2021 National Conference for Women & Teens with Hemophilia and Rare Factor Deficiencies

Hear Our Voices: Setting the Agenda

Friday, October 8, 4 - 9p
and Saturday, October 9, 1 - 8pm
(All times are eastern time)

Through a distinctive virtual experience

Vea la **página 24** sobre información para hispanohablantes

Left, Susan Fenters Lerch and right, Patrice Thomas

> “You will always belong anywhere you show up as yourself and talk about yourself and your work in a real way.”
>
> ~ Brené Brown, Braving the Wilderness

Dear Friends -

We are excited and grateful to have so many extraordinary women participate with the Hemophilia Foundation of Michigan’s (HFM) fourth annual **National Conference for Women and Teens with Hemophilia and Rare Factor Deficiencies, Hear Our Voices: Setting the Agenda.** We hoped 2021 would have allowed us to come together in person—yet, the continued challenges across the country and world make it all the more important and meaningful to come together—even in the virtual space. We are overjoyed to continue our specialized conference for women to reconnect, while welcoming and embracing new participants. Our conference planning committee encouraged this year’s addition of women and teens with other rare factor deficiencies together with those living with hemophilia A and B.

As always, we expect to offer exceptional learning, connection, celebration, and support. We appreciate each person’s flexibility during the 2021 virtual experience. We have a new platform we expect will be even more user friendly and engaging. We made tremendous efforts to maintain our commitment to offer a congenial, interactive, educational, supportive experience. We ask that each of us keep in mind the importance of kindness and patience as well as curiosity and participation.

We remain thankful to our medical, psychosocial, and organizational colleagues who are generously donating their expertise and time to come together with us.

Our HFM team is working virtually, continuing an outstanding, ongoing commitment to create this 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, and those across the country.

Thank you to each conference participant, HFM colleagues, presenters, sponsors, and supporters. It is our sincere desire that each of us will find HFM’s 2021 **Hear Our Voices: Setting the Agenda** conference 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 Your link to enter our virtual platform will be emailed to you on October 4.

The Hemophilia Foundation of Michigan (HFM) exists to enhance the quality of life for all affected by bleeding disorders. | **www.hfmich.org** | **HFM does not endorse any specific product or company.**

2021 National Conference for Women & Teens with Hemophilia and Rare Factor Deficiencies

Hear Our Voices: Setting the Agenda

CONFERENCE GUIDELINES

Welcome to the fourth 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 virtual conference this year. Since 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. 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.

HFM does not endorse any specific product or company.

round robin guidelines

The Round Robin sessions, which will take place on both Friday and Saturday, have been created to provide you with information and to offer a space to ask questions of our industry sponsors in a small group setting.

Here is what you can expect:
You will be placed in a small group with other event attendees for industry rep meetings, which we call "Round Robins." Each industry rep meeting will be brief but full of information. At the end of the allotted time, the industry reps will rotate so that you and the others in your group will have the opportunity to interact with each company. Once you enter the Zoom room, you will stay put, so don't worry about having to navigate between multiple rooms.

You do not need to do any advance preparation. Industry reps will come prepared with a topic, video, or information that they would like to share with you.

A HFM staff person will be present to keep conversation flowing, to keep everyone on track with time, and to answer any questions that you may have about the process.

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.

Here is what we ask of you:
Please come ready to participate with the people in your small group and the representatives. Ask any questions that you may have.

Please consider keeping your camera on. The quality of your experience is largely dependent on the participation of everyone.

CASCADE
HEMOPHILIA CONSORTIUM
SINCE 1994

CK Colburn Keenan Foundation, Inc.

We're so happy you're joining us!

All times are eastern time.

Friday, October 8

4:00 – 4:20p ~ Main Stage

Welcome!

► Traducción al español disponible

■ **Speaker:** Susan Fenters Lerch, Executive Director, Hemophilia Foundation of Michigan; Network Regional Director, Great Lakes Region V-E HTC

4:20 – 4:25p ~ Main Stage

Sponsor Notes

► Traducción al español disponible

■ **Speaker:** Laura Russo, Pfizer Rare Disease, US Patient Affairs Team Lead

4:25 – 5:25p ~ Main Stage

Going Deep and Making a Splash: Conference Kickoff with GutMonkey

► Traducción al español disponible

Let's dive in! Join us at the National Conference for Women and Teens with Hemophilia and Rare Factor Deficiencies kickoff as we explore the scope and spectrum of health, identity, and navigating vulnerability in the "rapids" of our changing world. We'll uncover what's in the water below the tip of the iceberg, paddle the tributaries between letting go and cultivating growth, and cast a net with others in the community to see what we catch. Let's make a splash!

■ **Speakers:** Haelynne Barron, Program Director, GutMonkey; Margaret Bridges, Program Manager, GutMonkey

◆ Supported by Pfizer

5:30 – 6:50p ~ Main Stage

Update: National Organizations Advocating for Women and Girls

► Traducción al español disponible

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

■ **Speakers:** Maureen Baldwin, MD, MPH, Associate Professor of Obstetrics & Gynecology, Oregon Health and Science University; Jeanette Jones, Program Manager, Hemophilia Federation of America; Kate Nammacher, MPH, Vice President of Education, National Hemophilia Foundation; Angela Weyand, MD, Co-Director, Pediatric Hematology-Oncology Program, University of Michigan

6:50 – 7:00p ~ Main Stage

Sponsor Notes

► Traducción al español disponible

■ **Speaker:** Jane Cavanaugh Smith, Sanofi Genzyme, Head, US Public Affairs & Patient Advocacy - Rare Blood Disorders

7:00 – 7:40p ~ Zoom Rooms

Round Robin Industry Partner Conversations

This is a great opportunity to talk with our industry partners in a small group setting.

● **Fill in your BINGO cards to earn prizes!**

◆ **Industry Partners:** Novo Nordisk, Sanofi Genzyme, Takeda, Pfizer

Questions About Our Virtual Platform

Once you receive the email on October 4 containing the link to enter our virtual platform, you may access "**Frequently Asked Questions**" at **www.hfmich.org/wc-platform-faq.**

7:45 – 8:45p ~ Zoom Rooms

Break Out Sessions

(Choose 1)

1

The Mature Woman's Guide to Living with a Bleeding Disorder

This session will be an informational discussion of the challenges that women face who are aging with a bleeding disorder.

■ **Speakers:** Anne Greist, MD, Co-Founder and Co-Medical Director, Indiana Hemophilia and Thrombosis Center; Jeanne White-Ginder, Mother of Ryan White, Hemophilia/AIDS Activist

2

TEEN SESSION: Social Challenges for Teens Living with a Bleeding Disorder

A highly interactive session for young women to discuss life with a chronic condition, including disclosure, coping with heavy periods, and self-care.

■ **Moderator:** Anne Henningfeld, MA, CTRS, Managing Partner, Beyond Recreation

■ **Speaker:** Sarah Watson, LPC, CST, ATR, Certified Sex Therapist

3

HELLO Talk: Salud emocional y bienestar: Explorando la conexión entre mente y cuerpo

► Presentado en español

La mente y el cuerpo están conectados —el cuidado de su salud emocional es imperativo para mejorar su bienestar físico y su bienestar en general. Esta presentación explorará cómo vivir con un trastorno sanguíneo puede afectar la salud mental y su bienestar. Al mismo tiempo cómo la salud emocional puede afectar la calidad de vida de la persona. También hay oportunidades a lo largo de la presentación para la autorreflexión, así como ejercicios para practicar la reducción del estrés y el aumento de la atención plena.

