a special interest in hemophilia, rare bleeding disorders, and women's health. She is the co-director of the GO (Girls and Women Only) clinic and the director of the hereditary hemorrhagic telangiectasia program at IHTC.

Shaveta Malik, MD, Obstetrics and Gynecology, Buffalo, NY

Shaveta Malik, MD, is a practicing OB-GYN (obstetrician & gynecologist) in Buffalo, NY. Dr. Malik graduated from St. George's University School of Medicine in 2010 and has been in practice for eight years. She completed a residency at Staten Island University Hospital. She currently practices at University of Buffalo Pediatric Associates Inc and is affiliated with Kaleida Health Millard Suburban Hospital.



Mary Martinez, CMI-Spanish, Medical Interpreter, Texas Children's Hospital, Houston, TX

Mary/Maria is our Spanish interpreter this weekend. Mary has eight grandchildren, enjoys traveling, and loves to read. Her involvement with the hemophilia community started 23 years ago when she was invited by Ed Kuebler, MSW, in El Paso, TX to translate at a 3-day conference for hemophilia. Mary shares, "I loved the experience and the families. I've participated in hemophilia programs all over the world with HTCs in Houston and Ft. Worth, TX ever since. Working with this community has been the most rewarding experience for me."

Ann-Marie Nazzaro, PhD

Ann-Marie is the (retired) founding Executive Director Emerita of the Foundation for Women & Girls with Blood Disorders (FWGBD). In 2009, along with Drs. Andi James, Roshni Kulkarni and Barbara Konkle, she helped to start the, then brand-new, Foundation to educate physicians and other healthcare providers about the whole array of blood disorders that do indeed directly impact women and girls. Prior to working with FWGBD, Ann-Marie was the leader, for 12 years, of the Education team at NHF, serving as Director and then VP. She continues her public health work as a lead volunteer for NJ Together–organizing efforts to improve policing through the inclusion and collaboration of behavioral health professionals.

Keri Norris, PhD, MPH, MCHES, Vice President, Health Equity, Diversity, and Inclusion, National Hemophilia Foundation

Dr. Keri Norris is a public health professional with extensive training and expertise in health equity, health promotion, and disease prevention at the local, state, and federal level. She has worked for some premiere public health and higher education institutions (including the CDC, The Fulton DeKalb Hospital Authority, Spelman College, Agnes Scott College, Baylor University and Morehouse School of Medicine). She is currently the vice president of health equity, diversity and inclusion for the National Hemophilia Foundation. She has a TEDx Talk on Hiding in Plain Sight: Health Equity and What's Missing. She is a graduate of Agnes Scott College, Morehouse School of Medicine, the University of South Carolina, and Emory University Law School. Keri serves on the board of Henry County Board of Health, Good Samaritan Health Center Atlanta, Haven of Light, International and the advisory board of the National Coalition Against Domestic Violence. She is a member of Junior League DeKalb and Alpha Kappa Alpha Sorority, Inc. Dr. Norris is an author, coach, and mentor. In her spare time, she enjoys binge watching a good series, bad karaoke, and spending time with family. She has a son and a grandson.

Mina Nguyen-Driver, PsyD, Psychologist, Oregon Treatment Center, Portland, OR

Dr. Nguyen-Driver is a professor in the Department of Pediatrics at the University of Arkansas for Medical Sciences (UAMS) in Springdale, AR. She is involved with direct patient care at the Hemophilia Treatment Center and has over 20 years of experience providing mental health treatment for patients and families with bleeding disorders. Dr. Nguyen-Driver's specialty includes adjustment to new diagnosis, coping, relaxation training, non-pharmacological treatment to pain management, adherence, transitioning, and effective disciplining.

Skye Peltier, MPH, PA-C, Director, Public Health Programs and Surveillance – Community Counts, American Thrombosis and Hemostasis Network

Skye Peltier is a physician assistant (PA) who has been involved in the care of patients with bleeding and clotting disorders since 2005. She earned an MPH in community health education from the University of Minnesota in 1999 and worked as a health educator before going to PA school. She joined ATHN in August 2021 as the director of Public Health Programs and Surveillance. As a woman with a bleeding disorder, she has a passion for improving the care of bleeding disorder patients. She is very excited to be in this role at ATHN.

Johnathan C. Roberts, MD, Associate Medical Director and Associate Research Director, Bleeding & Clotting Disorders Institute (BCDI); Assistant Professor of Pediatrics, University of Illinois College of Medicine at Peoria, Peoria, IL

Dr. Roberts graduated from the Southern Illinois School of Medicine in 2008 and completed his internship and residency in pediatrics at the University of Illinois College of Medicine at Peoria at OSF St. Francis Children's Hospital in 2011. After finishing his residency, Dr. Roberts completed fellowship in pediatric hematology/oncology/blood & marrow transplantation at the Medical College of Wisconsin/Children's Hospital of Wisconsin in 2014 and worked as a post-doctoral fellow under Dr. Robert Montgomery and Dr. Joan Cox Gill at the BloodCenter of Wisconsin Blood Research Institute.

