



Hemophilia Federation of America's 2020 Virtual Symposium AGENDA



Remember:

- The virtual platform works best when using Chrome as your browser.
- We recommend turning off pop-up blockers for a better experience.
- Some sessions will lead you to Zoom – we recommend downloading the Zoom app before joining Virtual Symposium.
- If at any time you experience trouble, click on **Help Desk** in the **Lobby**.

All times are eastern time zone.

MONDAY. AUGUST 24

2 to 3 p.m. | Welcome Session & Symposium Overview

Welcome to Symposium! During this review, participants will learn the ins and outs of Symposium 2020 and accessing all of the amazing capabilities our virtual platform has.

Presented by Michael DeGrandpre and Carrie Koenig, M.S. Ed.

3 to 4 p.m. | Children's Art

This family friendly session is a great way to take a break from bleeding disorders education and make some art! Learn about the artist Kandinsky and nonrepresentational art, and then try painting to music!

Presented by Nannette Howard

3 to 4 p.m. | Yoga for Joint Health

This one hour guided yoga practice will focus on gentle yoga poses and movement to loosen tension in the joint spaces.

Presented by Rachel Grant, PRYT, 200-RYT

3 to 4 p.m. | Safety Summit Update

The bleeding disorders community experienced an unexpected number of recalls and other product safety notices in 2019. These events were unsettling to many as they echoed tragedies of the past, showed gaps in the system that serves the community in the present day and highlighted a need to articulate standards that will serve the community as we enter into a new and uncharted era of gene therapy and other novel treatments. HFA and NHF partnered to convene a jointly-sponsored Safety Summit in early 2020 – we will share the findings from the Summit and what steps are next in order for the bleeding disorders community to remain vigilant.

Presented by Sonji Wilkes and Miriam Goldstein, J.D., with HFA and Nathan Schaefer with the National Hemophilia Foundation

4 to 5 p.m. | Making Medicare Work for You

With an aging bleeding disorders population, many are becoming eligible for health care coverage via Medicare. We'll review fundamentals of Medicare and the specifics for individuals living with a chronic condition. We'll cover the pitfalls to avoid and how to get the maximum benefits from your coverage.

Presented by Kathleen Holt



MONDAY, AUGUST 24

Industry Session

5 to 6:30 p.m. | Give It a Shot: A Different Type of Hemophilia A Therapy | Sponsored by Genentech

Our industry sponsor provides you with an opportunity to hear about the latest product and industry information. You will have an opportunity to ask questions and learn about the industry's latest happenings.

This engaging symposium led by and made for members of the hemophilia A community features panelists as well as community ambassadors sharing their personal experiences with treating and living with hemophilia A. This presentation will include information about a subcutaneous treatment option for hemophilia A, including important clinical trial data, its half-life and dosing options. Panelists will provide useful resources for the hemophilia A community and answer questions in a live Q&A.

Session content is independent of HFA's program sponsored by Genentech Inc.

Panelists: Joanna Davis, M.D., and Courtney Huckel Carr, R.N.-BC, MSN, CPNP

BREAKOUT SESSIONS

Hemophilia Breakout Session

6:30 to 7:30 p.m. | Digital Awareness in a World of Anonymity

In a small, insular communities such as ours, people often occupy multiple roles — patient, pharmacy, nonprofit, caregiver and homecare just to name a few. As use of online services such as video conferencing, social networking and virtual meetings have skyrocketed, it's important to keep track of who is who online. We'll examine unique players with unique motives within our bleeding disorder community, as well as pose some questions designed to have you think critically about who you interact with online.

Presented by Michael DeGrandpre

vWD Breakout Session

6:30 to 7:30 p.m. | The Context and History of Bias in Healthcare

With a look back in history, we better understand how medicine continues to leave the most marginalized people in our society sick and vulnerable. This eye-opening educational presentation explains why folks continue to experience bias in healthcare.

Presented by Christie VanHorne, M.Ed, MPH

Rare Diseases Breakout Session

6:30 to 7:30 p.m. | Self-Triage: Managing Bleeding & Pain

How much is too much? Do you know how to distinguish between symptoms that can be managed at home and when it's time to speak with a doctor?