■ **Speaker:** Patricia Espinosa-Thomson, Community Liaison, Takeda

Teen and young women sessions

4

HELLO Talk: Emotional Health and Well-being: Exploring the Mind-Body Connection

The mind and body are connected—taking care of your emotional health is imperative to bettering your physical and overall wellness. This presentation will explore how living with a bleeding disorder can affect one's general mental health and well-being, and how emotional health can affect someone's quality of life. There are also opportunities throughout the presentation for self-reflection, as well as exercises to practice reducing stress and increasing mindfulness.

■ **Speaker:** Honey Blankenship, MSN, MBA, RN, CCM, CPN, Senior Clinical Specialist, Takeda

5

World Federation of Hemophilia (WFH): Developing and Coordinating an Action Group for Women and Girls Worldwide

How do you bring together women and girls from such different communities? The chair of the WFH Women's Committee, Dawn Rotellini, and Dr. Roshni Kulkarni will discuss the timeline and steps taken to develop the committee, action items that have been achieved to date, and current action items and the steps to achieve these goals.

■ **Speakers:** Roshni Kulkarni, MD, Professor Emerita, Department of Pediatrics and Human Development, and former Director, Michigan State University Center for Bleeding and Clotting Disorders; Dawn Rotellini, Chief Operating Officer, National Hemophilia Foundation

6

Cognitive Conversations: Positive Self-Talk

This is the next generation of an interactive program which explains how different parts of our brain work and how we make some of the choices we do. It explores insights from the field of behavioral science and how they can be applied to conversations related to managing hemophilia.

■ **Speaker:** Gretchen Hover, Co-Founder and Managing Partner, Imbue Partners, LLC

◆ Sponsored by Sanofi Genzyme

8:50 – 9:00p ~ Main Stage

Day 1 Conference Wrap-Up

► Traducción al español disponible

Saturday, October 9

1:00 – 1:10p ~ Main Stage

Welcome!

► Traducción al español disponible

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

1:10 – 1:20 ~ Main Stage

Sponsor Notes

► Traducción al español disponible

■ **Speaker:** Heather Dean, Vice President, Hematology Franchise Head, Takeda

Special Guest Introduction

► Traducción al español disponible

Ruby Jane Smith, Singer and Songwriter, SongDivision; Patrice Thomas, Program Director, HFM

1:25 – 2:25p ~ Main Stage

Iron Deficient Anemia: What You Should Know

► Traducción al español disponible

Many women and girls with bleeding disorders suffer from undiagnosed iron deficient anemia. This session will discuss the symptoms, medical consequences, and provide suggestions for treatment of iron deficient anemia.

■ **Moderator:** Jill Johnsen, MD, Associate Member, Bloodworks Northwest Research Institute; Associate Professor, University of Washington

■ **Speakers:** Jim Munn, MS, BS, BSN, RN-BC, Program Administrator and Nurse Coordinator, Hemophilia and Coagulation Disorders Program, University of Michigan Health System; Alan Mast, MD, Senior Investigator, Blood Research Institute, Blood Center of Wisconsin

2:30 – 3:30p ~ Main Stage

Utilizing Ultrasound to Identify and Manage Joint Bleeds

► Traducción al español disponible

Are you no longer able to enjoy some physical activities like running or tennis due to joint pains? Could it be related to your bleeding disorder? In this session you will learn more about joint bleeds and utilizing ultrasound to specifically assess joint bleeds. An accurate diagnosis is very important in the success of a treatment plan.

■ **Speakers:** Stacie Akins, PT, MHS, Physical Therapist, Indiana Hemophilia and Thrombosis Center; Joanna Davis, MD, Medical Director, Pediatric Comprehensive Hemophilia Treatment Center, University of Miami

3:35 – 4:35p ~ Zoom Rooms

Break Out Sessions

(Choose 1)

1 Making Friends with your Treatment Center

► Traducción al español disponible

We all struggle with life challenges whether you are a patient or healthcare provider, especially in these times. This session will provide you with tips and suggestions to improve your relationship with your providers, no matter what life throws at us.

■ **Speakers:** Robina Ingram-Rich, RN, BSN, MS, MPH, Retired HTC Clinical Nurse; Mina D. Nguyen-Driver, PsyD, Psychologist, Oregon Treatment Center, Oregon Health and Science University

> “Women, if the soul of the nation is to be saved, I believe you must become its soul.”
>
> ~ Coretta Scott King

2

Dental and Oral Health: Disease, Prevention, Treatment, and Anxiety Considerations for Women and Girls with Bleeding Disorders

We will discuss the etiology, prevention, and treatment of dental and oral disease focusing on the challenges that patients with a bleeding disorder face when seeking oral care including financial concerns, mental health concerns, providing coping tools, and the importance of seeking regular dental care for overall health.

■ **Speakers:** Karen Boyd, LMSW, Clinical Social Worker, Michigan State University Center for Bleeding and Clotting Disorders; Jill Foley, RDH, RN, BSN, Nurse Clinician Michigan State University Center for Bleeding and Clotting Disorders; Steven Edwards, LMSW, Social Worker, Michigan State University Center for Bleeding and Clotting Disorders; Heather Lynn Messenger, MSDH, Registered Dental Hygienist, Michigan State University Center for Bleeding and Clotting Disorders

3

TEEN SESSION: Ask the Expert – Bleeding Disorders and Medical Challenges

This session provides the time and space needed to discuss questions you might not have time to talk about with your provider during yearly visits. Attendees can ask questions anonymously or in the general group so that all will have a path to speaking about issues that are sometimes hard to bring up.

■ **Moderator:** Anne Henningfeld, MA, CTRS, Managing Partner, Beyond Recreation

■ **Speaker:** Charity Stadler, RN, BSN, Nurse Coordinator, Detroit Medical Center

4

Pain Matters

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:** Corbett Reinbold, RN, BSN, CCRC, Nurse Coordinator, Comprehensive Center for Bleeding Disorders, Versiti Blood Center of Wisconsin

◆ Sponsored by Novo Nordisk

Teen and young women sessions

5

Double the Challenge: Bleeding Disorders and Uterine Problems

This session will provide an overview of endometriosis and fibroids, and how having a bleeding disorder increases the complexity of identifying and treating these issues.

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

4:40 – 5:20p ~ Zoom Rooms

Round Robin Industry Partner Conversations

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◆ **Industry Partners:** Novo Nordisk, Sanofi Genzyme, Takeda, Pfizer

5:20 – 5:30p ~ Main Stage

Sponsor Notes

► Traducción al español disponible

■ **Speaker:** Tammy Blain, RN, BSN, MBA, OCN, Hemophilia Biopharm Region Director, Novo Nordisk

5:30 – 5:35p ~ Main Stage

SongDivision

► Traducción al español disponible

Brief check-in with our song writer, Ruby Jane Smith, to assist with her end of the conference song presentation.

5:40 – 6:40p ~ Main Stage

Emergent Women and Girl's Health Challenges: A. Planning for Pregnancy and Delivery; B. Recognizing causes of abnormal bleeding when I'm not pregnant.

► Traducción al español disponible

Two important health issues are covered in this session. Planning for pregnancy and delivery is a critical aspect of self-care when you have a bleeding disorder, and this topic will be covered with specifics about communication with medical staff and having plans documented. We will also discuss the other possible causes of reproductive health bleeds that are not related to a woman's bleeding disorder.

Session continued next page

■ **Speakers:** Jill Johnsen, MD, Associate Member, Bloodworks Northwest Research Institute; Associate Professor, University of Washington; Judy Simms-Cendan, MD, Division Director of Pediatric Adolescent Gynecology, Department of Obstetrics, Gynecology and Reproductive Sciences, University of Miami, Miller School of Medicine

6:45 – 7:40p ~ Main Stage

Options for Treatment: Utilizing Factor and Prophylaxis

► Traducción al español disponible

Why isn't prophylaxis used with females, even if they have the same factor levels as males? This session will present information about the challenges of integrating prophy and factor use in treatment regimens for females.