Dr. Roberts' research areas of interest are in advancing novel laboratory assay development to improve the diagnosis of von Willebrand disease and to enhance individualized clinical management of hemophilia. He has received numerous young investigator research awards, has over 40 peer-reviewed research publications and abstracts including lead author publications in Blood and the New England Journal of Medicine, and has had grant funding from the National Hemophilia Foundation, World Federation of Hemophilia, and NIH among others.

Dr. Roberts has a personal passion for the bleeding disorders community as he is also an individual with severe hemophilia A.

Dave Rushlow, LMSW, Program Manager, Bleeding Disorder Center, Munson Medical Center, Traverse City, MI

Dave has over 30 years of experience as a licensed social worker and graduated from the University of Michigan with a Master of Social Work. He has worked in a medical setting for many years and has unique experience working with chronic health conditions, grief, loss, and end of life issues.

Cindy Sabo, CPNP, Pediatric Nurse Practitioner, Hematology, Children's Hospital of Michigan, Detroit, MI

Cindy received her Bachelor of Science in Nursing (BSN) from Eastern Michigan University and her Masters of Science in Nursing from Wayne State University. She serves as a member of a multidisciplinary team, providing care for children with bleeding and clotting disorders. Her focus is on educating families, fostering independence, preventing complication, and maximizing the quality of life for children affected with bleeding disorders and thrombophilia. Cindy staffs the Flow Clinic for adolescents with heavy menstrual bleeding with Dr. Chitlur, Adolescent Medicine and Gynecology. Cindy coordinates the outpatient care of all the thrombosis patients as well as maintaining a database of all the thrombosis patients. She is actively involved in the Foundation for Women and Girls with Bleeding Disorders. She also founded a program teaching healthy eating habits and exercise called Healthy Vibes.

Stephanie Sarazin, Author

Stephanie's work began with her own experience of mid-life trauma, which sparked an ambitious journey—spiritually and around the world to understand, name, and heal the grief she found within her. Her efforts revealed a first-of-its-kind definition for "ambiguous grief," whereby grief is onset by the loss of a loved one who is still living and wherein the experience of hope presents as a stage of the grieving process. Stephanie's work brings new resources to reframe disruptive, activating events as a gateway to discovering your highest self, in turn championing ambiguous grief as nuanced, natural, and navigable. She is the founder of RiseUpRooted, a TEDxWomen attendee, and a TEDx community curator. She has earned degrees from Michigan State University and the University of Chicago and is certified as a Grief Recovery Specialist through the Grief Recovery Institute and as a Grief Educator under the mentorship of grief expert, David Kessler. Her articles have been published via several outlets including ThriveGlobal, OptionB, and The Elephant Journal. Her book, Soulbroken: A Guide for Your Journey Through Ambiguous Grief is published by Balance, an imprint of GrandCentral Publishing, and will be available on October 11, 2022.

Michelle Leona Cecil, M.P.A.

Patient advocate

About Michelle

Michelle is a Novo Nordisk Hemophilia Community Liaison who lives with a bleeding disorder. She is passionate about supporting people in the community and helping them take full advantage of the trusted products of Novo Nordisk.

Connect with Michelle

VQMC@novonordisk.com
(614) 674-0147

Hemophilia Community Liaison

Great Lakes (MI and WI)

Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.

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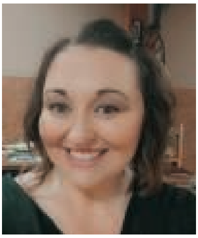
Michelle Sholzberg, MD, Division Head, Hematology-Oncology; Medical Director, Coagulation Laboratory, St. Michael's Hospital, Toronto, Canada

Dr. Michelle Sholzberg received her MDCM and residency training in internal medicine at McGill University, completed additional postgraduate training in hematology at the University of Toronto and a research hemostasis fellowship in Toronto and internationally. Dr. Sholzberg has a Master of Science from the University of Toronto in clinical epidemiology and health care research and was awarded the Claire Bombardier award for career promise as a scientist. She is a clinician-investigator with a focus on coagulation, the division head of hematology/oncology and the medical director of the Coagulation Laboratory at St. Michael's Hospital. She is also the Director of the Hematology-Oncology Clinical Research Group and co-director of the Hematology-Immunology Translational Research Theme of the Li Ka Shing Knowledge Institute. Dr. Sholzberg is the associate editor for illustrated materials at Research and Practice in Thrombosis and Haemostasis. Currently, she is involved in the study of prediction tools for perioperative and traumatic bleeding, the intersection of women's health and bleeding disorders, treatments for iron deficiency anemia, new treatments for immune thrombocytopenia and the management of COVID-19 coagulopathy.

Dr. Rebecca Spencer, MD, PhD, Anesthesiologist, Concord Hospital, Concord, NH

Dr. Rebecca Spencer is a practicing anesthesiologist at Concord Hospital in New Hampshire. In her clinical practice she consults patients with X linked and other rare diseases. Her PhD research focused on X chromosome inactivation. Dr. Spencer received her MD and PhD degrees from Harvard and trained in anesthesiology at Massachusetts General Hospital. She is a member of the medical advisory board for Remember the Girls.



