



COMMUNITY

SPRINGFEST2022

ABLOOM

We cannot wait to welcome you and provide an inspiring SpringFest via our virtual platform.

PRESENTED ONLINE VIA SOCIO

SATURDAY
APRIL 23

SUNDAY
APRIL 24

CONNECTION, EDUCATION,
AND ACTIVITIES AWAIT YOU!



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SPRINGFEST2022

WELCOME

As we join together online for SpringFest 2022, we are thankful for each other's company as we learn together and share our joys and challenges. We just have to look outside to see spring blossoming and know that the spreading warmth will encourage our growth.

SpringFest is a positive, community affirming event. Community members and HFM staff involved in planning this event hope for a conference 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. We have much more in common than we have differences, and so much to learn and share with each other. Enjoy your fellow community members!

ONLINE PLATFORM

HFM will be using Socio for our online platform. Socio is where you will go to find SpringFest sessions, sponsor information, and HFM resources. To participate in SpringFest programming, we will need a different email address for each individual logging into the site. A link to the Socio site will be sent the week of SpringFest. Once the link has been sent, you are welcome to log into Socio ahead of SpringFest to familiarize yourself with the platform and interact with fellow attendees.

This program is provided to you so you can plan your weekend according to your own schedule. Feel free to look through all the offerings before our SpringFest weekend arrives; perhaps marking sessions you don't want to miss. Please read the brief descriptions of the programs so you can make the best decision about how to spend your time. We also have included photos and biographies of our speakers so you can learn more about them.

HFM is pleased to offer compensation to assist with weekend food costs. One \$150 gift card will be sent to families who attend at least 2 sessions on Saturday and 2 on Sunday (all sessions count i.e., keynote, round robin, and breakouts). Companies are not affiliated with meal costs or gift cards.

ROUNDROBIN

GUIDELINES

The Round Robin was created to provide you with industry information and to offer a space to ask questions in a small group setting. This is your opportunity to interact with industry representatives.

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 preparation. Industry reps will come prepared with a topic, video, or information that they would like to share with you.

A moderator 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.

You can also expect:

Industry reps will not 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 keep your camera on. The quality of your experience, as well as the experience of your peers in your small group, is largely dependent on the participation of everyone.

HFM does not endorse any specific product or company.

QUESTIONS ABOUT SPRINGFEST?

Contact HFM via phone or email for SpringFest assistance. HFM staff will be available on weekdays from 9:00am – 5:00pm, and on Saturday, April 23 and Sunday, April 24 from 9:00am until 2:00pm.

Call: 734-544-0015

Email: hfm@hfmich.org

NO MATTER WHERE YOU ARE ON YOUR
BLEEDING DISORDER JOURNEY,
WE'RE HERE FOR YOU.

Every MILE OF THE JOURNEY



Join us at HFM SpringFest to learn how
Takeda will be there to help you navigate your
bleeding disorder, Every Mile of the Journey.

VISIT OUR VIRTUAL BOOTH

LEARN MORE ABOUT OUR PRODUCTS AND OUR COMMITMENT TO
CONTINUE TO SUPPORT YOU — EVERY MILE OF THE JOURNEY.

JOIN US FOR THE SESSIONS BELOW:

HELLO Talk: VWD A to Z

Sunday, 04/24 9:30 AM - 10:20 AM

HELLO Talk: Women's Empowerment

Sunday, 04/24 1:00 PM - 1:50 PM

And for more resources and information, visit and enroll at

myfactorfam.com



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AGENDA

Saturday, April 23

**10:30-11:00AM SPRINGFEST OPENING
SESSION MAIN STAGE**

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

WELCOME: SpringFest Sponsors

11:00-11:50AM KEYNOTE MAIN STAGE
**Treatment Advances in Hemophilia and
Von Willebrand Disease: Impact on
Clinical Care**

The aim of this presentation is to provide
an overview of caring for patients with
hemophilia and VWD. The following
discussion points will be addressed:
strategies to improve patient care, new
generations of therapeutics, gene therapy,
technological advancements, and evolution
and equalization of bleeding disorder care
in the 21st century.

Speaker: Magdalena Lewandowska,
MD, CACP, Adult Hematologist-Oncologist,
Indiana Hemophilia and Thrombosis Center,
Indianapolis, IN

11:50-12:00PM BREAK

**12:00-1:00PM LUNCH AND LEARN - ASK
THE EXPERTS: INSURANCE MAIN STAGE**

Join our Ask the Experts session to get
answers to the most common insurance
questions. Individuals with bleeding
disorders need health insurance to afford
the treatment they need to live healthy
lives. Unfortunately, insurance is often
complex and can frustrate and overwhelm
us at times. This session is intended to
give members of the bleeding disorders
community an opportunity to hear some
of the most common insurance questions
and to feel more comfortable engaging with
their insurance plan.

Please note: You will be able to submit your
questions prior to the session to ensure
they are answered. Unfortunately, we will
be unable to give individual insurance
plan advice during this session due to the
variability of each plan. If you have specific
questions about your insurance plan, please
contact your HTC social worker.

Speakers: Kollet Koulianos, MBA, VP Payer
Relations, National Hemophilia Foundation, MI
Colleen Joiner, LMSW, CCM, Clinical Care
Manager, Cascade, Ann Arbor, MI
Ellen Kachalsky, LMSW, ACSW, Social
Worker, Henry Ford Health System, Detroit, MI
Moderator: Sarah Procario, Advocacy
Director, Hemophilia Foundation of Michigan,
Ann Arbor, MI

1:00-1:10PM BREAK

**1:10-2:00PM ZOOM ROOMS - CHOOSE
ONE BREAKOUT SESSION TO ATTEND**

Breakout sessions will be presented
on Zoom. Go to the agenda board in
Socio and click the Zoom link for the
session you would like to attend.
After your Zoom session ends, please
join us back on Socio.