■ **Speaker:** Robert F. Sidonio, Jr., MD, MSc, Associate Director and Director of Clinical Operations and Clinical Research, Hemostasis and Thrombosis Program, Aflac Cancer and Blood Disorders Center, Children's Healthcare of Atlanta; Associate Professor of Pediatrics, Emory University School of Medicine

7:40 – 8:00p ~ Main Stage

Closing Session

► Traducción al español disponible

We will gather together and experience an original song that will capture our amazing time together this weekend!

■ **Presenters:** Ruby Jane Smith, Songwriter and Singer, SongDivision; Patrice Thomas, Program Director, HFM

Your Feedback Matters!

Please help us improve by evaluating our conference, sessions, and speakers. **We are listening to you!**

Go to: www.hfmich.org/wc-evaluate

We invite you to keep your computer camera on during the conference!

We hope you will join us with your computer cameras on for this virtual experience. The National Conference for Women and Teens with Hemophilia—and now rare factor deficiencies—has been a transformative event for attendees in part due to the interactions, conversations, and support between women. We hope to continue this connection through our online experience by inviting you all to show up, be present, and share your faces with one another.

We also understand that you may have personal reasons for not wanting to be on camera. We acknowledge this and **respect your right to participate in the way you feel most comfortable.**

We hope to see and hear from you during our two-day conference in the ways that make you feel most comfortable and connected.

It’s not too early to take some selfies!

We’re so grateful to these women who shared selfies from HFM’s Women’s Retreat this past spring.

For iPhone, in preferences, set camera to “Auto HDR.” This may be different from phone to phone. Email your photos, at the largest size, to **sprocario@hfmich.org**

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 pages,** and to take the many opportunities available this weekend to learn more about each company and their commitment to the hemophilia community. We invited our industry sponsors to share a few words with you about who they are.

Novo Nordisk

In hemophilia, there's one thing you can count on: Innovation from Novo Nordisk

For 30 years, Novo Nordisk has been a driving force for people living with rare bleeding disorders. We take pride in striving for innovative solutions to help improve patients' lives. This motivates us to uphold the highest standards in our product research and development. This vital research is just the beginning of our commitment in hemophilia.

We'll continue our research and connect with people with hemophilia and healthcare professionals to ensure we understand and respond to specific needs of the hemophilia community. We'll continue to develop innovative solutions that can help improve the lives of people with hemophilia in the future.

Please visit **www.rarebleedingdisorders.com** or **www.signup.novonordiskhemophilia.com** to connect with your Hemophilia Community Liaison.

Pfizer

At Pfizer, we apply science and our global resources to bring therapies to people that extend and significantly improve their lives. We strive to set the standard for quality, safety and value in the discovery, development and manufacture of health care products. Pfizer colleagues work across developed and emerging markets to advance wellness, prevention, treatments and cures that challenge the most feared diseases of our time.

Sanofi Genzyme

At Sanofi Genzyme, 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 strive to 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.

Learn more at **www.rareblooddisorders.com.**

Takeda

Welcome to HFM's National Conference for Women with Hemophilia and Rare Factor Deficiencies. For over 70 years, Takeda has been committed to this 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. No matter where you are on your journey, Takeda has the resources to support you.

Akins

Baldwin

Barron

Blankenship

Stacie Akins, PT, MHS, Physical Therapist, Indiana Hemophilia and Thrombosis Center, Indianapolis, IN
■ Stacie received her bachelor's degree in physical therapy from Marquette University and Master of Health Science from the University of Indianapolis. She has been employed at the Indiana Hemophilia and Thrombosis Center (IHTC) since 2006 where her focus is optimizing care and education for persons and families with bleeding disorders. Stacie served as a member of the National Hemophilia Foundation (NHF) Physical Therapy Working Group from 2009 to 2014. During her tenure with IHTC she has presented on physical therapy and activity related topics at several of the NHF and Hemophilia of Indiana annual meetings, and on the International Society on Thrombosis and Haemostasis webinars. She presented on the use of point of care ultrasound for hemophilia at the NHF Great Lakes Regional meeting and the pre-conference session of the Hemostasis and Thrombosis Research Society in 2017. Stacie is an active faculty member of the Partners in Hemophilia Program and presents throughout the year on physical therapy and orthopedic considerations for Basic Partners, Advanced Nursing Partners, and Advanced Physical Therapy Partners programs. For the past 9 years she has participated in a collaborative educational partnership with the medical professionals at Moi Teaching and Referring Hospital in Eldoret Kenya and continues to assist with development services for persons with bleeding disorders.

Maureen K. Baldwin, MD, MPH, Associate Professor of Obstetrics and Gynecology, Oregon Health and Science University, Portland, OR
■ Dr. Maureen Baldwin received her medical degree and Master of Public Health at Oregon Health and Science University (OSHU) and subsequently completed her obstetrics and gynecology residency and fellowship in family planning at OHSU. She has a practice focus designation in Pediatric and Adolescent Gynecology. She is clinical director of the Early Pregnancy Assessment Clinic and co-director of the interdisciplinary hematology and gynecology adolescent Spots, Dots and Clots clinic which takes care of teens with heavy menstrual bleeding. Dr. Baldwin serves as a medical advisor for NHF and the Foundation for Women & Girls with Bleeding Disorders. Her research has included abortion safety, diagnosis of early pregnancy loss, early postpartum IUD outcomes, system approaches to long-acting contraceptive uptake, and teaching with simulation.

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.

Honey Blankenship, MSN, MBA, RN, CCM, CPN, Senior Clinical Specialist, Takeda, Hebron, KY
■ Honey has been a senior clinical specialist with Takeda since September 2018. Prior to joining the Takeda team, Honey spent four years managing a case management team at the Cincinnati Children's Hospital. Honey also spent four years as a nurse care manager at the Cincinnati Children's Hospital Hemophilia Treatment Center. During that time Honey enjoyed educating patients and families and advocating for the bleeding disorder community. Honey received a master's in nursing leadership and management and a Master of Business Administration from Walden University. Honey is also a certified case manager and a certified pediatric nurse.


Boyd


Bridges


Davis


Edwards

Karen Boyd, LMS, Clinical Social Worker, Michigan State University Center for Bleeding and Clotting Disorders, Lansing, MI

■ Karen, a licensed clinical social worker, has been active in the community for over 17 years. She serves as the social worker for the Michigan State University Center for Bleeding and Clotting Disorders. Karen is a strong advocate for women and girls with bleeding disorders so that “their voices might be heard.” She specializes in promoting healthy intimacy with individuals and has enhanced many relationships at workshops and retreats. When away from her busy professional life, Karen enjoys ballroom dancing, gardening, entertaining, travel, and a good cup of coffee.

Margaret Bridges, Program Manager, GutMonkey

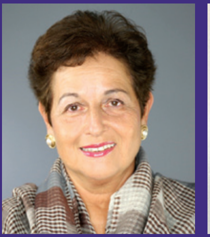
■ Margaret (she/her) is a Program Manager with GutMonkey. She believes in exploring the intersection of creativity and people’s connection with themselves, their communities, and our earth. She has facilitated programs globally in youth development, women’s leadership, arts and community engagement, 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 the commitment to comprehensive care.

