

# SPRINGFEST

SPRING INTO HARMONY

# 2023

CONNECTION, EDUCATION,  
AND ACTIVITIES AWAIT YOU!

**HYBRID • MAY 6 – MAY 7, 2023**

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WE CANNOT WAIT TO PROVIDE AN INSPIRING  
SPRINGFEST AT MARRIOTT EAGLE CREST  
YPSILANTI OR VIA OUR ONLINE PLATFORM.



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# SPRINGFEST2023

## W E L C O M E

As we join together in person and online for SpringFest 2023, 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!

This program is provided to you so you can plan to attend educational sessions and social opportunities according to your interests. For those attending virtually, the sessions that will be offered online are marked for your convenience. Please read the brief descriptions of the programs so you can make the best decision about how to spend your time.

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For those community members joining us in person at the Marriott Eagle Crest, all meals are provided from Saturday morning until lunch on Sunday. For those attending virtually, a gift card will be included in your HFM box to defray meal expenses incurred over the weekend.

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 both in-person and online.

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.

## A NOTE ABOUT THE ROLE OF INDUSTRY AT SPRINGFEST

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## LEARN MORE ABOUT HFM AT SPRINGFEST

We will have a Community Room in Auditorium 2 in the Marriott Conference Center. Come in and say hi during the day on Saturday. You will be able to get information about upcoming HFM events and activities, sign your children up for one of our camps this summer, and learn how to obtain a medical ID bracelet.

### OPPORTUNITIES TO WIN PRIZES!

In your registration packet you will find punch cards to use while going to educational sessions or visiting our sponsor tables. Have your card "punched" after attending a session or visiting a booth; drop it off at our registration table by 9:00am on Sunday morning and you'll be eligible for a prize when we have our raffle drawings at breakfast.

### ONSITE CHILD CARE

HFM has invited Corporate Kids to provide childcare at the hotel during SpringFest. Children ages 0-4 and 5-12 are eligible to participate. Our program will be open on Saturday from 10am – 5pm, and Sunday 9:30am – 12:30pm. Parents will drop children off in locations based on age:

**Ages 0-4:** Conference Room H

**Ages 5-12:** Elizabeth Ballroom

### SPRINGFEST ONLINE PLATFORM

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

SPECIAL THANKS TO  
OUR SPONSORS FOR  
HELPING TO MAKE THIS  
WEEKEND POSSIBLE!

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# AGENDA

All times are eastern standard time. All sessions in the Wilbanks ballroom at the Marriott Eagle Crest Conference Center will be broadcast to our virtual attendees through WebEx. For those attending SpringFest in person, we invite you to visit our industry sponsors in the Conference Center lobby for information and resources throughout the day, including breaks between sessions.

## SATURDAY, MAY 6

**9:00AM REGISTRATION AND EXHIBITOR SPACE OPENS**

**10:00AM CHILDCARE DROP OFF**

**Brunch will be available in the conference center lobby from 9:00-11:00am**

**10:30 – 10:45AM WELCOME  
Wilbanks Ballroom **

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

**HFM MEMBER RECOGNITION  
Wilbanks Ballroom **

**11:00 – 11:50AM KEYNOTE I  
Wilbanks Ballroom **

**Music Therapy for Stress Management**  
Chronic stress can cause a variety of symptoms and affect your overall wellbeing. In this music-filled, interactive keynote, the audience will sing along, shake along, and relax to live music as well as learn three ways we can incorporate music daily to decrease stress. Regardless of age, the healthier we are, the more successful we will be at fulfilling our goals, mission, and dreams.

**Speaker: Tim Ringgold, MT-BC, Music Therapist**

**12:00 - 12:50PM BREAKOUT SESSIONS I**

**a. Tai Chi: Harmonizing with Spring  
Conference Room D**

Spring is the time of increased flexibility and renewal. During our time together we will focus on gentle stretches, opening up, and refreshing your physical and mental connections. Master Wasantha Young will also share self-care techniques for neck and shoulder release, as well as tai chi movements that promote balance.