Presented by Becki Burkowitz

Inhibitors Breakout Session

6:30 to 7:30 p.m. | What Triggers You: Combating Isolation

It's not easy living with an inhibitor; even within the inhibitor community there are differences in health outcomes. Learn how to recognize the triggers of negative emotions, including depression, anxiety and PTSD. Our speaker will provide hands-on, interactive coping strategies and ways we can help each other combat isolation.

Presented by Gary McClain, Ph.D.

LIVE ONLY 6:30 to 7:30 p.m. | Rap Session: Partners and Spouses

A roundtable discussion on issues important to YOU! A moderator will guide this discussion allowing for a safe space for spouses and partners to share about their personal experiences. Individuals 18+ who are the partner/spouse of an individual living with a bleeding disorder and welcome and encouraged to attend.

Moderated by Catherine Melton



MONDAY, AUGUST 24

7:30 to 8:30 p.m. | Symposium Keynote - Lindsay Vos: Sharing Her Journey

We welcome Lindsay Vos, patient advocate extraordinaire, to share her journey from diagnosis through battling Hereditary Hemorrhagic Telangiectasia, a malformation of blood vessels, which affects multiple organs of the body. Tune in to engage, support, and understand how Lindsay's upbeat and positive attitude has helped her to navigate the management of her chronic disorder.

TUESDAY, AUGUST 25

3 to 4 p.m. | Zumba

Get your body moving with this high-energy, dance-based exercise class to unwind and have some fun!

Presented by with Wanda McClendon

LIVE ONLY 4 to 5 p.m. | Rap Session: Blood Sisterhood Happy Hour | Session 1 of 2

An annual tradition at HFA's Symposium, join this roundtable discussion with fellow adult women with bleeding disorders to connect and learn. This session is only for adult women living with a bleeding disorder and will be closed to industry representatives who are not an adult woman with a bleeding disorder.

Moderated by Andy Anderson and Anna Bell LICSW, LSCSW-C, LISW

4 to 5 p.m. | 140 Countries, One Global Community: Help WFH Attain Treatment for All

Bleeding disorders patients live all across the world. Learn more about the World Federation of Hemophilia and the work WFH does to reduce the inequities in diagnosis and access to treatment. See how WFH invests in the bleeding disorder community's future and hear how you can get involved with their work.

Presented by Roddy Doucet, World Federation of Hemophilia and Jennifer Laliberté

Industry Session

5 to 6:30 p.m. | The Path Forward: Importance of Healthy Lifestyles and High Factor Levels | Sponsored by Novo Nordisk

Our industry sponsor provides an opportunity to hear about the latest product and industry information. You will have an opportunity to ask questions and learn about the industry's latest happenings.

We will discuss the importance of healthy living in people with hemophilia, including weight management and explain how small changes, such as managing portion sizes and engaging in the right physical activities, can improve the overall health of people with hemophilia. Information on a new treatment option for hemophilia A will also be presented.

Session content is independent of HFA's program, sponsored by Novo Nordisk Inc.

Presented by Tammuela Chrisentery-Singleton, M.D. and Daniel Martinez

BREAKOUT SESSIONS | SESIÓN DE TRABAJO

Rare Diseases Breakout Session

LIVE ONLY 6:30 to 7:30 p.m. | Rap Session: Rare Disorders

This peer-support discussion is a space to celebrate your wins, share what you've learned, and find a shoulder to lean on. Open to individuals with rare bleeding disorders and their family/friends and is closed to industry representatives not affected by a rare bleeding disorder.

Moderated by Anna Bell, LICSW, LSCSW-C, LISW



TUESDAY, AUGUST 25

vWD Breakout Session

6:30 to 7:30 p.m. | Find Your Voice

Through this interactive storytelling session, we use practical strategies to identify essential medical information to share with doctors and your medical team. Participants will learn how to best prepare for appointments and how to describe their symptoms effectively. We will practice learned concepts through reflective journaling exercises and storytelling.