Steven Edwards, LMSW, Social Worker, Michigan State University Center for Bleeding and Clotting Disorders, Lansing, MI

■ Steven graduated from Michigan State University with his Master of Social Work in 2010. His previous professional experience involved outpatient therapy and community-based therapy with at-risk youth and their families. His professional interests include post-traumatic stress disorder, substance abuse, and anxiety management. When he’s not working, Steven enjoys spending time with his family.



Espinosa-Thomson

Foley

Greist

> "If you don't like the road you're walking, start paving another one."
>
> ~ Dolly Parton

Patricia Espinosa-Thomson, Community Liaison, Takeda

■ Patricia obtuvo su licenciatura en Antropología de la Universidad de los Andes en Bogotá, Colombia. Durante ese tiempo, su deseo de entender los matices multiculturales entre los diferentes grupos étnicos llevó a la experiencia de investigación práctica tanto viviendo como trabajando junto a las remotas tribus indígenas de la Amazonía. Esta investigación se convirtió en la base de su carrera en conectividad humana y comprensión cultural. Patricia tiene una maestría en Administración de Recursos Humanos de la Universidad Nova Southeastern en Florida en 1977, un estado que ha llamado hogar desde entonces. Durante casi tres décadas, Patricia ha trabajado en el campo de la salud especialmente en el área de salud mental proporcionando apoyo, educación y liderazgo en una variedad de roles. Esta pasión por la educación y el desarrollo comunitario la ha llevado a su trabajo actual como "Enlace Comunitario" en Takeda desde 2007.

Patricia earned her bachelor's degree in anthropology from the University of los Andes in Bogota, Colombia. During that time, her desire to understand the multicultural nuances among different ethnic groups led to the hands-on research experience both living and working alongside the remote indigenous tribes of the Amazon. This research became the foundation for her career in human connectivity and cultural understanding. Patricia received a master's degree in human resource management from Nova Southeastern University in Florida. For nearly three decades, Patricia has served the healthcare system in Florida focusing her attention on the mental health service community by providing support, education, and leadership across a variety of roles. This passion for education led to her current role as community liaison at Takeda since 2007.

Jill Foley, RDH, RN, BSN, Nurse Clinician, Michigan State University Center for Bleeding and Clotting Disorders, Lansing, MI

■ Jill proudly joined Michigan State University Center for Bleeding and Clotting Disorders staff in 2019 as a registered nurse with over 10 years' experience in the hospital setting, including ICU, code nurse, and case management. Prior to her nursing career, she practiced as a registered dental hygienist for over 20 years. She obtained her dental hygiene degree from Mott Community College where she earned the Golden Scaler Award. She received her Associate Degree in Nursing at Mott Community College, where she earned the Hurley School of Nursing for Clinical Excellence, and her Bachelor of Science in Nursing from Capella University. She has great passion for both the medical and dental fields and is thrilled that her current position with MSU allows her to utilize both degrees. Jill lives near East Lansing and loves spending time with her adult daughter and son (a senior at MSU, Go Green!). She enjoys spending time with her family and friends, walking, jogging, dancing, cooking, sports, and spending time outside.

Anne Greist, MD, Co-Founder and Co-Medical Director, Indiana Hemophilia and Thrombosis Center, Indianapolis, IN

■ Dr. Anne Greist is co-founder and co-medical director of the Indiana Hemophilia and Thrombosis Center (IHTC). A board-certified hematologist/oncologist, she graduated from King's College Medical School in London and completed an internal medicine residency and hematology/oncology fellowship at Indiana University. Since 1998, she has served as co-medical director at IHTC and clinical associate professor at the Indiana University Medical Center. Her focus is on bleeding and thrombotic disorders, sickle cell disease, other non-cancerous conditions, and global health issues. Since 2010, Dr Greist has led a team from IHTC in a collaboration with a hematology program in Western Kenya.

Gusba

Henningfeld

“Be yourself, know what you want from life, and go get it.”
~ Ghada Gebara

Laura Gusba, CNP, MSN, Nurse Practitioner, Hemophilia Treatment Center and Benign Hematology, Henry Ford Hospital, Detroit, MI
■ Laura is a native of Michigan and has many nurses in her family. She married, and moved to Windsor, Canada and completed 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!

Anne Henningfeld, MA, CTRS, Managing Partner, Beyond Recreation, NC
■ Anne has more than ten years’ experience directing summer resident, day, and travel camps for a variety of populations, including hemophilia, traumatic brain injury, and at-risk youth. Since 2014, she has spent her summers executing her favorite part of summer camp: staff training. Anne completed her master’s degree in therapeutic recreation from the University of Toledo and is a Certified Therapeutic Recreation Specialist. A two-time recipient of the Health Education Award of Distinction from NHF and the 2009 Michigan Hemophilia Professional of the Year, Anne is in demand as a speaker and presenter. She was the 1998 Central Florida Yo-Yo Champion and toured the United States doing motivational school assembly programs. Prior to COVID-19, Anne spent the off-season researching and improving her staff training modules while accompanying her husband Michael as he performed in the global tour of Cirque du Soleil’s Kooza. Currently, Anne develops virtual programming and produces virtual events and camps for non-profit organizations.

Hover

Ingram-Rich

Johnsen

Jones

Gretchen Hover, Co-Founder and Managing Partner, Imbue Partners, LLC

■ Gretchen is a trusted speaker, trainer, author, and facilitator with over 25 years of experience working with patients, families, doctors, nurses, specialty pharmacists and others, for many rare diseases. She has continued developing content and delivering cognitive and behavioral programs for nearly 10 years. Gretchen earned a master's degree in Organization Development and Change from The Pennsylvania State University. She is an active member of the Massachusetts Biotechnology Council (MassBio). Her previous work includes master faculty and change agent for the United States National Security Agency (NSA), lecturer at Boston University and Bentley University in Massachusetts, and featured speaker with Women in Technology International (WITI).

Robina Ingram-Rich, RN, BSN, MS, MPH, Retired HTC Clinical Nurse

■ Robi worked at the Oregon Hemophilia Center at the Oregon Health and Science University (OSHU) for 30 years [1986-2016] in the roles of clinic nurse, genetic counselor, Region X coordinator, grant writer, quality improvement lead, and hemophilia camp nurse. She also worked on developing the parenting program, PEP 2.0. Robi also served as part-time nursing training coordinator for the Leadership in Neurodevelopmental and related Disabilities [LEND] training program at Oregon Institute of Development & Disability at OSHU from 1985 to 2020, including mentoring trainee of underrepresented ethnic/racial group. In addition to Robi's earlier work at Cowell Student Health at the University of California Davis, Robi has also worked as an orthopedic research nurse at UC Davis Medical Center, Sacramento; operating room nurse at UC Davis Medical Center; and critical care nurse, UC Davis Medical Center & Sutter General Hospital, Sacramento.

Jill Johnsen, MD, Associate Member, Bloodworks Northwest Research Institute; Associate Professor, University of Washington, Seattle, WA

■ Dr. Jill Johnsen is an associate member of Bloodworks Northwest Research Institute, and an associate professor, Department of Medicine, University of Washington. Dr. Johnsen's research is focused on blood clotting disorders that are inherited, such as von Willebrand disease, familial platelet disorders, and acquired blood-related diseases, including pregnancy-related vascular complications.

Jeannette Jones, Program Manager, Hemophilia Federation of America, OK

■ 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.

> "True belonging doesn't require you to change who you are; it requires you to be who you are."
>
> ~ Brené Brown, Braving the Wilderness

Kulkarni

"I raise up my voice—not so I can shout but so that those without a voice can be heard… We cannot succeed when half of us are held back."