**Speaker: Wasantha Young,** Founder, Owner, and Director of Peaceful Dragon School

**b. Sounds Familiar? A Thought-Provoking Team Competition and Discussion Based on Familiar Bleeding Disorder Challenges**  
Conference Room B

This industry-sponsored educational session is presented by BioMarin. 100 points are on the board. Survey says?! Join the bleeding disorders community and BioMarin for this fun, interactive program where two teams will play for bragging rights and learn what others have said their top challenges are in living with severe hemophilia A. Will we agree, disagree or land somewhere in the middle with the trials and tribulations faced by ourselves or loved ones? There's only one way to find out. Come play, join the conversation and express yourself with us—Game on!

**Speaker: Evangelina Zavala, MBA, Senior Account Manager, Gene Therapy, BioMarin Pharmaceutical Inc.**

*This session is sponsored by BioMarin.*

**c. VERO: A 4-step formula to manage change**

**Wilbanks Ballroom** 

In this musical breakout Tim plays his way through a simple and easy to implement 4-step formula for transforming the challenges of change that come with aging in a 'cafe style' delivery. The audience will be inspired, entertained, and educated all at the same time.

**Speaker: Tim Ringgold, MT-BC, Music Therapist**

**d. Life with Siblings: Households with Children with Different Diagnoses**  
Conference Room F

Life can be challenging for parents of a child with a chronic condition. Add another child that does not have a chronic condition, and new challenges arise. How do parents balance the issues of spending more time with one physically challenged child, when attention is also needed for another child without those physical limitations? This session will explore the ups and downs of raising children with differing diagnoses.

**Speaker: Alice Cakebread, LMSW, Clinical Social Worker, Michigan Medicine**

**e. HELLO Talk:  
Von Willebrand Disease: A to Z**  
Conference Room A

Get to know inheritance patterns and 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 Horstman RN, BSN, Community Education Specialist, Takeda**

*This session is sponsored by Takeda.*

**12:00 – 12:50PM TEEN SESSION:  
COMMUNICATION AND CONSENT**  
Conference Room C

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**

**1:00PM LUNCH AND SCHOLARSHIP AWARDS**  
Wilbanks Ballroom

*(Adults and Teens – children will be served lunch in the childcare rooms)*

**2:00 – 2:50PM TEEN SESSION:  
FAILURE IS AN OPTION**  
Conference Room C

We often hear that "failure is not an option." However, by acknowledging and understanding our greatest failures, we can experience some of our deepest moments of personal growth. In this interactive workshop, you will learn how to celebrate your failures in a safe environment and walk away feeling more empowered and confident.

**Speaker: Eunice Brady, MSW, LICSW, Community Health Professional**

**2:00 – 2:50PM EMERGENCY RESPONSE IN MICHIGAN: RISKS AND CHALLENGES FOR PEOPLE WITH BLEEDING DISORDERS**

**Wilbanks Ballroom** 

This panel session will discuss the importance of communication with your hemophilia treatment centers in emergency situations to ensure the best possible outcome. Participants will discuss the importance of being your own advocate and also selecting a trusted person who can speak for you if you are incapacitated. HFM's special guest speaker, Teresa Tabel, will share the story of her brother who tragically lost his life due to improper coordination of services. She hopes her advocacy leads to more awareness of these challenges and improvement in communication.

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

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

**Teresa Tabel**, CFP, Financial Planner

**Matt Sterling**, Sterling Advisory and Logistics

**3:00 – 3:50PM BREAKOUT SESSIONS II**

**a. HEMGENIX (ETRANACOGENE DEZAPARVOVEC-DRLB) The first and only FDA-approved gene therapy for hemophilia B.**

**Conference Room A**

This educational program offers you and your family members the opportunity to:

- Learn about HEMGENIX, the first and only gene therapy approved for hemophilia B
- Gain insightful information and deepen your understanding of HEMGENIX through a LIVE Q&A session
- Ask questions and receive new resources on gene therapy

**Speaker:** **Corbett Reinbold**, RN, BSN, CCRCD Nurse Coordinator, Comprehensive Center for Bleeding Disorders, Versiti BloodCenter of Wisconsin

*This session is sponsored by CSL Behring.*

**b. Factor Up With Now Approved Altuviio. Discover the Possibility of Higher Factor VIII Levels for Longer**

**Conference Room B**

This presentation is intended to provide education and stimulate discussion on select topics in Hemophilia A. It reviews the role of Factor VIII activity levels in Hemophilia A. While also providing an overview on Altuviio: how it works, clinical results, and dosing/administration. As well as resources and support for eligible patients. This program is HCP led with assistance from the CoRe.