Charity Stadler, RN, BSN, Nurse Coordinator, Detroit Medical Center, Detroit, MI

Charity is the nurse coordinator for the Jeanne M. Lusher Center for Hemostasis and Thrombosis. She serves as a member of the center's multidisciplinary team which provides comprehensive care to pediatric patients diagnosed with bleeding and clotting disorders. Charity coordinates the Girl Squad comprehensive clinic for adolescents with heavy menstrual bleeding, staffed by hematology providers Dr. Meera Chitlur, Dr. Katherine Regling, nurse practitioner Cynthia Sabo, along with adolescent medicine or gynecology physicians. Charity is the nursing subcommittee chair for the Foundation for Women and Girls with Blood Disorders. Charity is actively involved in research activities at her center and proudly stands beside her mentor, Dr. Meera Chitlur, in assisting with the development of the Girl Squad Outreach Program. The outreach program's focus is to provide heavy menstrual bleeding education to adolescents in the community, promoting early awareness of abnormal menstruation symptoms, expediting diagnosis, and aiding in prevention of severe complications that impact quality of life. She is on the nursing board for Thrombosis and Hemostasis Societies of America (THSNA) and her primary focus is education of patients and providers on bleeding disorders, with a special focus on females with bleeding disorders.

Lena Volland, DPT, Director of Education, National Hemophilia Foundation

Lena Volland holds a Doctor of Physical Therapy from Mount St. Mary's University and is working towards her PhD in translational health sciences from The George Washington University. Her research is grounded in implementation, dissemination, and complexity science with a specific focus on knowledge translation, learning health systems, and health service delivery. Lena has served as an educator with the University of St. Augustine for Health Sciences and spent numerous years as a practicing physical therapist, including her role at the HTC at UC San Diego Health. Currently, Lena is the director of education at the National Hemophilia Foundation.

Natalia Winberry, MNLM, Manager of Education, National Hemophilia Foundation

Natalia Winberry started her career as an AmeriCorps VISTA working on community outreach and continued to work in refugee resettlement for eight years by helping refugees and immigrants thrive in their new communities. She earned her graduate degree in nonprofit leadership and management from Arizona State University and focused on supporting nonprofit organizations to improve accountability to the populations they serve.

Throughout her nonprofit career, Natalia has worked on community development, advocacy, and social service efforts in collaboration with a wide variety of community partners. Natalia is currently a manager of education for the National Hemophilia Foundation.

hfm©

CONFERENCIA DE LA HFM 2022 PARA MUJERES Y NIÑAS ADOLESCENTES QUE VIVEN CON LA HEMOFILIA Y DEFICIENCIAS DE FACTORES RAROS

CAPACITACIÓN, EDUCACIÓN Y POLÍTICA

7-9 de octubre de 2022


Left, Susan Fenters Lerch and right, Patrice Thomas

Queridas amigas,

Estamos encantadas de que tantas mujeres extraordinarias participen en la quinta conferencia nacional anual de la Fundación de la Hemofilia de Michigan para mujeres y adolescentes con hemofilia y deficiencias de factores raros. Entendemos que el COVID sigue afectando a la salud de nuestras comunidades y puede ser un obstáculo para la asistencia. Este año hemos previsto dos vías de participación: virtual y presencial. Aunque esperamos que la mayoría de nosotros estaremos reunidos físicamente, no olvidaremos a los que se unen virtualmente, e incluiremos a nuestros participantes virtuales en los procedimientos tanto como sea posible.

Estamos enctantadas de ofrecer esta conferencia especializada para que las mujeres se reencuentren con antiguas conocidas, a la vez que damos la bienvenida y acogemos a nuevas participantes. Como siempre, esperamos ofrecer un aprendizaje excepcional, conexión, celebración y apoyo.

Agradecemos la flexibilidad de cada persona durante esta experiencia de conferencia híbrida del 2022. Nuestra plataforma en línea, los asistentes y los ponentes se unirán de una manera nueva y única.

Pedimos a todas que tengan en cuenta la importancia de la amabilidad y la paciencia, así como la curiosidad y la participación. Seguimos agradecidos a nuestros colegas médicos, psicosociales y organizativos que están donando generosamente su experiencia y tiempo para reunirse en esta importante conferencia. Nuestro equipo de la HFM está enfrentando muchos desafíos este año y continuará con nuestro compromiso continuo de ofrecerle la experiencia de una conferencia interesante y educativa. Juntos, estamos haciendo todo lo posible para asegurar que las participantes, los oradores, los patrocinadores y seguidores tengan una experiencia auténtica y edificante. Sepan que seguimos comprometidos con cada una de ustedes; las que viven en nuestro estado natal de Michigan, nuestra región, en todo el país, así como las de otros países.

Gracias a todos los participantes en la conferencia, a los colegas de la HFM, a los presentadores, patrocinadores y seguidores. Es nuestro deseo sincero que cada una de nosotras encuentre la conferencia nacional 2022 de la HFM para mujeres y niñas como un momento de empoderamiento y de verdadera comunidad.