1. TEEN Session: Communication and Consent

In this session you will learn how to
communicate your thoughts, feelings, and
needs in a meaningful way. We will discuss
how communication is absolutely necessary
for healthy relationships and friendships. We
will discuss consent and how it plays a role
in all relationships.

Speaker: Sarah Watson, LPC & CST,
Licensed Professional Counselor and
Certified Sex Therapist, MI

2. Take Care of You: Strategies for Improving Your Mental Health

This presentation incorporates information on how the pandemic has impacted mental health, evidence-based stress reduction strategies, information on how to utilize your HTC social worker, and ways to seek out local resources in your area.

Speaker: Steve Edwards, LMSW, Social Worker, Hemophilia Treatment Center, Michigan State University, Lansing, MI

3. Discovering What's Possible: Switching Hemophilia A Therapies in Adulthood

When did the feeling of being an adult truly kick in for you? Maybe it was when you stopped staying up late and sleeping in, or when you started getting a side of salad instead of fries with your burger. Or maybe it was when you hit amazing milestones, like starting a family or finally feeling confident in yourself.

And while you've probably figured out how to manage life with hemophilia A, maybe there is a treatment that could offer you something different.

Join us to hear from Steven, who has hemophilia A without inhibitors, as he shares his journey and how he discovered a subcutaneous treatment option in his late 40's. He will be joined by nurse practitioner, Maya Bloomberg, who will share her perspectives from treating adults with hemophilia A, and answer your questions live. See you there!

Speakers: Maya Bloomberg, MSN, APRN, University of Miami Hemophilia Treatment Center, Miami, FL

Steven L., Patient, Non-Inhibitor, Hemilbra Connections Ambassador

**Session sponsored by Genentech.*

4. Relationship Challenges During the Daily Grind: Let's Talk About It

During this highly interactive session, we will have an opportunity to enhance the

relationship with your spouse or intimate partner. We will be exploring how effective communication skills help to create authenticity in your intimate relationships. Further discussion will surround how to navigate intimacy while coping with challenging times. Come ready to share your experiences in a safe environment.

Speakers: Karen Boyd, LMSW, ACSW, DCSW, Social Worker, Olin Health Center, Michigan State University, Lansing, MI
Dave Rushlow, LMSW, Program Manager, Northern Regional Bleeding Disorder Center, Munson Medical Center, Traverse City, MI

5. Aging with a Bleeding Disorder:

Session 1 (Session 2 takes place at 2:10pm in the same breakout room covering different subjects related to the topic)

In session 1 of 2, the discussion will focus on health issues and preventive care related to aging with a bleeding disorder followed by a physical therapy presentation with tips for joint health and safety.

Speakers: Laura Gusba, CNP, Henry Ford Health System, Hemophilia and Thrombosis Treatment Center, Detroit, MI
Dhanmeet K. Singh, PT, Henry Ford Health System, Detroit, MI

2:00-2:10PM BREAK

2:10-3:00PM ZOOM ROOMS - CHOOSE ONE BREAKOUT SESSION TO ATTEND

1. Escape Room Game!

Unlock the Science of Investigational Gene Therapy Research for Hemophilia

If you like to play games, have fun, and learn at the same time, this is one event you don't want to miss. Join us and play a virtual adventure game where solving each clue gets you one step closer to unlocking the science behind an investigational gene therapy for hemophilia. The game helps players understand the genetics of hemophilia, learn about an investigational gene therapy, and discover the science of gene therapy research for hemophilia.

**Session sponsored by Spark Therapeutics.*

2. Oral Health for Patients with a Bleeding Disorder

Does going to the dentist make you nervous? In this session, we'll cover dental health in relation to bleeding disorders such as hemophilia A and B, von Willebrand disease, and platelet dense granule deficiency. We'll go over everything from home care routines and the prevention of dental problems to the dental office's health history interview and management of a wound. You'll learn tips and treatments to visit the dentist without the added stress from having a bleeding disorder. With a team approach, some basic understanding, and tools you have at home, you can be on your way to better overall health. This session will provide the valuable criteria and resources necessary to improve your health and visit the dentist safely and comfortably.

Objectives:

- establish a plan for dental visits
- become familiar with how to discuss your bleeding disorder with dental professionals
- understand how dental health affects your overall health

Speaker: Jennifer Kerns, BS, RDH, Dental Outreach Coordinator, Northern Regional Bleeding Disorder Center, Munson Medical Center, Traverse City, MI

3. Aging with a Bleeding Disorder:

Session 2 (Session 1 attendance is not required to attend Session 2)

In session 2 of 2, the discussion will focus on working with the HTC nurse to coordinate care for tests, surgeries, rehabilitation, and dental care. This session will address mental and emotional health, insurance tips and tricks, living environment, finances and Advanced Directives.

Speakers: Ellen Kachalsky, LMSW, ACSW, Integrated Case Manager/Social Worker, Henry Ford Health System, Hemophilia and Thrombosis Treatment Center, Detroit, MI

M. Linda Mueller, MSN, RN, Nurse Coordinator, Henry Ford Health System, Hemophilia and Thrombosis Treatment Center, Detroit, MI

4. Raising Resilience

"The bamboo that bends is stronger than the oak that resists."