~ Malala Yousafzai

Roshni Kulkarni, MD, Professor Emerita, Department of Pediatrics and Human Development, and former Director, Michigan State University Center for Bleeding and Clotting Disorders, Lansing, MI

■ Dr. Roshni Kulkarni is currently professor emerita of Pediatrics and Human Development and former director of the Michigan State University (MSU) Center for Bleeding and Clotting Disorders, and Pediatric and Adolescent Hematology/Oncology (PHO). She was the director and distinguished Hematology Consultant, Division of Blood Disorders, at the Centers for Disease Control and Prevention (CDC), Atlanta GA. She is a founding member of the Foundation for Women and Girls with Blood disorders. She is a member of various professional societies and committees, including the World Federation of Hemophilia Women with Inherited Bleeding Disorder Committee, CDC Joint Outcomes Committee, and Inhibitor Committee. She is a past member of NHF's Medical and Scientific Advisory Committee, American Thrombosis and Hemostasis Network Leadership Committee, American Society of Pediatric Hematology/Oncology, and the Hemophilia and Thrombosis Research Society. She is a founding member of the MSU Women and Girls Blood Disorder Clinic, a collaborative comprehensive care clinic of the MSU Departments of Pediatrics and Human Development, OB-GYN and Reproductive Biology, and Internal Medicine. She has received numerous awards that include NHF's "Physician of the Year," MSU "Distinguished Faculty" award, distinguished service award from the FDA and CDC, and has been named to the Best Doctors in America since 2007. HFM's National Women's Conference considers Dr. Kulkarni to be the 'Fairy Godmother' of women with hemophilia and related bleeding disorders.

Martinez

Mast

> “Do you have the courage to bring forth the treasures that are hidden within you?”
>
> ~ Elizabeth Gilbert

Mary (Maria) Martinez, CMI-Spanish, Medical Interpreter, Texas Children’s Hospital, Houston, TX

■ Mary received a bachelor’s degree in criminology and criminal justice at the University of El Paso in El Paso, Texas. During an internship in the juvenile and adult detention facilities at the El Paso County Jail/Annex, she was assigned to support the prison healthcare staff with the Spanish speaking population in the medical clinics. Through this work, she quickly grew to love helping others resolve language barriers, assisting communication, and interpreting. Since then, interpretation and translation have played important roles in her life. Mary has been working as an interpreter at Texas Children’s Hospital in Houston, Texas since 2011. In 2015, she received her Certified Medical Interpreter (CMI) credentials from the National Board of Certification for Medical Interpreters. Mary has been interpreting for the hemophilia community for over 23 years—an experience that has been deeply rewarding.

Alan Mast, MD, Senior Investigator, Blood Research Institute, Blood Center of Wisconsin, Milwaukee, WI

■ Dr. Alan Mast is a senior investigator at the Blood Research Institute of Blood Center of Wisconsin where he holds the Walter A. Schroeder Endowed Chair for Blood Research. Dr. Mast received a Bachelor of Science in biochemistry from the University of Illinois and MD and PhD degrees from Duke University. He performed residency training in Laboratory Medicine at Washington University in St. Louis.


Messenger


Munn


Nammacher


Nguyen-Driver

Heather Lynn Messenger, MSDH, Registered Dental Hygienist, Michigan State University Center for Bleeding and Clotting Disorders, Lansing, MI

■ Heather joined MSU's Center for Bleeding and Clotting Disorders team in 2017 as a registered dental hygienist with more than 15 years of experience. She graduated from the University of Michigan where she obtained her Master of Science in Dental Hygiene. She received her associate degree in dental hygiene at Lansing Community College where she later served as an adjunct faculty member for three years. She received the 2020 CARE AWARD from the American Thrombosis of Hemostasis Network. Her current research titled: "A Cross-Sectional Study of the American Thrombosis and Hemostasis Network Cohort for Outcomes of Dental Extractions in People with Hemophilia" was submitted to the Journal of American Society of Hemophilia in August 2021. She loves spending time with her two daughters and additional family and friends, gardening, walks, camping, and drinking coffee.

Jim Munn, MS, BS, BSN, RN-BC, Program Administrator and Nurse Coordinator, Hemophilia and Coagulation Disorders Program, University of Michigan Health System, Ann Arbor, MI

■ Jim is the program administrator and nurse coordinator at the Hemophilia and Coagulation Disorders Program at Michigan Medicine in Ann Arbor, where he has worked since 1996. In addition to caring for pediatric and adult patients at the clinic, Jim has served as chair, vice chair, and regional representative for the NHF Nursing Working Group and as the US representative, vice chair, and chair of the World Federation of Hemophilia Nurses Committee. He is a board member of Partners in Bleeding Disorders Education, which provides comprehensive, broad-based education for providers from a variety of disciplines throughout North America's HTC network. Jim also co-founded Adult Fellowship for Integrating Responsible Mentors (AFFIRM) with retired social worker Edward Kuebler. AFFIRM is a two-year international advocacy and leadership development program to enhance participants' leadership and advocacy skills to improve care, programs, and treatment in their communities.

Kate Nammacher, MPH, Vice President of Education, National Hemophilia Foundation

■ Kate is the vice president of education at the National Hemophilia Foundation and oversees educational programs for women, youth, and those affected by VWD, Steps for Living, inhibitors, and rare bleeding disorders. Kate has a passion for education, training, and supporting people to live their lives to their fullest.

Mina D. Nguyen-Driver, PsyD, Psychologist, Oregon Treatment Center, Oregon Health and Science University, Portland, OR

■ Dr. Mina Nguyen-Driver was recruited to Oregon Health and Science University (OHSU) in 2007 as a pediatric psychologist at the Institute on Development and Disability. Prior to her appointment at OHSU, she held a pediatric psychologist position at Children's Hospital Los Angeles (CHLA). During her CHLA tenure her work included direct patient care in the Division of Clinical Immunology and Allergy, as well as the Department of Plastic and Maxillofacial Surgery. She also shared her time at the Maternal Child and Adolescent Clinic at USC Keck School of Medicine.

Reinbold

> “A woman with a voice is by definition a strong woman. But the search to find that voice can be remarkably difficult.”
>
> ~ Melinda Gates

Corbett Reinbold, RN, BSN, CCRC, Nurse Coordinator, Comprehensive Center for Bleeding Disorders, Versiti Blood Center of Wisconsin, Milwaukee, WI

Corbett graduated with a Bachelor of Science in microbiology from the University of Wisconsin and later completed a Bachelor of Science in Nursing from Columbia College of Nursing, Mount Mary College, Milwaukee, Wisconsin. Corbett is a nurse coordinator at the Comprehensive Center for Bleeding Disorders at the Versiti Blood Center of Wisconsin, with more than 10 years of experience working with adult and pediatric hematology populations. Corbett’s experience includes patient centric education and coordination of individualized care for patients and families. He is personally involved in the hemophilia community, attending national meetings, and presenting at local educational events. Corbett was an influential voice in developing the hemophilia camp in Wisconsin for children affected by genetic bleeding disorders, Camp Klotty Pine, and actively takes part in camp and as an organizing committee member with the regional HTC chapter. His professional certifications include American Heart Association-Basic Life Saving and Association of Clinical Research Professionals- Certified Clinical Research Coordinator.