Presented by Christie VanHorne, M.Ed, MPH

Sesión de trabajo en español

6:30 to 7:30 p.m. | Cuidado de la salud mental, un reto en familia

En esta presentación, hablaremos de la importancia de cuidar y mantener su salud mental como objetivo de toda la familia. Hablaremos a fondo de: Atención plena en familia: ¿Qué es la atención plena o la Atención Consciente? Hablemos de los sentimientos y las emociones difíciles Cómo fomentar la resiliencia y el bienestar en tiempos difíciles La importancia de las rutinas y la necesidad de realizar ajustes. Aprendiendo a ser más flexible como familia y cómo cultivar la flexibilidad.

Presentado por Erika Bocanegra

7:30 to 8:30 p.m. | Annual Awards Ceremony

Our annual recognition ceremony honors the service of special individuals who have gone above and beyond in support of the bleeding disorders community. We will have an overview of our exciting Final Night Event, reveal a fun photographic project we've been creating just for the bleeding disorders community, and make a special announcement about Symposium 2021!

WEDNESDAY, AUGUST 26

2 to 3 p.m. | Celebration of Life

Lest we forget: we commemorate and pay tribute to the trailblazers of our community who have passed and allow family and friends a special time to celebrate our loved ones who lost their lives due to complications related to hemophilia and other bleeding disorders.

Moderated by Carletha Gates, Ph.D., HS-BCP

3 to 4 p.m. | Who Hasn't Had an Insurance Issue?

It's inevitable — at some point in your bleeding disorders journey you are likely to face an insurance barrier. Now it is your opportunity to ask questions to a panel of bleeding disorders policy experts. We will share common insurance issues and the pathways to resolution.

Moderated by Sonji Wilkes, Panelists: Miriam Goldstein, J.D., Mark Hobracszk J.D., MPA, Kimberly Ramseur J.D., MPH, Michelle Rice

4 to 5 p.m. | HFA's FIRST Project Update

We wrap up year one of a two-year award from the Patient Centered Outcomes Research Institute (PCORI) entitled Females In Research Sharing and Translation (FIRST) by sharing the work that has been completed thus far, including the results and findings of our listening sessions across the U.S. with women in the bleeding disorders community. We will present the work planned for the second year, including the formation of a Community-Based Research Network (CBRN), and how this network of community stakeholders can further efforts to increase women's participation in research studies.

Presented by Janet Chupka, BSN, R.N.



WEDNESDAY, AUGUST 26

Industry Session

5 to 6:30 p.m. | How Often Do You Use Your Joints? | Sponsored by Sanofi Genzyme

Our industry sponsor provides an opportunity to hear about the latest product and industry information. You will have an opportunity to ask questions and learn about the industry's latest happenings.

Whether you're going about your day or doing the things you love, you may not realize how much you rely on your joints. Taking care of your bleeds and joint bleeds play an essential role in managing hemophilia A. Join Community Relations and Education Manager Tanya Stephenson and physical therapist Cindy Bailey as they share their insights into what it takes to care for your joints.

Session content is independent of HFA's program, sponsored by Sanofi Genzyme.

Presented by Physical Therapist Cindy Bailey and Tanya Stephenson

6:30 to 7:30 p.m. | Barrier to Care: The Impact of Accumulator Adjuster Programs

Accumulator adjuster programs are increasingly worrisome for the bleeding disorders community. AAP's are when a health insurer can exclude manufacturer copay assistance amounts when calculating a patient's overall deductible or out-of-pocket maximum. As a community, we must advocate to decision-makers and educate them that this practice results in higher out-of-pocket costs and causes a serious barrier to access to care. Learn more about how your voice can be heard!

Presented by Stephanie Hengst

BREAKOUT SESSION

LIVE ONLY 6:30 to 7:30 p.m. | Rap Session: People of Color

It's no secret that there are existing disparities and inequities within bleeding disorders; unfortunately, there is also not much talk about it. This session is the first of many conversations we will have with members of the bleeding disorders community regarding challenges faced getting diagnosed, accessing quality comprehensive care, educating others on your rare condition, and so much more. HFA wants to hear from you so that we can work together to eradicate barriers to care for all members of the bleeding disorders community. This session is focused on centering the experiences of People of Color.