While this proverb refers to bamboo, it's really about people. Just like bamboo, people are strong, tough, and flexible. We recognize these characteristics as signs of resilience. In this program, we will explore aspects of resilient behaviors and thoughts, learn how to build resilience in children and adults, and discuss how resilience may play a part in hemophilia management.

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

**Session sponsored by Sanofi.*

3:00-3:10PM BREAK

3:10-3:30PM TIME FOR A LAUGH!

MAIN STAGE

Stand-up Comedian: Leighann Lord

SpringFest is all about community, and laughter is one of the many ways we come together in joy, celebration, and renewed spirits. We look forward to blooming anew with you and spreading seeds of happiness and connection as we wrap up our first day with this special treat.

3:30PM FAREWELL SEE YOU TOMORROW! MAIN STAGE

**VISIT US ONLINE
AT [HFMICH.ORG/
SPRINGFEST](https://hfmich.org/springfest)**

Sunday, April 24

9:00-9:30AM WELCOME BACK!

MAIN STAGE

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

WELCOME: SpringFest Sponsors

9:30-10:20AM HELLO TALK: VWD A TO Z

MAIN STAGE

Get to know inheritance patterns, the types of VWD, and its various symptoms, including those that are specific to women. Treatment approaches available to people living with VWD will be described, as well.

Speaker: Lisa Hortsman, RN, BSN, Takeda

**Session sponsored by Takeda.*

10:20-10:30AM BREAK

10:30-11:20AM ZOOM ROOMS - CHOOSE ONE BREAKOUT SESSION TO ATTEND

Breakout sessions will be presented on Zoom. Go to the agenda board in Socio and click the Zoom link for the session you would like to attend. After your Zoom session ends, please join us back on Socio.

1. TEEN Session: Crazy Disco Trivia Bingo

Crazy Disco Trivia Bingo is all that it sounds like. Music, bingo, dancing, lights, prizes... what more can you ask for? Join as your friendly neighborhood GutMonkeys run this fun and engaging program at SpringFest. This program has been a hit around the country, and GutMonkey is excited to now bring CDT Bingo to Michigan. You can relax into the bingo side or go big on the disco side, it's up to you. There is sure to be fun, laughing, dancing...and you might

just learn something too! Come join us, see some friends from the bleeding disorders community, and get ready to yell BINGO!

Speakers: Pat Torrey, CEO and Founder, GutMonkey
Margaret Bridges, Program Manager, GutMonkey

2. My Journey: The Untold Story

Most men in the community are aware of the effects of tainted blood supplies, HIV, Hepatitis, physical challenges, pain issues, and the current struggles with COVID. This session acknowledges how men respond differently to grief, loss, and sadness. We will explore how you are coping during these tough times in a nonjudgmental way.

Speakers: Karen Boyd, LMSW, ACSW, DCSW, Social Worker, Olin Health Center, Michigan State University, Lansing, MI
Dave Rushlow, LMSW, Program Manager, Northern Regional Bleeding Disorder Center, Munson Medical Center, Traverse City, MI

3. VWD: New Treatments & National Guidelines

This session will review current guidelines and treatment options available for patients with VWD. Additionally, we will discuss promising up and coming therapies that are currently being studied in clinical trials.

Speaker: Gianna Guzzardo, MD, Pediatric Hematology Fellow at the Children's Hospital of Michigan, Detroit, MI

4. You Grow, Girl: Creating an Affirming Environment for Girls Growing Up

For many girls with bleeding disorders, one of the biggest challenges is feeling comfortable in their own skin and with their natural maturation process. Menstrual cycles can be the most difficult aspect of their bleeding disorder, and it can also be a source of embarrassment and shame. A safe and comfortable home environment can make a big difference with a girl's bleeding disorder challenges. This involves the whole family's attitude and comfort level

with the changes that puberty brings. You will learn three strategies to creating an affirming environment for the girls in your life.

Speaker: Mina Nguyen-Driver, PsyD, Associate Professor, Psychologist, Oregon Hemophilia Center, Portland, OR

11:20-11:30AM BREAK

11:30AM-12:45PM ROUND ROBIN SESSIONS WITH OUR INDUSTRY PARTNERS - ZOOM ROOMS

If you attend this session, you will be entered in a drawing with others in your Zoom room for a \$25 gift card. Companies are not affiliated with any prizes or gift cards.

12:45-1:00PM BREAK

1:00-1:50PM ZOOM ROOMS - CHOOSE ONE BREAKOUT SESSION TO ATTEND

Breakout sessions will be presented on Zoom. Go to the agenda board in Socio and click the Zoom link for the session you would like to attend. After your Zoom session ends, please join us back on Socio.

1. TEEN Session: Teen Mental Health and Wellness: An Open and Honest Conversation

Health and mental health were drastically impacted for everyone over the last two years. Join Annie as she has an open conversation about teen mental health and how we can gain strength and resilience through these unprecedented experiences.

Speaker: Annie Phillips, LMSW, PMH-C, Healing Home Counseling Group, Bloomfield, MI

2. HELLO Talk: Women's Empowerment

This HELLO Talk explores women's awareness and advocacy, how bleeding disorders uniquely impact women's health, and ways in which women function as

caregivers for loved ones with bleeding disorders.

Speaker: Lisa Hortsman, RN, BSN, Takeda

** Session sponsored by Takeda.*

3. Pain: A Different Approach

This session will provide an overview of pain and what causes it. We will also discuss non-opioid pain treatment options.