Rotellini

Sidonio

Simms-Cendan

> "Don't look at your feet to see if you are doing it right. Just dance."
>
> ~ Anne Lamott

Dawn Rotellini, Chief Operating Officer, National Hemophilia Foundation, New York, NY

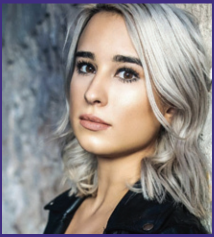
■ Dawn has been a leader in the bleeding disorders community for many years. As a parent of a son with hemophilia, she founded the Rocky Mountain Hemophilia & Bleeding Disorders Association in Bozeman, Montana, and served as its executive director. After moving to Pittsburgh, Pennsylvania, she served as a board member for the Hemophilia Center of Western Pennsylvania for six years and then as executive director of the Western Pennsylvania Chapter. She has been with the National Hemophilia Foundation for 12 years and serves as the Chief Operating Officer. Dawn also serves on the Board of Directors for the World Federation of Hemophilia and World Federation of Hemophilia USA. She chairs the Women with Inherited Bleeding Disorders Committee. She holds a Bachelor of Science in political science from Montana State University.

Robert F. Sidonio, Jr., MD, MSc, Associate Director and Director of Clinical Operations and Clinical Research, Hemostasis and Thrombosis Program, Aflac Cancer and Blood Disorders Center, Children's Healthcare of Atlanta; Associate Professor of Pediatrics, Emory University School of Medicine, Atlanta, GA

■ Dr. Robert Sidonio is a member of the Emory University and Children's Healthcare of Atlanta comprehensive care team. He attended medical school at the University of Alabama at Birmingham and completed his residency at the University of Louisville/Kosair Children's Hospital in Louisville, Kentucky. He was a fellow at the University of Pittsburgh Children's Hospital where he also attended graduate school for his Master of Science in clinical research. He continues to be a vocal advocate for women, teens and girls living with hemophilia and other rare disorders.

Judith Simms-Cendan, MD, Division Director of Pediatric Adolescent Gynecology, Department of Obstetrics, Gynecology, and Reproductive Sciences, University of Miami, Miller School of Medicine, Miami, FL

■ Dr. Judy Simms-Cendan is the founding division director of Pediatric Adolescent Gynecology at the University of Miami Miller School of Medicine OB-GYN Department. Dr. Simms-Cendan graduated from the University of Miami with her Bachelor of Science, and from the University of Florida College of Medicine with her medical degree. She completed her residency training in OB-GYN at the University of Florida in 1995, then served on the faculty and started a pediatric adolescent gynecology weekly clinic. She joined the founding faculty at the UCF College of Medicine in 2010 and opened the first practice in Florida fully dedicated to pediatric adolescent gynecology patients in 2010 at Winnie Palmer Hospital in Orlando. She founded a combined hematology/gynecology clinic for adolescent girls with heavy menses and bleeding disorders in 2017. In July 2021 she joined the University of Miami faculty to develop dedicated pediatric adolescent gynecology practices and is excited to be working with the faculty of the Pediatric Hematology Division to build a hematology/gynecology clinic at UM. Dr. Simms-Cendan enjoys teaching her patients and their families, medical students, pediatrics, and OB-GYN residents in her clinic. She has written national guidelines for care of adolescents with heavy menses and bleeding disorders (ACOG CO 785, 2019), and international advocacy statements to call attention to the need for improved care for adolescent girls with menstrual disorders.


Smith


Stadler


Watson

> “What is it you plan to do with your one wild and precious life?”
>
> ~ Mary Oliver

Ruby Jane Smith, Singer and Songwriter, SongDivision

■ Ruby Jane Smith is an American fiddle player, singer, and songwriter in the traditional bluegrass and Americana music genres. The youngest fiddler ever invited to play the Grand Ole Opry, Smith has toured and recorded with Asleep at the Wheel’s Ray Benson, Drake Bell, and Willie Nelson, and has performed on Austin City Limits. She currently lives in Nashville, Tennessee where she is writing for her next full-length album.

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.

Sarah Watson, LPC, CST, ATR, Certified Sex Therapist, Troy, MI

■ Sarah is a licensed professional counselor, AASECT certified sex therapist, and sexuality educator. Sarah has a private practice where she works with individuals and couples struggling with relationship and sexual health issues via telehealth. In addition to her private practice Sarah is also the founder of Simple Sex Education (SSE) which provides online workshops for parents to prepare themselves for starting and continuing discussions about sex and relationships with their kids. SSE also provides support for women who are struggling with sexual shame. Sarah attended Wayne State University for her graduate degree and the University of Michigan for her post graduate certification in sexual health and sexuality education. Sarah has been with her partner of 19 years and they have a daughter, who is 4 years old. Sarah enjoys providing therapy and is passionate about bringing sexual health to the masses and plans on doing so through parenting, relationships, and women’s workshops. She facilitates workshops around the country for those impacted with hemophilia. Sarah is very passionate about providing a safe and caring environment to discuss and process sexual and mental health issues. Sarah spends her “down” time with her family, exercising, reading, and enjoying her family farm in northern Michigan where they have a miniature donkey named Burrito!

> “What you do makes a difference, and you have to decide what kind of difference you want to make.”
>
> ~ Jane Goodall


Weyand


White-Ginder

> "I've been absolutely terrified every moment of my life—and I've never let it keep me from doing a single thing I wanted to do." ~ Georgia O'Keeffe

Angela Weyand, MD, Co-Director, Pediatric Hematology-Oncology Program, University of Michigan, Ann Arbor, MI

Dr. Angela Weyand is a native of Kansas City, Kansas and graduate of Northwestern University in Evanston, Illinois. She attended medical school at the University of Michigan and completed her pediatrics residency at the University of Washington/Seattle Children's Hospital. She returned to the University of Michigan for a pediatric hematology and oncology fellowship and subsequently stayed on as faculty. Clinically, she is interested in von Willebrand disease and young women and girls with bleeding or clotting disorders. She is co-director of a combined hematology/gynecology program and an active member of the Foundation for Women and Girls with Blood Disorders. Her research interests are in women and girls with bleeding disorders, hormone provoked thrombosis, and von Willebrand disease. She was a member of the management panel for the latest ASH/ISTH/NFH/WFH VWD guidelines and is national Co-Principal Investigator on an observational study of severe VWD.

Jeanne White-Ginder, Mother of Ryan White, Hemophilia/AIDS Activist

One week before Christmas in 1984 Jeanne White-Ginder was told that her son Ryan, a hemophiliac, had contracted AIDS from a tainted blood product. Although the doctors gave him only six months to live, Ryan's outlook was positive, and he was determined to live a relatively normal life. He wanted to stay in school and Jeanne was determined to give her son his dream. His crusade to remain in school captured the nation's attention and forever changed our view of AIDS and those living with it. Ryan White died five and a half years after being diagnosed with AIDS. Today, his name is an invitation to enjoy life, a call for understanding, and a cry for increased research. In the past 30 years since Ryan died, Jeanne has remained an advocate for the HIV/AIDS community. To this day she takes her story on the road, inspiring people throughout the country and the world by sharing Ryan's messages and her story as a mom. In recent years Jeanne has learned her health is impacted by hemophilia and received care and support from Dr. Greist.

Conferencia Nacional 2021 para Mujeres y las Adolescentes con Hemofilia y Deficiencias de Factores Raros*

Hear Our Voices: Setting the Agenda

(Escuchen Nuestras Voces: Establecer la Agenda, por su título en inglés)

del 8 de octubre de 2021, De 4 a 9pm y
del 9 de octubre de 2021, De 1 a 8pm Hora del Este (EST)

una experiencia virtual inconfundible

Izquierda, Susan Fenters Lerch/ derecha, Patrice Thomas

> «Piensa como una reina. Una reina no tiene medo a fracasar. El fracaso es otro peldaño hacia la grandeza.»
>
> ~ Oprah Winfrey

Queridos Amigos -

Estamos entusiasmados y agradecidos por la participación de tantas mujeres extraordinarias en la cuarta **Conferencia Nacional para Mujeres y Adolescentes con Hemofilia de la Fundación de la Hemofilia de Michigan (HFM)**, Hear Our Voices: Setting the Agenda. Esperábamos que el año 2021 nos permitiera reunirnos en persona; sin embargo, los continuos desafíos en todo el país y el mundo hacen que sea aún más importante y significativo reunirse, incluso en el espacio virtual. Estamos encantados de continuar con nuestra conferencia especializada para que las mujeres vuelvan a conectarse, a la vez que damos la bienvenida y acogemos a nuevas participantes. Nuestro comité de planificación de la conferencia alentó la incorporación este año de mujeres y adolescentes con otras deficiencias raras de factor junto con quienes viven con hemofilia A y B.