Moderated by Kimberly Ramseur J.D., MPH, Dr. Mabel Crescioni and Martha Boria Negron

7:30 to 8:30 p.m. | Journey to Healthier Joints

Are you interested in increasing your activity level, and in turn, improving your joint health? This panel of Blood Brothers is eager to share their experience participating in HFA's 2019 Best of You: Journey to Healthier Joints men's activity challenge. The Bleeders of the Great Northwest are committed to increase your knowledge and awareness of safe physical activities for people with bleeding disorders and how to build a team, using competition to improve joint and overall health.

**Your Journey to Healthier Joints Activity Challenge is supported by Cooperative Agreement Number NU27 DD001151-05, funded by the Centers for Disease Control and Prevention.*

Presented by Bleeders of the Great Northwest, Activity Challenge Winners representing Hemophilia Foundation of Oregon, now called, Pacific Northwest Bleeding Disorders and Ann LeWalk



THURSDAY, AUGUST 27

2 to 3 p.m. | Research Poster Session and Chat with Poster Presenters

This patient-centered research poster session gives bleeding disorders community members a chance to learn about research in layman's terms. Posters feature research on topics such as parenting stress and social support among hemophilia families, literature review findings on quality of life and health utility for people with hemophilia, and developments in cell therapy in hemophilia. Patients will have the opportunity to ask questions to gain a better understanding about the research and what has been done on behalf of the bleeding disorders community.

Research posters are available to view throughout the conference by visiting the Research Room.

Presented by Whitney Armijo

3 to 4 p.m. | Bodyweight Bootcamp

No equipment is required for this calorie blasting workout – a 45-minute bodyweight workout with Coach John Blake to improve balance, increase mobility, build core strength and lay the foundation for a healthy mind, body and spirit. All ability levels are welcome!

Presented by Jonathan Blake, Certified Personal Trainer

4 to 5 p.m. | The Fight for Health Equity

Your access to health care and positive health outcomes should not be tied to your race, religion, gender, sexual preference, age or where you live. However, it's the reality for many in the bleeding disorders community. We'll hear from our speaker and a panel of patients who have faced disparities and explore mechanisms to combat and eliminate gaps in care.

Moderated by Michael Robinson, Panelists: Kelly Cribbs, Shellye Horowitz, Manuel Lopez and Dr. Robert Sidonio

5 to 6:30 p.m. | Industry Session | Sponsored by BioMarin

Our industry sponsor BioMarin will provide you with an opportunity to hear about the latest product and industry information. You will have an opportunity to ask questions and learn about the industry's latest happenings.

BREAKOUT SESSION | SESIÓN DE TRABAJO

6:30 to 7:30 p.m. | Terapia Física y estilos de vida saludables

Conozca lo que dice la ciencia sobre los trastornos de sangrados y el ejercicio y sobre las técnicas de autocontrol, y discuta los cambios saludables en el estilo de vida que pueden ayudar a reducir la frecuencia de daños y severidad de sangrados. El objetivo de esta sesión es capacitar a los pacientes para mejorar su calidad de vida.

Presentado por Dr. Edwin Porras

7:30 to 8:30 p.m. | Mental Health During a Time of Crisis

We are living in challenging times and many of us are now asking how to move forward and to create much needed and lasting change. This session addresses these concerns from a mental health perspective with guidance on having honest conversations, helping children to talk about what happened, and for families to take constructive action.

Presented by Gary McClain, Ph.D.

BREAKOUT SESSION

LIVE ONLY 9 to 10 p.m. | Rap Session: LGBTQ+

A roundtable discussion on issues important to YOU allowing for a space of safety and inclusivity. Individuals 18+ living with a bleeding disorder who identify as LGBTQ+ are welcome and encouraged.

Moderated by Shellye Horowitz



FRIDAY, AUGUST 28

3 to 4 p.m. | Yoga to Help Relieve Pain and Anxiety

Join us for a slow and relaxed yoga flow to get you in a calm and relaxed state.

Presented by Rachel Grant, PRYT, 200-RYT

4 to 5 p.m. | On the Horizon

We will discuss where we've been and where we're going with respect to treatments and therapies for bleeding disorders with a panel discussion. Each panelist will present information on topics such as our history, current treatments and emerging treatments and attendees will have an opportunity to submit questions to be answered by presenters.