Speaker: Rosanne Ososki, NP, Karmanos Cancer Center, Detroit, MI

4. Stop Waiting to Thrive: Six Principles of Empowerment

The hardest part of thriving is getting started. This presentation will provide tips to explore gratitude and inspire yourself and those around you!

Speaker: Michelle Leona Cecil, MPA, Hemophilia Community Liaison – Great Lakes, Novo Nordisk

**Session sponsored by Novo Nordisk.*

1:50-2:00PM BREAK

2:00-2:30PM COMMUNITY AWARDS AND RECOGNITION

- Life Milestones
- Scholarship Awards

2:30PM FAREWELL TO CONFERENCE ATTENDEES. HFM MEMBERS ARE INVITED TO JOIN US FOR THE ANNUAL MEETING.

2:35PM HFM ANNUAL MEETING

- Share 2021 Year in Review
- Present survey results from community assessment; directions for the future
- Vote on bylaws change
- Vote on 2022-2024 Board

Jim Mohnach, President, Hemophilia Foundation of Michigan Board of Directors

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

COMMUNITY SPRINGFEST2022 ABLOOM

A NOTE ABOUT THE ROLE OF INDUSTRY AT SPRINGFEST:

The Hemophilia Foundation of Michigan (HFM) does not endorse any specific product or company.

It is our commitment to be transparent in relation to all HFM activities including industry support. As always, we encourage medical decisions be made under the advice of your treating physician and care team.

SpringFest provides multiple opportunities for information sharing, education, and connection. We invite you to visit our SpringFest industry partners throughout the weekend through the many opportunities available. In addition to meeting with representatives in the “round robin” sessions on Sunday, you may also use the chat feature during SpringFest to reach out to sponsors to initiate a conversation (**please note, not all sponsors will be available via chat**). You will find contact details on the “Meet Your Reps” document that was included in your SpringFest conference box, and you can find both company resources and educational materials, as well as local representative information, on the SpringFest sponsor site.

If you wish to have further conversations after SpringFest, 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.

HFM, in conversation with both the National Hemophilia Foundation and the Hemophilia Federation of America leadership, agrees that industry has a place in supporting our efforts in Michigan. HFM believes that SpringFest is an opportunity to share and receive information and education that is respectful of community members with the emphasis that medical decisions should be physician-led.

WHAT'S NEXT? YOU DECIDE.

At Genentech, we're committed to creating programs for you, with you. From a web series focused on finding the *magic* in life, to a tournament for gamers, to workshops designed to help you think well, do well, and be well, we're here to help you take on what comes next.

VISIT [GENENTECHHEMOPHILIA.COM](https://www.genentechhemophilia.com)
TO SEE HOW WE'RE CREATING
WHAT'S NEXT, TOGETHER.

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GENENTECH IN
HEMOPHILIA

Genentech
A Member of the Roche Group

Connected to milestones.

Life shouldn't be defined by limits. Through research and support, we're focused on making more possible for people living with rare blood disorders.



Let's connect.
rareblooddisorders.com
1-855-SGZHEME

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SANOFI GENZYME

COMPANY STORIES

We are very pleased to welcome our sponsors as true partners at this year's SpringFest. Each and every one 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 ONLINE SPONSOR PAGES, AND TO TAKE THE MANY OPPORTUNITIES AVAILABLE THROUGHOUT SPRINGFEST TO LEARN MORE ABOUT EACH COMPANY AND THEIR COMMITMENT TO THE BLEEDING DISORDERS COMMUNITY.

We invited our sponsors to share a few words with you about who they are.



SPRINGFEST PRESENTING SPONSOR

Takeda

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

SOARING EAGLE SPONSORS

Genentech

Genentech is a leading biotech company. Our partnership with the hemophilia community began over 30 years ago when we developed the first cloned, virus-free, nonblood-derived version of the factor VIII protein.* Since then, we haven't stopped working toward our goal of advancing and improving treatment. But this partnership goes far beyond developing medicines.

Genentech is committed to advancing all aspects of life with hemophilia A, starting with patient care. We strive to provide **Treatment for All** who need it, including underserved communities around the globe.

We Support the Person through education, resources, and tools designed to help individuals thrive throughout their treatment journey.

We Connect the Community through active engagements that help bring these individuals together to learn and grow.

Each day, we work alongside the community to improve life with hemophilia A by creating what's next together.

**Genentech outlicensed worldwide production and marketing of factor VIII.*

Sanofi

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 do everything we can to make a difference in the lives of patients, caregivers, and physicians. It's why we pursue the best possible therapies, services, and resources. Why we research, develop, and discover groundbreaking advancements. Why we use our global scale to create a true, lasting difference. From pipeline to patients, we know that our commitment has the power to truly transform. To shift the trajectory. To change lives.

HFM HAPPY CAMPER SPONSORS

CSL Behring

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

Novo Nordisk Our Philosophy

At Novo Nordisk, with each new treatment we develop, and every new patient we meet, we are expanding our commitment to helping people live better lives. Together with patients and the people who care for them, we are working toward bigger goals and visions for our world, and with any new advancement comes the question, What's next? For more than three decades, one

of our main focuses has been Changing Hemophilia®. We are changing how people with hemophilia A and B, acquired hemophilia, factor FXIII deficiency, Factor VII deficiency, Glanzmann thrombasthenia, and congenital hemophilia with inhibitors, live and how health care providers understand these conditions.