Con admiración,

Susan Fenters Lerch
Directora Ejecutiva de la HFM
Great Lakes Region V-E HTC
Network Regional Director

Patrice Thomas

Patrice Thomas, MSW, MS
Directora de Servicios de
Programa HFM

PD Asistentes virtuales – Su enlace para entrar en nuestro programa virtual se le enviará por correo electrónico el **miércoles, 5 de octubre.**

DIRECTRICES DE LA CONFERENCIA

Bienvenidos a la quinta Conferencia Nacional Anual para Mujeres y Adolescentes con Hemofilia y Deficiencias de Factores Raros. El personal de la HFM y nuestro grupo de planificación de la conferencia esperan un fin de semana lleno de interacción social constructiva, educación y camaradería. En este espíritu, agradecemos la participación de todas en las actividades para demostrar el respeto por las diferentes opiniones y métodos de autocuidado. Debido a los problemas nacionales de salud pública relacionados con el COVID-19, hemos optado por organizar una conferencia híbrida este año. Ya que algunos de nuestros asistentes y ponentes estarán en casa frente a sus computadoras, no podemos garantizar la confidencialidad de las conversaciones que tengan lugar durante la conferencia. Esperamos que todos sean conscientes de compartir la pantalla y el audio con los demás mientras participa en la conferencia. Por favor, téngalo en cuenta a la hora de compartir información personal con otros de forma verbal o escrita.

Reconocemos que puede haber algunos asistentes este fin de semana que trabajen con una empresa de atención domiciliaria o con una empresa relacionada a la industria. Si este es su caso, se espera que su participación este fin de semana sea únicamente como consumidor. Los asistentes no podrán solicitar la participación de otros asistentes en futuros programas o servicios.

Si desea que su empresa esté representada como patrocinadora en una futura conferencia de mujeres, hable con un miembro del personal de la HFM.

Los invitamos a visitar a nuestros patrocinadores de la industria a lo largo de la conferencia. Gracias a su generoso apoyo podemos celebrar este evento.

Durante la conferencia, los asistentes tienen derecho a determinar si comparten su información personal en las sesiones de grupos grandes en las que pueden estar presente socios de la industria, así como la forma de compartir su nombre en la sección de asistentes. Si desea continuar la conversación con alguno de nuestros patrocinadores de la industria después del fin de semana, puede compartir su información de contacto, aunque no está obligado a hacerlo. Respetamos su derecho a la privacidad: Aunque usted puede elegir compartir cualquier información con la que se sienta cómodo, los representantes de la industria no le preguntarán específicamente sobre su historial médico personal, tratamiento o trastorno hemorrágico. Los representantes de la industria no ofrecerán asesoramiento médico, ya que se trata de una conversación que debe tener lugar entre usted y su equipo de salud. Si en algún momento se siente presionado para proporcionar información personal, informe inmediatamente a un miembro del personal de la HFM.

Creemos que este fin de semana es una oportunidad para compartir y recibir información y educación de la manera más beneficiosa y cómoda para usted.

POLÍTICA DEL COVID - EN PERSONA

Las actividades presenciales de la Conferencia de Mujeres requieren una prueba de vacunación contra el COVID. La HFM reserva el derecho de exigir cubreboca/mascarillas obligatorias a todos los asistentes.

La HFM no respalda ningún producto o empresa específica.

AGENDA

TODO EL HORARIO SERÁ EN EL HORARIO DEL ESTE DE NORTEAMÉRICA. TODAS LAS SESIONES QUE SE CELEBREN EN EL SALÓN LINDBERGH SE INTERPRETARÁN AL ESPAÑOL Y SE TRANSMITIRÁN A NUESTROS ASISTENTES VIRTUALES A TRAVÉS DE SOCIO.

viernes,
7 de octubre

3:00pm

Registración comienza y se abre el espacio de exhibidores

Pre-función en Salón Lindbergh

4:00-6:00pm

Recepción de Bienvenida con aperitivos ligeros y bebidas

Pre-función en Salón Lindbergh

5:30-7:00pm

Cena bufé

Salón Lindbergh

6:40-6:55pm

Bienvenida

Salón Lindbergh ES 💻

Orador de apertura: Susan Fenters Lerch, Directora Ejecutiva, La Fundación de Hemofilia de Michigan; Directora Regional, Great Lakes Federal HTC Network

6:55-7:00pm

Notas del patrocinador

Salón Lindbergh ES 💻

7:00-8:00pm

Inicio de la Conferencia

Salón Lindbergh ES 💻

El grupo será guiado a través de actividades divertidas para que podamos conocernos un poco mejor y establecer las pautas de inclusión para el fin de semana.

Facilitadores: Haelynne Barron, Directora de Programa, GutMonkey

Margaret Bridges, Gerente de Programa, GutMonkey

Sesión patrocinada por Pfizer

8:00-9:00pm

Alma Rota: Una guía para su viaje a través del duelo ambiguo

Salón Lindbergh ES 💻

La Srta. Sarazin hablará de los conceptos del duelo ambiguo y de cómo éste se relaciona con muchos aspectos de nuestra vida cotidiana.