**Speakers:** **Christian J (CJ) Hansen**, RN, BSN, Clinical Program Manager, Hemophilia Treatment Center, Ohio State Wexner Medical Center, Columbus, Ohio

**Angel Guess**, RN, BSN, Community Relations and Education (CoRe) Manager, Michigan Rare Blood Disorders, Sanofi

*This session is sponsored by Sanofi.*

**c. Dads and Daughters – what a bond!**

**Conference Room D**

Are you a dad who has a daughter with a bleeding disorder? Attend this interactive session where we will explore the challenges of being an influential dad. We will explore emotions and reactions stemming from your daughter's diagnosis, from anxiety and fear to guilt and grief. We will identify the many ways a dad can impact their daughter's life through communication, values, and modeling positive behaviors – making you the best dad a daughter could have!

**Speakers:** **Karen Boyd**, LMSW, ACSW, DCSW, Social Worker, Olin Health Center, Michigan State University

**Dave Rushlow**, LMSW, Manager, Northern Regional Bleeding Disorder Center, Munson Medical Center

**d. Challenges for Children Diagnosed as Mild or Moderate**

**Wilbanks Ballroom** 

This session will address the diagnosis and treatment for children with a mild bleeding disorder. Some of the topics covered will be:

1. Use of Amicar, factor on demand, or prophylaxis? What are other treatment options?



2. Changes in bleeding patterns during childhood and adolescence.
3. What are the variations of treatment among family members who are diagnosed with the same disease state?

Bring your questions to this interactive session

**Speaker: Meera Chitlur, MD, Director,** Hemophilia and Thrombosis Treatment Center

## e. Creative Expression Activity

### Conference Room E

*This session is limited to 20 participants*

Kintsugi is the Japanese art of putting broken pottery pieces back together with gold — built on the idea that in embracing flaws and imperfections, you can create an even stronger, more beautiful piece of art. In this session participants will creatively explore kintsugi and discuss how this relates to their everyday life.

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

## 3:00 – 5:30PM TEEN SESSION: ADVENTURE LEADERSHIP

### Conference Room C

Looking to build new friendships and develop leadership skills? Teens (ages 13-17) are welcome to join us for this interactive workshop comprised of fun and engaging activities that explore group dynamics and utilize problem-solving skills. Discover new ways to communicate, collaborate, and work better together while you connect with other teens in the bleeding disorders community!

**Speaker: University of Michigan Adventure Leadership Staff**

## 4:00 – 4:50PM BREAKOUT SESSIONS III

### a. Physical Therapists “Spill the Tea”

#### Wilbanks Ballroom

Do you have questions about sports/activity/occupations/muscle or joint injury/infant development/surgeries/getting physical therapy? Come and ask this panel your burning questions! This session will be an open and interactive discussion.

**Speakers: Sherry Herman-Hilker, MS, PT,** University of Michigan Hemophilia Treatment Center

**Danielle Wagley, PT, DPT, MedSport,** University of Michigan

**Steve Houghton, PT, FAAOMPT,** The Therapy Institute

**Bill Polley, Senior Systems Analyst,** Michigan Medicine

### b. Community Counts!

#### Conference Room A

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

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

**Speaker: Skye Peltier, MPH, PA-C, Director,** American Thrombosis and Hemostasis Network Community Counts Project

### c. Understanding Gene Therapy Research and its Potential Application to Hemophilia

#### Conference Room B

This presentation will help the community understand genetics; look at what investigational gene therapy is meant to do; review history, past research and some challenges of gene therapy; and consider the potential of gene therapy research for those living with hemophilia.

**Speaker: Lesley Milliner, RN, BSN, MBA,** Patient Education Liaison, Spark Therapeutics  
*This session is sponsored by Spark Therapeutics.*

### d. So what is it like to have a partner with a bleeding disorder?

#### Conference Room D

You do not have a bleeding disorder, yet your partner does. What is that like? How do you feel? How do you manage? Come and meet other individuals who are sharing the same experience as you. This interactive session will provide an opportunity to explore your feelings and thoughts on how living with a person with a bleeding disorder impacts you even though it doesn't belong to you. It belongs to your partner. How do you manage the bleeding disorder together, or do you? We will explore these issues and more as we take on challenges and focus on how to strengthen your relationship when living with a person who has a bleeding disorder.