FRIENDS OF HFM SPONSORS

Pfizer

The Pfizer focus on rare disease builds on more than two decades of experience, a dedicated research unit focusing on rare disease, and a global portfolio of multiple medicines within a number of disease areas of focus, including rare hematologic, neurologic, cardiac and inherited metabolic disorders. Pfizer Rare Disease combines pioneering science and deep understanding of how diseases work with insights from innovative strategic collaborations with academic researchers, patients, and other companies to deliver transformative treatments and solutions. We innovate every day leveraging our global footprint to accelerate the development and delivery of ground-breaking medicines and the hope of cures.

Octapharma

Octapharma has a long history of dedication to hemophilia A and von Willebrand disease patients and the bleeding disorders community. Since its founding in 1983, the company has established a unique portfolio of hematology products and patient support programs used and trusted all around the world. Hemophilia A and von Willebrand disease patients alike take confidence in our products, our production expertise with the highest standards for purity, and our years of commitment to improving the lives of those in the bleeding disorders community. Octapharma is proud to support HFM and the Michigan bleeding disorders community.

SPRINGFEST DISPLAY SPONSORS

Accredo

At Accredo, we understand it can be difficult to live with a chronic or complex illness and subsequent care. As one of the nation's leading and largest providers of specialty pharmaceuticals, our dedicated therapy teams work diligently to coordinate solutions for the challenges of those living with a bleeding disorder. With accurate and timely delivery of medication, as well as expert guidance through ongoing therapy directives, you can trust Accredo to provide experienced care.

Email: bleedingdisorders@accredo.com

Bayer

From our inception, Bayer has been a leader in treatments for hemophilia A with strong relationships in the hemophilia community in the United States. Our commercial hemophilia products that reach patients around the world are made in our facilities in Berkeley, CA. We have products on the market in the United States to treat and control bleeding, and we are investigating specific gene therapy approaches.

HEMA Biologics

HEMA Biologics is a privately held biopharmaceutical company focused on the rarest bleeding disorders. We aspire to support patients living with these disorders, partner with the broader community that cares for them, and bring meaningful treatments and services to help better their daily lives.

Spark Therapeutics

Spark Therapeutics is creating a path for advancements in hemophilia gene therapy research. We are dedicated to challenging the inevitability of genetic disease by striving to discover, develop, and deliver treatments in ways unimaginable. Join us in the sponsor section to Explore the Science of Gene Therapy Research.

PROGRAM SPONSORS

Cascade Hemophilia Consortium

Cascade is proud to have provided excellent and personalized service for the bleeding disorder community in Michigan, Indiana, and Ohio since 1994. We are considered part of your HTC network, and our team is dedicated to providing you the best individualized care and quickest delivery possible.

As a non-profit 340B pharmacy, most of our revenues go the community to fund services such as educational programming, consumer financial assistance, HTC medical staff, and camp programs. In fact, we have provided over \$60 million in support to the community for close to 30 years. We hope to continue providing these services to you for many years to come.

Have a great SpringFest!
The Cascade Staff www.cascadehc.org

Hemophilia Alliance

Our Mission

The Hemophilia Alliance works to ensure member Hemophilia Treatment Centers have the expertise, resources and public support to sustain their integrated clinical and pharmacy services for individuals with bleeding and clotting disorders.

Our Vision

Through the work of the Hemophilia Alliance, the clinical and pharmacy programs of the Hemophilia Treatment Centers are integrated, stable and sustainable within a changing healthcare environment. They are trusted and respected as the preferred way to provide people with hemophilia and other bleeding disorders access to the full range of care they need.

Michelle Leona Cecil, M.P.A.

Patient advocate

About Michelle

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

Connect with Michelle

VQMC@novonordisk.com
(614) 674-0147

Hemophilia Community Liaison

Great Lakes (MI and WI)

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

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SPEAKERS



Maya Bloomberg, MSN, APRN, University of Miami Hemophilia Treatment Center, Miami, FL

Maya Bloomberg is a board-certified family nurse practitioner and the adult nurse coordinator at the

University of Miami Hemophilia Treatment Center in Miami, Florida. She earned her Bachelor of Science in nursing and Master of Science in nursing from University of Miami. She has worked in her current role for over 6 years, caring for hundreds of unique bleeding disorder patients. She is actively involved in nursing research and in 2018 had her first manuscript published in an international medical journal on the topic of home infusion of factor replacement.

Karen Boyd, LMSW, ACSW, DCSW, Social Worker, Olin Health Center, Michigan State University, Lansing, MI

Karen Boyd is a licensed clinical social worker and has been privileged to work with the bleeding disorders community for over 17 years. She was instrumental in creating retreats for men, women, couples, and families to learn more about their disorder. Karen has conducted research focusing on children with chronic illness and its impact on the family. She has been involved in conducting research for the National Impact Quality of Life on Pain Study in conjunction with sponsoring treatment centers. As a therapist, she is privileged



to work with families and adults who are impacted by a chronic health condition. Karen's priority in working with the bleeding disorders community is facilitating collaboration between consumers and providers and enhancing intimate relationships. When away from her busy professional life, Karen enjoys a delicious cup of coffee, ballroom dancing, gardening, entertaining, and travel.



Margaret Bridges, Program Manager, GutMonkey

Margaret Bridges (she/her) is a facilitator and creative that devises innovative programs connecting

communities with each other and the world around them. Her consistent curiosity and drive to explore emerging practices in community engagement stems from a decade of experience in civic practice, arts and creative development, and experiential outdoor programming. She carries degrees from Carnegie Mellon University (BFA) and The University of Texas at Austin (MA) and has developed youth, community, and cultural programs throughout the US and abroad. Notable projects include co-created and local-led trainings for women's leadership in rural southwest Morocco, the advancement of accessibility for cultural experiences in Chicago, IL, and the production of a live audio-cast series for a global audience during the pandemic. She joins GutMonkey with the belief that healthcare lies at the intersection of a connection to nature, a nurturing community, and a patient-first relationship with providers.