Presented by Paul Limberis R.Ph., David Clark Ph.D., Lisa Hensley, Ph.D.

5 to 6:30 p.m. | Industry Session | Sponsored by Takeda

Our industry sponsor Takeda will provide you with an opportunity to hear about the latest product and industry information. You will have an opportunity to ask questions and learn about the industry's latest happenings.

BREAKOUT SESSIONS | SESIÓN DE TRABAJO

6:30 to 7:30 p.m. | Welcome to the Bleeding Disorders World: Now What?

Welcome to the Bleeding Disorders World! The phrase that no parent has ever enjoyed hearing. Learn who's who in at an HTC, how to make the most of your clinic visit and where to find trusted sources of information. Sue Geraghty, R.N. M.B.A., former HTC nurse coordinator, will also share some of her experiences working with new bleeding disorders parents.

Presented by Sue Geraghty, R.N., M.B.A.

6:30 a 7:30 p.m. | Sesión de Rap: Sangre Latina Familias

Apoyo a Nuestras Familias: Esta discusión de apoyo de familias hispanas es un espacio para celebrar nuestros triunfos, compartir lo que hemos aprendido y encontrar nuevos amigos el apoyo. Esta sesión será en español y no tendrá traducción a otro lenguaje y está abierta a personas con trastornos de sangrados, sus familiares y amigos, y está cerrada a miembros de la industria no afectados por un trastorno de sangrado.

Moderado por Alexandra Abreu, MSSW

7:30 to 8:30 p.m. | Wounds That Don't Bleed

As parents of children with bleeding disorders, we are in tune with all wounds that bleed. There are times when a child has a wound that doesn't follow typical bleeding disorders style. Parents will learn to identify common mental health disorders in children and explain the signs and symptoms of more serious mental health issues. Attendees will also learn about valuable resources to support parents of children either diagnosed or seeking a diagnosis of a wound that doesn't bleed.

Presented by Jeffrey Karst, Ph.D.

7:30 to 8:30 p.m. | On the Horizon Q&A Rap Session

This facilitated rap session about current, new and emerging treatments and therapies is a follow-up to our On the Horizon session at 4 p.m. ET on Friday, Aug. 28. Feel free to join us whether you attended On the Horizon or not!

Moderated by Lori Long

Blood Brotherhood Breakout Session

LIVE ONLY 7:30 to 8:30 p.m. | Rap Session: Blood Brotherhood | Session 1 of 2

An annual tradition at HFA's Symposium, join this roundtable discussion with fellow adult men with bleeding disorders to connect and learn. This session is only for adult men living with a bleeding disorder and will be closed to industry representatives who are not an adult male with a bleeding disorder.

Moderated by Michael Hargett and Steve Long



SATURDAY, AUGUST 29

BREAKOUT SESSIONS

2 to 3 p.m. | Back to School: How to Advocate for Your Child with a Bleeding Disorder

Life during a pandemic is full of challenges. School during a pandemic is even more challenging. Dr. Juliana Bloom will review basic school advocacy protections for children with a bleeding disorder and will also share how to find balance in managing school expectations during this pandemic. She will share how to best work with school systems to continue to provide the outlined appropriate modifications and accommodations your child may have.

Presented by Juliana Bloom, Pediatric Neuropsychologist Ph.D.

Blood Brotherhood Breakout Session

LIVE ONLY 2 to 3 p.m. | Rap Session: Blood Brotherhood | Session 2 of 2

An annual tradition at HFA's Symposium, join this roundtable discussion with fellow adult men with bleeding disorders to connect and learn. This session is only for adult men living with a bleeding disorder and will be closed to industry representatives who are not an adult male with a bleeding disorder.

Moderated by Steve Long and Michael Bishop

Blood Sisterhood Breakout Session

2 to 3 p.m. | Managing Reproductive Tract Bleeding

From menarche to menopause and beyond, managing reproductive tract bleeding is a tricky business. Dr. Sarah O'Brien, M.D., shares her knowledge about taming the tides.