Orador: Stephanie Sarazin, Autora

9:00–10:00pm

Socializar y postres

Pre-función Salón Lindbergh y Salón Lindbergh

sábado,
8 de octubre

7:30am

Se abre el espacio de exhibidores

Pre-función Salón Lindbergh

7:30-9:00am

Desayuno bufé

Pre-función Salón Lindbergh y Salón Lindbergh

8:15-8:55am

Consulta de GutMonkey

Salón Lindbergh ES 💻

Facilitadores: Haelynne Barron, Directora de Programa, GutMonkey

Margaret Bridges, Gerente de Programa, GutMonkey

9:00-10:30am

Equidad en salud y acceso a la atención para mujeres y niñas con hemofilia

Salón Lindbergh ES 💻

Hay muchos profesionales médicos y personas de la comunidad de trastornos hemorrágicos que están preocupados por cómo cambiará el acceso

a la atención médica dada la reciente decisión del Tribunal Supremo sobre el aborto. Esta sesión explorará lo que entendemos por acceso a la atención y cómo las barreras a la atención se interrelacionan con la equidad en salud.
Oradores: Miriam Goldstein, JD, Director de Política y Asesor Legal Principal, Federación de Hemofilia de América, Washington, D.C.
Magdelena Lewandowska, MD, Hematólogo de Adultos, Indiana Hemophilia and Thrombosis Center, Indianapolis, IN
Shaveta Malik, MD, Obstetrics and Gynecology, Buffalo, NY
Keri Norris, PhD, MPH, MCHES, Director de Diversidad, Fundación Nacional de Hemofilia, Atlanta, GA
Moderadora: Ann-Marie Nazzaro, PhD, Director Emeritus, Fundación para Mujeres y Niñas con Trastornos Sanguíneos, New Jersey

10:30-10:45am

Receso

10:45-11:45am

Sesiones educativas en grupo

1 Envejecer con un trastorno hemorrágico

Salón Lindbergh ES

A medida que envejecemos, nuestro cuerpo y nuestras necesidades médicas cambian. Las personas que padecen un trastorno hemorrágico se enfrentan a desafíos de envejecimiento únicos. Este taller explorará los desafíos médicos comunes que acompañan al proceso de envejecimiento relacionados con la salud cardiovascular y ósea, y el riesgo de hemorragia.
Orador: Angela Lambing, MSN, ANP, GNP, Asesora Independiente
Sesión patrocinada por la Federación de Hemofilia de América

2 Salud articular e hipermovilidad

Earhart A

El diagnóstico y el tratamiento de la hipermovilidad articular se han ampliado en la última década. Algunas mujeres con hemofilia y otros trastornos hemorrágicos raros también pueden tener hipermovilidad. Para muchas personas puede ser instructivo darse cuenta de que las anomalías en su tejido conectivo pueden ayudar a explicar algunos de los síntomas aparentemente únicos.

En esta sesión de grupo, presentaremos una breve revisión del diagnóstico de la hipermovilidad articular, cómo reconocerla y el papel del fisioterapeuta en la identificación y la gestión de esta condición. Hablaremos de la estructura general de un programa de ejercicios eficaz para la hipermovilidad articular generalizada y de algunos conceptos útiles relacionados con la vuelta gradual al ejercicio y la actividad. Acompaña a Dave – que tiene muchos años de experiencia trabajando con personas con hipermovilidad, y a Sherry – un especialista en trastornos hemorrágicos, mientras comparten un poco de su experiencia y facilitan un debate animado e interactivo con los participantes.
Oradores: Sherry Herman-Hilker, PT, MS, Fisioterapeuta, Centro de Tratamiento de la Hemofilia, University of Michigan, Ann Arbor, Michigan
David Johnson, PT, MS, Fisioterapeuta, Michigan Medicine MedRehab, Ann Arbor, Michigan

3 Proyecto Community Counts: ¿Por qué es importante para la comunidad de trastornos hemorrágicos?

Earhart B

«Community Counts» (CC) es un programa de monitoreo de la salud pública financiado por la División de Trastornos de la Sangre de la CDC. El objetivo de este proyecto es recopilar y compartir información sobre los problemas de salud comunes, complicaciones médicas y las causas de muerte que afectan a las personas con trastornos hemorrágicos atendidas en los centros de tratamiento de la hemofilia (HTC) de Estados Unidos.

En esta sesión se repasará cómo se recopila la información para el proyecto y se discutirá lo que se ha aprendido. Se invitará a la audiencia a compartir sus ideas y a dar su opinión sobre cómo mejorar la participación y proporcionar retroalimentación sobre lo que haría que el proyecto fuera más impactante para las mujeres de la comunidad de trastornos hemorrágicos.

Orador: Skye Peltier, MPH, PA-C, Directora, Programas de Salud Pública y Vigilancia - Community Counts, American Thrombosis and Hemostasis Network

4 PREGUNTAS Y RESPUESTAS: Discusión sobre la salud reproductiva para adolescentes y adultos jóvenes

Wright A

¿Tiene preguntas o preocupaciones sobre la menstruación y la hemorragia abundante? ¿No está segura de cuáles son las distintas opciones para tratar la hemorragia abundante? ¿Tomar una terapia hormonal puede causar retrasos en la concepción más adelante? ¡Esta sesión es el lugar para tener estas conversaciones y más!