Como siempre, esperamos ofrecer un aprendizaje, una conexión, una celebración y un apoyo excepcionales. Agradecemos la flexibilidad de cada persona durante la experiencia virtual de 2021. Tenemos una nueva plataforma que esperamos sea aún más fácil de usar y atractiva. Hemos hecho grandes esfuerzos para mantener nuestro compromiso de ofrecer una experiencia agradable, interactiva, educativa y de apoyo. Pedimos que cada uno de nosotros tenga presente 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 generosamente donan su experiencia y su tiempo para reunirse con nosotros.

Nuestro equipo de HFM está trabajando de forma virtual, continuando con un compromiso extraordinario y continuo para crear esta conferencia. Juntos, estamos haciendo todo lo posible para asegurar que los participantes, ponentes, patrocinadores y simpatizantes tengan una experiencia auténtica y edificante. Por favor, sepan que seguimos comprometidos con cada uno de ustedes; con los que viven en nuestro hermoso estado de Michigan y con los de todo el país.

Gracias a cada uno de los participantes en la conferencia, a los colegas de HFM, a los presentadores, a los patrocinadores y a los colaboradores. Es nuestro sincero deseo que cada uno de nosotros encuentre la conferencia de HFM 2021 **Hear Our Voices: Setting the Agenda de HFM** sea 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
del Programa HFM

P.D. El enlace para entrar en nuestra plataforma virtual le será enviado por correo electrónico el 4 de octubre.

La Fundación de Hemofilia de Michigan (HFM, por sus siglas en inglés) existe para mejorar la calidad de vida para todas las personas afectadas por trastornos hemorrágicos. La HFM no endosa ningún producto específico o compañía.

Conferencia Nacional 2021 para Mujeres y las Adolescentes con Hemofilia~
Hear Our Voices: Setting the Agenda

DIRECTRICES DE LA CONFERENCIA

Bienvenidos a la cuarta Conferencia Nacional anual para Mujeres y Adolescentes con Hemofilia y Deficiencias Raras de Factores. El personal de HFM y nuestro grupo ad hoc de planificación de la conferencia esperan un fin de semana lleno de interacción social constructiva, educación y camaradería. Con este espíritu, agradecemos la participación de todos en las actividades para demostrar el respeto por las diferentes opiniones y métodos de autocuidado.

Debido a los problemas de salud pública nacionales relacionados con COVID-19, hemos optado por realizar una conferencia virtual este año. Dado que 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 todo el mundo sea consciente de compartir la pantalla y el audio con otras personas mientras participan en la conferencia. Por favor, tenga esto en cuenta cuando compartan 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 asistencia domiciliaria o con una empresa del sector relacionada. 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 HFM.

Le 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 decidir si comparten su información personal en las sesiones de grupos grandes en las que pueden estar presentes los socios de la industria, así como la forma de compartir su nombre en la sección de asistentes. Si desea continuar la conversación con patrocinadores de la industria después del fin de semana, puede compartir su información de contacto, pero no está obligado a hacerlo. Si en algún momento se siente indebidamente presionado para proporcionar información personal, por favor, informe a un miembro del personal de la HFM inmediatamente. 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.

HFM no respalda ningún producto o empresa específica.

¡Estamos muy contentos de que nos acompañe!

Todos los horarios corresponden a la hora del este.

viernes, 8 de octubre

4:00 – 4:20p ~ Escenario Principal
¡Bienvenido!
► Traducido al español

■ Oradora: Susan Fenters Lerch, Directora Ejecutiva, Fundación de Hemofilia de Michigan; Network Regional Director, Great Lakes Region V-E HTC

4:20 – 4:25p ~ Escenario Principal
Notas del Patrocinador
► Traducido al español

■ **Oradora:** Laura Russo, Enfermedades Raras Pfizer, Jefe del Equipo de Asuntos de Pacientes en EE.UU.

4:25 – 5:25p ~ Escenario Principal
Profundizando y haciendo un chapuzón: Inicio de la conferencia con GutMonkey
► Traducido al español

¡Vamos a sumergirnos! Acompáñanos en el inicio de la Conferencia Nacional para Mujeres y Adolescentes con Hemofilia y Deficiencias Raras de Factores mientras exploramos el objetivo y el espectro de la salud, la identidad y la navegación de la vulnerabilidad en los «rápidos» de nuestro mundo cambiante. Descubriremos lo que hay en el agua por debajo de la punta del iceberg, remaremos los afluentes entre el dejar ir y el cultivar el crecimiento, y echaremos una red con otros en la comunidad para ver lo que pescamos. ¡Hagamos un chapuzón!

■ **Oradores:** Haelynne Barron, Directora del Programa, GutMonkey; Margaret Bridges, Gerente del Programa, GutMonkey

◆ Apoyados por Pfizer

5:30 – 6:50p ~ Escenario Principal
Actualización: Organizaciones Nacionales Abogando por las Mujeres y Niñas
► Traducido al español

Nuestras organizaciones nacionales de trastornos hemorrágicos, la Federación de Hemofilia de America (HFA) y la Fundación Nacional de Hemofilia (NHF), presentarán resúmenes de sus recientes actividades de divulgación entre las mujeres y las niñas, así como planes para futuros proyectos.

■ **Oradores:** Maureen Baldwin, MD, MPH, Associate Professor of Obstetrics & Gynecology, Oregon Health and Science University; Jeanette Jones, Gerente del Programa, Federación de Hemofilia de America; Kate Nammacher, MPH, Vice Presidente de Educación, Fundación Nacional de Hemofilia; Angela Weyand, MD, Co-Director, Programa Pediátrico de Hematología/Oncología, Universidad de Michigan

6:50 – 7:00p ~ Escenario Principal
Notas del Patrocinador
► Traducido al español

■ **Oradora:** Jane Cavanaugh Smith, Sanofi Genzyme, Jefe, Asuntos Públicos y Abogacía de los Pacientes—Trastornos Hemorrágicos Raros

viernes, 8 de octubre

7:45 – 8:45p ~ Salas de Zoom

Grupo de Discusión

3 **HELLO Talk: Salud emocional y bienestar: Explorando la conexión entre mente y cuerpo**

► Presentado en español

La mente y el cuerpo están conectados—el cuidado de su salud emocional es imperativo para mejorar su bienestar físico y su bienestar en general. Esta presentación explorará cómo vivir con un trastorno sanguíneo puede afectar la salud mental y su bienestar. Al mismo tiempo cómo la salud emocional puede afectar la calidad de vida de la persona. También hay oportunidades a lo largo de la presentación para la autorreflexión, así como ejercicios para practicar la reducción del estrés y el aumento de la atención plena.

■ **Oradora:** Patricia Espinosa-Thomson, Community Liaison, Takeda

8:50 – 9:00p ~ Escenario Principal

Resumen y cierre del primer día de la Conferencia

► Traducido al español

«Nos deleitamos con la belleza de la mariposa, pero rara vez admitimos los cambios que ha sufrido para alcanzar esa belleza.»