Michelle Leona Cecil, MPA, Hemophilia Community Liaison - Great Lakes, Novo Nordisk

Michelle is a Novo Nordisk Hemophilia Community Liaison

who lives with a bleeding disorder. She is passionate about supporting people in the community. Prior to joining Novo Nordisk in spring 2021, Michelle served the higher education and nonprofit communities.

Steve Edwards, LMSW, Social Worker, Hemophilia Treatment Center, Michigan State University, Lansing, MI



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



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

Throughout her career, Rebecca has dedicated herself to empowering individuals and families through

challenging times and encouraging them to live their best lives. Whether she's traveling, volunteering, or learning a new skill, Rebecca loves experiencing other cultures, finding interesting adventures, and meeting new people.

Laura Gusba, CNP, Henry Ford Health System, Hemophilia and Thrombosis Treatment Center, 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!



Gianna Guzzardo, MD, Pediatric Hematology Fellow at the Children's Hospital of Michigan, Detroit, MI

Dr. Gianna Guzzardo is a second-year pediatric hematology/

oncology fellow at the Children's Hospital of Michigan in Detroit, MI. She completed her undergraduate education at the University of Michigan, and her medical training at Trinity School of Medicine. She completed her pediatric residency at Beaumont Children's Hospital. Her clinical interests are in classical hematology.



Colleen Joiner,
LMSW, CCM, Clinical
Care Manager,
Cascade, Ann Arbor,
MI

Colleen feels very fortunate to have worked in the bleeding

disorders community for

the last 22 years. Colleen worked at the Hemophilia Foundation of Michigan for 15 years providing educational programming and social work services. She currently works for Cascade Hemophilia Consortium in Ann Arbor as a clinical care manager providing case management and education to the community. Colleen loves to spend quality time with her friends and family and go on adventures (near or far) to explore new cultures and experiences. As someone wise once said, "Never stop learning because life never stops teaching!"

Ellen Kachalsky, LMSW,
ACSW, Integrated
Case Manager/Social
Worker, Henry Ford
Health System,
Hemophilia and
Thrombosis Treatment
Center, Detroit, MI



Ellen has her Master of Social Work degree from Adelphi University in New York, but moved to Michigan after obtaining her degree. After working in several hospital systems, Ellen came to Henry Ford Hospital in 1997 to work in Bone Marrow Transplant and Hematology-Oncology, and covered several clinics, including the Multi-Disciplinary Clinics for Breast Cancer and the Head and Neck Clinic. She has worked in hemophilia since 1999, but prior to that, she worked in hematology & oncology, family practice, and the ICU and Step-Down units at Harper Hospital, Sinai Hospital, Providence Hospital, and St. Mary Hospital. She also worked for 3 years at HUD-subsidized

senior congregate living, where she helped residents maintain their independence by linking them with community resources and providing support, counseling, and programs. Ellen has two adult children, a son who keeps her on her toes with puns and trivia contests, and a daughter who is in film and production. She enjoys teaching clients about coping with conditions, and also teaching about the ins and outs of insurance so that they can get the maximum benefit from their insurance plans. Ellen also helps clients realize their full potential in education and employment so that they may lead happier and productive lives, while dealing with pain and other issues related to bleeding disorders.



Jennifer Kerns, BS,
RDH, Dental Outreach
Coordinator, Northern
Regional Bleeding
Disorder Center,
Munson Medical
Center, Traverse
City, MI

Jennifer Kerns, BS,

RDH is a practicing clinician, continuing education provider, and grant writer. She is the dental hygienist for the Thomas Judd Care Center as well as the Northern Regional Bleeding Disorder Center at Munson Healthcare, and she often consults for various national and community projects. Jennifer is also the dental outreach coordinator for Northwest Michigan Health Services in Traverse City, where she oversees dental students as an adjunct clinical faculty member for the University of Michigan, providing free dental care to veterans. She also holds two special permits with the state, allowing her to practice dentistry in a mobile capacity without the direct supervision of a dentist, traveling throughout seven counties in a mobile dental van providing dental services to vulnerable patients. Contact Jennifer at (231) 721-5337 or jkerns@nmhsi.org.



Kollet Koulianos, MBA,
VP Payer Relations,
National Hemophilia
Foundation, MI

Kollet is responsible for developing and overseeing all of the National Hemophilia

Foundation's (NHF) healthcare

payer education strategies, policies, programs and standards, which includes identifying and subsequent awareness campaigns to address any health plan provisions that have the potential to threaten patient access or contribute to less-than-optimal health outcomes. Kollet also provides project leadership and oversight of the NHF Comprehensive Care Sustainability Collaborative. The NHF CCSC's mission is to develop and execute ongoing strategies to elevate the visibility of the integrated comprehensive model of care as the gold standard for optimizing bleeding and clotting disorder patient outcomes, at the lowest total

cost of care. Prior to her tenure at NHF, Kollet was the Executive Director of the Bleeding & Clotting Disorders Institute (BCDI) in Peoria, IL.

Steven L., Patient,
Non-inhibitor,
Hemlibra
Connections
Ambassador



Steven is in his early 50s and lives in Pennsylvania with his wife. They have 3 wonderful daughters together. Steven previously worked in the investment business. He is an avid traveler and hopes to have visited all 50 states by the end of 2022! Since his brother had already been diagnosed, Steven was tested and diagnosed with hemophilia A without factor VIII inhibitors at birth.