Oradores: Cynthia Sabo, CPNP, Enfermera Pediátrica Especializada Titulada, Centro Médico de Detroit

Charity Stadler, RN, BSN, Coordinadora de Enfermeras, Centro Médico de Detroit

5 Espera lo inesperado: Prepárate para cualquier cosa

Wright B

El personal de los servicios de urgencias, incluidos los médicos, puede tener poca experiencia en la gestión de pacientes con trastornos hemorrágicos porque son afecciones poco frecuentes. Esta presentación le ayudará a evitar y a prepararse para un posible viaje a la sala de urgencias, en cualquier momento y en cualquier lugar – incluso cuando esté de viaje o durante un desastre natural.

Orador: Lisa Horstman, RN, BSN, Takeda

Sesión patrocinadq por Takeda

11:45-12:00pm

Receso

12:00-1:10pm

Almuerzo bufé con mesas temáticas

Pre-función Salón Lindbergh y Salón Lindbergh

Disfrute compartiendo su almuerzo con nuevos amigos o familiares; también es bienvenido a unirse con los representantes de los patrocinadores de la industria en sus mesas reservadas en el salón para discutir temas relevantes para las mujeres con hemofilia y deficiencias de factores raros. Los temas de estas mesas se compartirán con anticipación para que pueda participar en el debate y aprender de los demás.

1:10-1:15pm

Notas del patrocinador

Salón Lindbergh ES 💻

1:15–3:30pm

Sesión de jóvenes adultos con líderes del Centro de Salud Corner

Sala Armstrong

Esta sesión de la tarde está abierta a los adolescentes y jóvenes adultos (de 24 años de edad y menor). El Consejo de Liderazgo de los Jóvenes y el personal del Centro de Salud Corner en Ypsilanti, MI, nos acompañarán a pasar una tarde de actividades divertidas y conversación mientras exploramos los desafíos de crecer con un trastorno hemorrágico. Los asistentes tendrán la oportunidad de conectar con compañeros que pueden compartir experiencias similares, discutir cómo el aislamiento puede afectar a nuestra salud mental y aprender nuevas habilidades para hacer frente a los desafíos de la vida.

Oradores: Líderes juveniles y empleados de Corner Health

1:15–2:15pm

Barreras para el diagnóstico: Mujeres y los trastornos ligados al cromosoma X

Salón Lindbergh ES 💻

Esta presentación está diseñada para mujeres con trastornos genéticos ligados al cromosoma X, proveedores de atención médica y cuidadores, y abordan los desafíos a los que se enfrentan las mujeres con trastornos ligados al cromosoma X. Se discutirán los desafíos y las barreras para el diagnóstico y la atención, así como una explicación de las mujeres y la manifestación de los síntomas de los trastornos ligados al cromosoma X. También habrá un tiempo para preguntas y respuestas al final.

Orador: Dr. Rebecca Spencer, MD, PhD, Anestesiólogo, Concord Hospital, Concord, New Hampshire

2:30-3:30pm
Sesiones educativas en grupo

1 Actualización de las deficiencias de factores raros

Salón Lindbergh ES 👤

El Dr. Davis hablará de las mejores prácticas relacionadas con el diagnóstico y el tratamiento de las deficiencias de factores raros y responderá a las preguntas de los asistentes.

Orador: Joanna Davis, MD, Director Médico, Centro de Tratamiento de Hemofilia Integral Pediátrico, University of Miami, Miami, FL

2 Salud pélvica: más que «Medicina de Bikini»

Earhart A

A menudo hablamos de la menstruación abundante y de los problemas reproductivos de las personas con trastornos hemorrágicos, pero rara vez hablamos del impacto en el sistema musculosquelético. En esta sesión se profundizará en el tema de la salud pélvica a través del lente de la fisioterapia. Exploraremos la anatomía y la funcionalidad de la región pélvica femenina, así como discutiremos las disfunciones del suelo pélvico, destacando al mismo tiempo las innovadoras formas en que la fisioterapia puede mejorar su calidad de vida.

Orador: Lena Volland, DPT, DPT, Directora de Educación, Fundación Nacional de la Hemofilia

3 Procesando el impacto continuo de la 3H (o HHH)

Earhart B

La 3H se refiere a los afectados por la hemofilia, hepatitis C y/o VIH debido a la crisis de la sangre contaminada de los años 80. Esto incluye a los que viven con hemofilia y hepatitis/VIH o a los familiares de los afectados por la hemofilia y la hepatitis/VIH. Este es un espacio para hablar de los seres queridos y para procesar el impacto de la 3H en los individuos, familias y la comunidad.

Facilitador: Shellye Horowitz, MA, Director Asociado de Educación, Federación de Hemofilia de América, Trinidad, CA

4 Asuntos del dolor

Wright A

El dolor puede afectar la vida diaria de las personas con hemofilia. Conozca las opciones de la gestión del dolor y las herramientas para ayudar a hablar del dolor con los proveedores de atención médica.