Presented by Sarah O'Brien, M.D., MSc

Blood Brotherhood Breakout Session

3 to 4 p.m. | Telehealth Now ... And Forever

With clinics and check-ups moving online during the COVID-19 crisis, many Blood Brothers and Sisters are left with questions about telehealth. How do I prepare? Will I get the same level of care I'm used to? Will this function be accessible after the crisis has passed? We will look into the best strategies to prepare for your telehealth visits, as well as do our best to forecast if this is a service we can expect to stick around.

Presented by Christie VanHorne, M.Ed., MPH

Blood Sisterhood Breakout Session

LIVE ONLY 3 to 4 p.m. | Rap Session: Blood Sisterhood | Session 2 of 2

An annual tradition at HFA's Symposium, join this roundtable discussion with fellow adult women with bleeding disorders to connect and learn. This session is only for adult women living with a bleeding disorder and will be closed to industry representatives who are not an adult woman with a bleeding disorder.

Moderated by Andy Anderson and Anna Bell LICSW, LSCSW-C, LISW

Families Breakout Session

3 to 4 p.m. | Family Cooking Demonstration

Looking for a healthy, quick, family meal in 30 minutes or less? Join Blood Brother and chef Mike Hargett during this live cooking demonstration! Mike will be demonstrating how to make a meal for the whole family using common pantry ingredients and will also share a bit of his experience with hemophilia and his career path.

Presented by Mike Hargett

Families Breakout Session

4 to 5 p.m. | Roundtable Discussion: Back to School: How to Advocate for Your Child with a Bleeding Disorder

Education during a global health pandemic can be overwhelming and Dr. Juliana Bloom will lead this roundtable discussion to help you process this new normal.

Moderated by Juliana Bloom, Ph.D. and Anna Bell LICSW, LSCSW-C, LISW



SATURDAY, AUGUST 29

Industry Session

5 to 6:30 p.m. | My Journey to Jivi | Sponsored by Bayer

Our industry sponsor provides an opportunity to hear about the latest product and industry information. You will have an opportunity to ask questions and learn about the industry's latest happenings.

Join Bayer for a virtual "My Journey to Jivi" event to learn more about Jivi antihemophilic factor (recombinant) PEGylated-aucL. Special guest speakers from the community will share stories about their life experiences and transition to Jivi, a treatment option from Bayer. You'll also learn more about the science behind Jivi, including results from the Jivi extension study.

Session content is independent of HFA's program, sponsored by Bayer.

Presented by Tiago Dias, Ryan Moulton, Juan Pablo Lopez Padilla, Stacey Mollinet

7:30 to 9 p.m. | FINAL NIGHT EVENT

Sponsored by Novo Nordisk Inc.

Gathering top tier performers from some of the best entertainment groups in the world, Michael Jay Garner and Beyond Recreation will shape a Final Night performance in the brand-new arena of virtual online performance. Talent will draw from artists who have toured with Cirque du Soleil and Britney Spears World Circus Tour, hold multiple Guinness World Records, and appeared on Broadway and films such as The Greatest Showman, performing from across the U.S., Mongolia, Russia and Taiwan.

MEMBER ORGANIZATION TRACKS AND SESSIONS

The following sessions are for executive directors and staff of HFA's member organizations only.

Tuesday, August 25

2 to 4 p.m. | Navigating a Changing Landscape - Member Organization Survival Plans for a Post-Pandemic World

Executive Directors join their colleagues to hear what approaches they have taken to keep their organizations on mission during the pandemic and how they are preparing for survival in 2021. This panel discussion setting will provide time for Q & A and identify critical topics for follow-up breakout room discussions.

Presented by a Panel of Member Organization Executive Directors, Ann LeWalk and Michelle Burg

Friday, August 28

2 to 3 p.m. | Hill Day Roundtable

In a changing advocacy climate, it is hard to plan for an in-person state legislative day. Hear from two HFA member organizations on what has worked from them in 2020. Let's collaborate and share ideas on how we can continue to advocate and provide avenues for legislative outreach in our new normal.

Moderator: Kimberly Ramseur, J.D., MPH | Panelists: Mark Hobracsck, J.D., MPA, Miriam Goldstein, J.D.