DEDICATION AND PERSONAL SUPPORT



Introducing your **Pfizer Patient Affairs Liaison**, a professional dedicated to serving the rare disease community by connecting patients, caregivers, and patient advocacy organizations with Pfizer Rare Disease tools and resources. A Patient Affairs Liaison's work is guided by the principles of **compassion, commitment, and connection.**

Chris Liddell

Southern OH, MI, KY, IN

I'm here to:



Provide compassion by understanding the needs of patients, caregivers, and patient advocacy organizations and serving as a point of contact for questions they may have



Maintain commitment by educating patients and caregivers about Pfizer Rare Disease patient support resources



Facilitate connection by providing educational programs that bring patients, caregivers, and patient advocacy organizations together to share experiences and support advocacy for their communities

“I've worked in rare disease for 15 years, and I have experience collaborating with and advocating for different members of this community.”



To get in touch with Chris:

248-660-7384

chris.liddell@pfizer.com

Pfizer Rare Disease

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



Susan Fenters Lerch is an accomplished leader who has served in the nonprofit sector for more than three decades. Sue joined HFM as the executive director in June 2014; however, she came to this role having previously served as the HFM associate director from 1983-1996. In 1997 Sue joined Make-A-Wish Foundation of Michigan as president and CEO until 2010 when she launched Autism Alliance of Michigan. Additionally, Sue has served as the lead consultant in implementing World AIDS Day Detroit, initiated the Hospice of Michigan Foundation, and created Bring Joy consulting services. Currently, as the executive director at HFM, Susan is responsible for statewide patient educational programming and advocacy services and also serves as the Great Lakes and Region V-East Hemophilia Treatment Centers' regional director.

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



Dr. Magdalena Lewandowska serves as an adult hematologist at the Indiana Hemophilia and Thrombosis Center (IHTC) in Indianapolis, IN. She graduated from Jagiellonian University in Cracow, Poland, and completed postgraduate medical education in Internal Medicine and Hematology/Oncology at St. Elizabeth's Medical Center in Boston, MA. She is involved in medical education and clinical research at IHTC, with a special interest in hemophilia, rare bleeding disorders, and women's health. She is

the co-director of the GO (Girls and Women Only) clinic and the director of the Hereditary Hemorrhagic Telangiectasia program at IHTC.

Leighann Lord,
Stand-up Comedian



Dr. Leighann Lord is a veteran stand-up comedian and the author of *Dict Jokes* and *Real Women Do It Standing Up*.

She is the creator of the *People with Parents* podcast and has been a co-host on StarTalkRadio, with Neil de Grasse Tyson. She has been seen on Comedy Central, HBO, and The View, and was recently seen on Netflix in the Def Comedy Jam 25th Anniversary Special. Leighann was also one of the five national finalists in the 2018 ABFF-HBO Comedy Wings Competition. She's the winner of the 2019 Humanist Arts Award, from the American Humanist Association. Leighann is a proud member of House Ravenclaw (with a dash of Slytherin).

Jim Mohnach,
Marketing Lead,
Ford Motor
Company,
Detroit, MI



Jim serves as the president of the Board of Directors for the

Hemophilia Foundation of Michigan. Jim is also a member of the Cascade Board of Directors. In his professional life Jim is a marketing lead at Ford Motor Company where he has worked since 2018. Prior to that he held various leadership positions at GTB/Team Detroit, the advertising agency for Ford Motor Company. Jim has been involved in the hemophilia community for more than 10 years. He's so appreciative of the bleeding disorders community and

the people he's been fortunate enough to meet. He loves seeing so many old friends at events like SpringFest and the Walk. In his free time, Jim loves spending time with his family, which includes his wife Lauren, son Aiden, and daughters Emma and Isla.

M. Linda Mueller, MSN,
RN, Nurse Coordinator,
Henry Ford Health
System, Hemophilia
and Thrombosis
Treatment Center,
Detroit, MI



Linda has been a nurse for over 38 years. She has vast experience in oncology and hematology. For the past 12 years she has worked exclusively with bleeding disorders.

Mina Nguyen-Driver,
PsyD, Associate
Professor,
Psychologist, Oregon
Hemophilia Center,
Portland, OR



Dr. Nguyen-Driver is an associate professor at the Oregon Health and Science University and is directly involved with patient care at the Oregon Hemophilia Center. Dr. Nguyen-Driver is a clinical psychologist and has over 20 years of experience. She provides mental health treatment and neuropsychological evaluations to all patients and families with bleeding disorders. Dr. Nguyen-Driver's specialties include: adjustment to new diagnosis, coping, relaxation training, non-pharmacological treatment to pain management, adherence, transitioning, and effective disciplining.

Rosanne Ososki, NP,
Karmanos Cancer Center,
Detroit, MI



Rosanne Ososki has been a nurse practitioner at the

Detroit Receiving Hospital Hemophilia Treatment Center since 2009. She is interested in helping patients maximize their treatment options.