Orador: Jonathan C. Roberts, MD, Director Médico Asociado y Director de Investigación Asociado, Bleeding & Clotting Disorders Institute (BCDI); Assistant Professor of Pediatrics, University of Illinois College of Medicine at Peoria, Peoria, IL

Sesión patrocinada por Novo Nordisk

3:45-4:45pm
Desafíos uterinos y atención ginecológica

Salón Lindbergh ES 👤

Esta sesión ofrecerá un resumen de los desafíos uterinos, incluyendo la endometriosis y fibromas. Discutiremos la complejidad de identificar y tratar la hemorragia uterina en personas con trastornos hemorrágicos. En la sesión también se hablará de cuándo hay que acudir a un ginecólogo y de cómo coordinar la atención con el proveedor de trastornos hemorrágicos.

Oradores: Laura Gusba, CNP, MSN, Enfermera Especializada, Centro de Tratamiento de Hemofilia y HematologíaHemtología Benigna, Henry Ford Hospital, Detroit, MI

Andrea Lausman, MD, Especialista en Medicina Materno-Fetal, St. Michael's Hospital, Toronto, Canada

Michelle Sholzberg, MD, Director de División de Hematología-Oncología y Director Médico de Laboratorio de Coagulación, St. Michael's Hospital, Toronto, Canada

4:45–5:30pm
Receso

5:30–7:00pm
Cena bufé

Pre-función Salón Lindbergh

6:45–6:55pm

Introducción a las actividades nocturnas

Salón Lindbergh ES 👤

6:55–7:00pm

Notas del patrocinador

Salón Lindbergh ES 👤

7:00-9:00pm

Actividades tarde-noche

1 Taller intergeneracional de cuentacuentos

Salón Lindbergh ES 👤

Este taller interactivo reunirá a personas de todas las edades y procedencias para que tengan la oportunidad de crear una comunidad y colaborar entre multiples generaciones. Los participantes descubrirán el poder de la narración y cómo el hecho de compartir la propia historia puede ayudar a sensibilizarla concienciación, desafiar los estigmas perjudiciales y abogar por los recursos y la atención de calidad. Exploraremos el valor de escuchar y la fuerza que se desarrolla al fomentar las conexiones con otras personas dentro de la comunidad de trastornos hemorrágicos.

Oradores: Coming soon

2 Noche de juegos

Wright A y B

¡Venga a relajarse con otros mientras se charla y se juega a una variedad de juegos; : cartas, juegos de mesa, o Pictionary – su elección!

domingo, 9 de octubre

8:00am

Se abre el espacio de exhibidores

Pre-función Salón Lindbergh

7:30-9:00am

Desayuno Bufé

Pre-función Salón Lindbergh y Salón Lindbergh

8:55–9:00am

Notas del patrocinador

Salón Lindbergh ES 👤

9:00-10:00am

Actualización nacional: Noticias sobre mujeres y niñas con trastornos hemorrágicos

Salón Lindbergh ES 👤

Nuestras organizaciones nacionales de trastornos hemorrágicos, la Federación de Hemofilia de América (HFA) y la Fundación Nacional de Hemofilia (NHF), presentarán resúmenes de sus recientes actividades de divulgación en un panel dirigido a mujeres y niñas, así como planes para futuros proyectos.

Oradores: Rose Bender, Representante de Pacientes, Medical and Scientific Advisory Council (MASAC), NHF

Amy Dunn, MD, Directora de Hematología Pediátrica, Hospital de Niños Nationwide, Columbus, Ohio, Presidente de MASAC NHF

Jeanette Jones, MEd, Administradora de Programa, HFA

Natalia Winberry, MNLM, Gerente de Educación, NHF

10:15-11:15am

Sesiones educativas en grupo

1 La Mujer Maravilla: Descreditando el mito que la mujer se tiene que encargar de todo

Salón Lindbergh ES 👤

¿Es usted el director general de la familia, el asistente administrativo, el organizador social, el ama de casa, el conductor de Uber, el árbitro de los niños y el cuidador? En los Estados Unidos, las mujeres representan casi la mitad de la mano de obra, pero una gran parte de las responsabilidades domésticas recaen sobre ellas. Las mujeres hacen un trabajo increíble en el cuidado de los demás, pero a veces se ven tan atrapadas en el cuidado de los demás que se han perdido de vista a sí mismas. Asiste a esta sesión para descubrir estrategias para cuidarte, sentirte empoderada y renovar tu espíritu.

Orador: Mina Nguyen-Driver, PsyD, Psicóloga Pediátrica, University of Arkansas for Medical Sciences, Fayetteville, AR

2 ¿Qué hacemos con las sobras del duelo?

Earhart A

Durante este fin de semana hemos aprendido que podemos experimentar el dolor en muchos niveles de nuestra vida. Estas experiencias de duelo pueden crear sentimientos y pensamientos persistentes —algunas agradables y otros llenos de dolor y tristeza, para otros puede despertar el impacto de sentimientos y pensamientos descubiertos que salieron a la luz este fin de semana.

Esta sesión altamente interactiva le dará la oportunidad de compartir sus sentimientos y pensamientos relacionados con su experiencia de duelo. Compartiremos de forma solidaria las experiencias de este fin de semana mientras te preguntas, ¿qué hago?

Dos trabajadores sociales con experiencia del centro de tratamiento de hemofilia estarán disponibles para facilitar esta conversación tan importante.