~ Maya Angelou

sábado, 9 de octubre

1:00 – 1:10p ~ Escenario Principal

¡Bienvenidos!

► Traducido al español

■ **Oradora:** Susan Fenters Lerch, Directora Ejecutiva, Fundación de Hemofilia de Michigan; Network Regional Director, Great Lakes Region V-E HTC

1:10 – 1:20 ~ Escenario Principal

Notas del Patrocinador

► Traducido al español

■ **Oradora:** Heather Dean, Vice President, Jefe de Franquicia de Hematología, Takeda

Presentación del Invitado Especial

► Traducido al español

Ruby Jane Smith, Cantante y Compositor, SongDivision; Patrice Thomas, Directora del Programa, HFM

1:25 – 2:25p ~ Escenario Principal

Anemia por Deficiencia de Hierro: Lo Que Debe Saber

► Traducido al español

Muchas mujeres y niñas con trastornos hemorrágicos sufren de anemia ferropénica no diagnosticada. En esta sesión se analizarán los síntomas, las consecuencias médicas y se ofrecerán sugerencias para el tratamiento de la anemia ferropénica.

■ **Moderadora:** Jill Johnsen, MD, Miembro Asociado, Bloodworks Northwest Research Institute; Profesor Asociado, Universidad de Washington

■ **Oradores:** Jim Munn, MS, BS, BSN, RN-BC, Administrador del Programa y Enfermero Coordinador, Programa de Trastornos de Hemofilia y de la Coagulación, Sistema de Salud de la Universidad de Michigan; Alan Mast, MD, Investigador Superior, Blood Research Institute, Blood Center of Wisconsin

2:30 – 3:30p ~ Escenario Principal

Utilización de la ecografía para identificar y gestionar las hemorragias articulares

►Traducido al español

¿Ya no puede disfrutar de algunas actividades físicas como correr o jugar al tenis debido a los dolores articulares? ¿Podría estar relacionado con su trastorno hemorrágico? En esta sesión aprenderá más sobre las hemorragias articulares y la utilización de la ecografía para evaluar específicamente las hemorragias articulares. Un diagnóstico preciso es muy importante para el éxito de un plan de tratamiento.

■ **Oradores:** Stacie Akins, PT, MHS, Fisioterapeuta, Centro de Hemofilia and Trombosis de Indiana; Joanna Davis, MD, Director Médico, Centro Pediátrico de Tratamiento Integral de la Hemofilia, Sistema de Salud de la Universidad de Miami

3:35 – 4:35p ~ Salas de Zoom

Grupo de Discusión

1 Hacer amigos con su Centro de tratamiento

►Traducido al español

Todos luchamos con los desafíos de la vida, ya sea un paciente o un proveedor de atención médica, especialmente en estos tiempos. Esta sesión le proporcionará consejos y sugerencias para mejorar su relación con sus proveedores, sin importar lo que que la vida nos depare.

■ **Oradores:** Robina Ingram-Rich, RN, BSN, MS, MPH, Enfermera Clínica del HTC Jubilada; Mina D. Nguyen-Driver, PsyD, Psicóloga, Centro de Tratamiento de Oregon, Oregon Health and Science University

5:20 – 5:30p ~ Escenario Principal

Notas del Patrocinador

►Traducido al español

■ **Oradora:** Tammy Blain, RN, BSN, MBA, OCN, Hemophilia Biopharm Region Director, Novo Nordisk

5:30 – 5:35p ~ Escenario Principal

SongDivision

►Traducido al español

Breve revisión con nuestro compositor, Ruby Jane Smith, para asistir a su presentación de la canción del final de la conferencia.

5:40 – 6:40p ~ Escenario Principal

Retos de la Salud Emergentes de Las Mujeres y Niñas: A. Planificación para el Embarazo y Parto; B. Reconocer las causas de las hemorragias anormales cuando no estoy embarazada.

►Traducido al español

En esta sesión se tratan dos importantes cuestiones de salud. La planificación del embarazo y del parto es un aspecto fundamental de los cuidados personales cuando se tiene un trastorno hemorrágico, y este tema se tratará con detalles sobre la comunicación con el personal médico y tener planes documentados. También hablaremos de otras posibles causas de hemorragias en la salud reproductiva que no están relacionadas con el trastorno hemorrágico de la mujer.

■ **Oradores:** Jill Johnsen, MD, Miembro Asociado, Bloodworks Instituto de Investigación del noroeste; Profesor Asociado, Universidad de Washington; Judy Simms-Cendan, MD, Directora de División de Ginecología Pediátrica Adolescente, Departamento de Obstetricia, Ginecología y Ciencias de la Reproducción, Universidad de Miami, Miller School of Medicine

6:45 – 7:40p ~ Escenario Principal
Opciones de Tratamiento: Utilización del Factor y Profilaxis

► Traducido al español

¿Por qué no se utiliza la profilaxis con las mujeres, aunque tengan los mismos niveles de factor que los hombres? En esta sesión se presentará información sobre los retos de integrar la profilaxis y el uso del factor en los regímenes de tratamiento para las mujeres.

■ **Orador:** Robert F. Sidonio, Jr., MD, MSc, Director Asociado y Director de Operaciones Clinicas e Investigacion Clinica, Programa de Hemostasis y Trombosis, Aflac Cancer and Blood Disorders Center, Children's Healthcare of Atlanta; Associate Professor of Pediatrics, Emory University School of Medicine

7:40 – 8:00p ~ Escenario Principal
Sesión de cierre

► Traducido al español

¡Nos reuniremos y experimentaremos una canción original que capturará nuestro increíble tiempo juntas este fin de semana!

■ **Ponentes:** Ruby Jane Smith, Cantante y Compositor, SongDivision; Patrice Thomas, Directora del Programa, HFM

> «¿Tienes el valor de sacar a la luz los tesoros que tienes escondidos?»
>
> ~ Elizabeth Gilbert

¡Tu opinión es importante!

Por favor, ayúdenos a mejorar, evaluando nuestra conferencia, sesiones y oradores.
¡Los estamos escuchando!

Vaya en línea al:
www.hfmich.org/wc-evaluate

¡Le invitamos a mantener su computadora encendida durante la conferencia!

Esperamos que se unan a nosotros con las cámaras de sus computadoras encendidas para esta experiencia virtual. La Conferencia Nacional para Mujeres y Adolescentes con Hemofilia—y ahora con deficiencias raras de factor—ha sido un evento transformador para las asistentes, en parte debido a las interacciones, conversaciones y apoyo entre mujeres. Esperamos continuar con esta conexión a través de nuestra experiencia en línea invitando a todos ustedes a estar presente y compartir sus rostros con las demás.

También entendemos que usted puede tener razones personales para no querer salir en la cámara. Lo reconocemos y respetamos su derecho a participar de la forma en que se sienta más cómodo.

Esperamos verle y oírle durante nuestra conferencia de dos días de la manera que le haga sentirse más cómoda y conectada.

¡No es demasiado pronto para tomarse selfies!

Estamos muy agradecidos con estas mujeres que compartieron sus selfies del Retiro de Mujeres de la HFM esta primavera pasada.

Para el iphone, en las preferencias, ponga la cámara en «Auto HDR». Esto puede ser diferente de un teléfono a otro. Envíe sus fotos por correo electrónico, en el tamaño más grande, a **sprocario@hfmich.org**

with gratitude

Thank you to all our amazing speakers 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.

We'd like to express our appreciation to our exceptional content advisors:

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Tim Wicks

As well as all HFM staff members who serve many roles in the community, including help with this year's conference.

Save the dates, October 7-9, 2022!