Annie Phillips, LMSW,
PMH-C, Healing Home
Counseling Group,
Bloomfield, MI



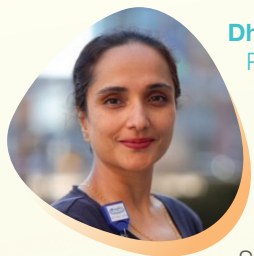
Annie Phillips is a licensed clinical social worker and the co-owner of Healing Home Counseling

Group. She spent the beginning of her career working at Children's Hospital of Michigan Hemophilia Treatment Center, and recently left that position to open her own therapy practice. As a therapist certified in perinatal mental health, she can better understand and assist families who are struggling with fertility issues, difficult pregnancies, perinatal mood disorders and postpartum struggles. Annie has devoted her career to individual people as well as her community; she led the development of a swim program in Detroit for children, adolescents, and teens diagnosed with a bleeding disorder and their siblings. These experiences have helped her develop strong therapeutic relationships and techniques with adolescents, teenagers, young adults, and parents.

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



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



Dhanmeet K. Singh,
PT, Supervisor,
Rehabilitation Services,
Henry Ford Health
System, Detroit, MI

Dhanmeet graduated
as a University
Meritorious Student in
September 2002 with a

Bachelor of Science in physical therapy from Guru Nanak Dev University (GNDU) located in India. She has over 17 years of experience as a physical therapist spanning acute care, outpatient, and home care. She has initiated several research projects in collaboration with Henry Ford Hospital head and neck cancer surgeons. She was the lead therapist to develop physical therapy treatment protocols for post-surgical head and neck cancer patients in the acute care setting and outpatient clinic. Dhanmeet was the first physical therapist to present at the 2019 Henry Ford Hospital Head and Neck Cancer Symposium. In addition to her research pertaining to head and neck cancer patients, she is a supervisor of the Rehabilitation Services Department at Henry Ford Hospital. She is responsible for managing day-to-day operations and oversight of over 110 full-time, part-time, and contingent occupational and physical therapists, rehab techs, and support staff.



**Pat Torrey, CEO and
Founder, GutMonkey**

Pat (he/him) is the
CEO and founder
of GutMonkey, an
adventure education
company providing
foundational, life
changing experiences

for communities with chronic health
conditions, that improve health outcomes,
build communities, dismantle stigma, and

increase awareness. He has designed and implemented experiential and adventure education experiences, trainings, and expeditions for thousands of teams and individuals nationwide for over 20 years. Pat unwittingly began his career traversing mountains and rivers, while working at camps and in therapeutic wilderness programs across the country. Along the way he discovered the power that shared experiences in awe-inspiring environments can have on individuals' lives, and he got hooked. His passion for quality professional training has inspired him to continue traversing mountains and rivers (more often from a plane these days) to deliver engaging and animated keynote speeches and workshop presentations at regional, national, and international events.



**Sarah Watson, LPC,
CST, Licensed
Professional
Counselor, Certified
Sex Therapist, MI**

Sarah is a licensed
professional
counselor, AASECT
certified sex therapist,

and sexuality educator. Sarah has a therapy practice located in Michigan, where she works with individuals and couples struggling with relationship and sexual health issues. In addition to her private practice Sarah is also the founder of Simple Sex Education. SSE provides online workshops for parents to prepare themselves for starting and continuing discussions about sex and relationships with their kids. SSE provides support for women who are struggling with sexual shame. Sarah also facilitates sexual health coaching for couples and individuals through Simple Sex Education.



Strength, Support and Community for People Living with Bleeding Disorders

Factor My Way is a robust patient support program from Octapharma designed for people living with hemophilia A and von Willebrand disease, and for those who care for them. We spoke with you and we listened. The insights we gathered form the foundation of our bleeding disorders patient support program. Built around your needs, Factor My Way includes resources for patients and caregivers, support for those navigating care, reliable educational materials, and uplifting community connection.



Join Today!
factormyway.com/join

Member benefits include:

- ✓ Financial assistance, including free trials and co-pay assistance for eligible patients
 - ✓ A dedicated, local Factor My Way Patient Experience Manager, a specialist in dealing with bleeding disorders
 - ✓ Access to a wide range of digital programs and events
 - ✓ On-demand access to practical and informative educational resources
- ... and lots more. Membership in Factor My Way is complimentary. Join the program at factormyway.com/join, or call 1-855-498-4260

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- Non-profit pharmacy dedicated to respond to the needs of persons affected by bleeding disorders
- A 340B covered entity offering among the lowest prices for factor available
- Governed by a volunteer board of directors from the bleeding disorders community
- Returns all excess revenues to the community for support of patient services and HTC programs

For more information visit us at cascadehc.org

PLEASE FILL OUT SESSION
& SPEAKER EVALUATIONS

THANK YOU!



Eagle Journeys Camping Programs

HFM is looking forward to hosting Eagle Journeys camping programs in-person in 2022!



NEW THIS YEAR - EAGLES NEST FAMILY CAMP JULY 24-27, 2022

Eagles Nest Family Camp is intended to introduce young children with bleeding disorders and their families to the Camp Bold Eagle experience. Eagles Nest is open to the immediate families of children with bleeding disorders ages 5-9 who have not previously attended Camp Bold Eagle.

Eagle Quest (Open to adults)
June 11-17, 2022

Eagle Outpost (Ages 14-17)
July 24-30, 2022

Camp Bold Eagle
Session 1 (Ages 6-9): July 10-15, 2022
Session 2 (Ages 10-12): July 17-23, 2022
Teen Camp (Ages 13-17): June 26-July 2, 2022

Old Beagle (Open to adults and their families)
September 9-11, 2022

Register for camp by May 27, 2022

www.hfmich.org/camp

*To participate in an HFM camp, all attendees must provide proof of full COVID vaccination.
Learn more at www.hfmich.org/covidpolicy*

HFM EXISTS TO ENHANCE THE QUALITY OF LIFE FOR ALL AFFECTED BY BLEEDING DISORDERS.