Oradores: Karen Boyd, LMSW, Trabajador Social Clínico, Universidad Estatal de Michigan, Centro para Trastornos Hemorrágicos y Coagulación

Dave Rushlow, LMSW, Gerente de Programa, Centro de Trastornos Hemorrágicos, Munson Medical Center, Traverse City, MI

3 Conversación CoRe: La crianza y teniendo una condición crónica

Wright A

La crianza de los hijos es un reto. Y se complica aún más con un trastorno hemorrágico de por medio. Para los padres con un trastorno hemorrágico, existen retos únicos que pueden afectar directamente a la vida familiar. Usted puede tener muchas preguntas, como por ejemplo: ¿Cómo puedo hablar con mis hijos sobre mi enfermedad? ¿Se siente mi pareja abrumada? ¿Qué pasa si una hemorragia interfiere en nuestra rutina diaria? Hemos desarrollado este programa para que los padres- y los futuros padres- puedan hablar de los problemas a los que se enfrentan en un entorno de apoyo y aliento.

Orador: Rebecca Gorde, MSW, BSN, RN, Gerente de Educación y Relaciones Comunitarias, MI & IN Rare Blood Disorders, Sanofi

Sesión patrocinada por Sanofi

4 Terapia génica en la Hemofilia B

Wright B

En esta charla se repasará un breve resumen de la hemofilia y su historia junto con la evolución del tratamiento y los enfoques terapéuticos. Centrándonos en las necesidades insatisfechas de las personas con hemofilia, exploraremos el potencial de la terapia génica y cómo puede hacer avanzar el panorama del tratamiento de la hemofilia B, incluyendo la investigación sobre una terapia génica mediada por virus que se está estudiando.

Orador: Rhonda Fritz, MSN, CPNP, Asuntos Médicos, Coagulación, CSL Behring

Sesión patrocinada por CSL Behring

11:15-11:30am

Receso

11:30-12:00pm

Despedida a los asistentes de la conferencia, evaluación y almuerzo para llevar

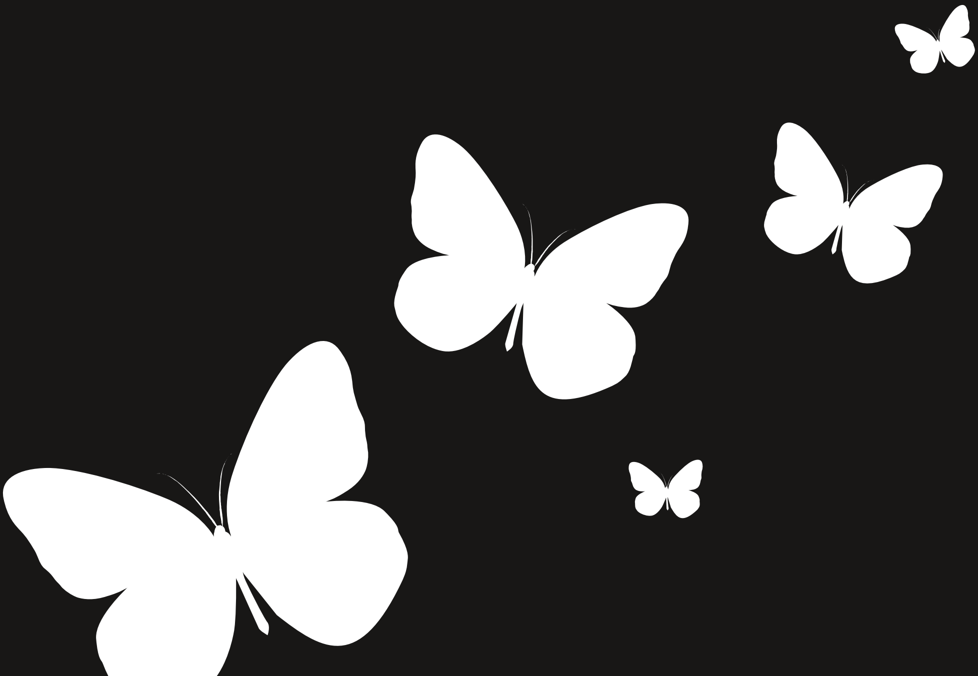
Pre-función Salón Lindbergh y Salón Lindbergh

ES 👤

SU RETROALIMENTACIÓN ES IMPORTANTE!

POR FAVOR AYÚDENOS A MEJORAR EVALUANDO NUESTRA CONFERENCIA, LAS SESIONES Y ORADORES.

El domingo se facilitará a todos los asistentes un enlace a la evaluación en línea de la conferencia.



WITH GRATITUDE

Thank you to all our amazing speakers and volunteers for their time and energy in helping to make this a unique educational experience and to our sponsors for their support and commitment to the community.

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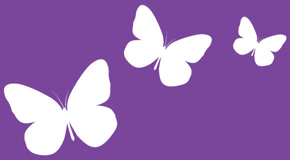

PLEASE HELP US IMPROVE BY EVALUATING OUR CONFERENCE, SESSIONS, AND SPEAKERS.

A link to the online conference evaluation will be provided to all attendees on Sunday, October 9.

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The Hemophilia Foundation of Michigan (HFM) exists to enhance the quality of life for all affected by bleeding disorders.