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

**e. Super Seven: Family Fireside Chat**  
**Conference Room F**

Living with or taking care of someone with an ultra-rare bleeding disorder can feel confusing and isolating. This discussion-based workshop will explore the National Hemophilia Foundation's children's book Super Seven. Caregivers and affected individuals will participate in a variety of activities to explore some of the book's themes. By the end of the workshop you will be able to identify steps to foster independence and include the entire family in the experience.

**Speaker:** Nikole Scappe, Program Manager, National Hemophilia Foundation

**5:15 – 6:00PM HFM ANNUAL MEMBER MEETING AND RECEPTION**  
**Conference Room E**

All HFM dues-paying members are invited to attend the annual meeting, which will include a report of HFM's activities for the past year, as well as an acknowledgment of our outgoing Board members. Light refreshments will be provided.

Interested in learning more about membership? Stop by the Community Connections Room on Saturday to learn more.

**6:00 – 7:30PM DINNER**  
**Wilbanks Ballroom**

**7:30 – 9:00PM BELIEVE LTD PRESENTS: THE SCIENCE FAIR ROAD SHOW**  
**Auditorium 2 – Community Connections Room**

The Science Fair was created to provide teens, adults, and families the opportunity to learn about the science behind bleeding disorders by combining the interactivity of a true "science center" exhibit with the visual style of the classic science fairs we all grew up with.

Come join us this evening! Prizes and snacks will be available.

**SUNDAY, MAY 7**

**8:00AM EXHIBITOR SPACE OPENS**

**9:00 – 10:00AM BREAKFAST**  
**Wilbanks Ballroom**

**9:30 – 10:00AM COMMUNITY STAFF TRANSITIONS**  
**Wilbanks Ballroom** 

**10:00-10:50AM KEYNOTE II**  
**Wilbanks Ballroom** 

**Coagulation Disorders: Fishing for new diagnostics and therapeutics**

Dr. Shavit will discuss his current groundbreaking research on the topic of genome editing, including how and why he uses zebrafish in his research.

**Speaker:** Jordan Shavit, MD, PhD Professor of Pediatrics and Human Genetics, University of Michigan

## 11:00 – 11:50AM BREAKOUT SESSIONS IV

### a. Von Willebrand Guidelines: What They Mean For You

#### Conference Room A

In 2021 the new VWD guidelines on diagnosis and treatment were published. In this workshop, you will learn more about the innovative international development and the most important changes. But even more so, you will learn what these guidelines mean for you and how to use these as a foundation for shared decision making to advocate for your own best care.

**Speaker: Nikole Scappe**, Program Manager, National Hemophilia Foundation

### b. Management Beyond Bleed Rates: Hemophilia Disease State Education, What to Consider & When

#### Conference Room D

Join us to discuss all things hemophilia A from joint and bone health, the importance of bleed prevention, and understanding some additional considerations for hemophilia management. Come learn from others about their treatment journey and making informed choices.

**Speaker: Dakota Rosenfelt**, PharmD, RPh, MBAC, Sr. Medical Science Liaison, Genentech  
*This session is sponsored by Genentech.*

### c. Aging with a Bleeding Disorder

#### Wilbanks Ballroom

Aging is a big topic, so this session will focus on consumer requested information related to bleeding with aging, bone health, and cardiovascular disease risks. A review of the health-related recommendations for older adults will be summarized.

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

### d. Smiling into the Golden Years

#### Conference Room B

We will look at how oral health affects our body and how the aging body affects oral health. How do diet and sleep affect oral health? We will look at the cost of dental care and ways to manage. Bring questions and concerns for a lively discussion.

**Speaker: Karen Ridley**, MSDH, Dental Hygienist, University of Michigan

### 11:00 – 11:50AM TEEN SESSION: MENTAL HEALTH FOR TEENS

#### Conference Room C

Mental health issues do not just impact adults but also affect younger generations. It is important to recognize and understand the mental health challenges impacting teenagers in the inherited blood disorder community. This workshop will equip you with a greater knowledge, innovative strategies, skills, and resources about these challenges.

**Speaker: Eunice Brady**, MSW, LICSW, Community Health Professional

### 12:00PM FAREWELL TO CONFERENCE ATTENDEES, EVALUATION, RAFFLE DRAWINGS, AND LUNCH TO GO OR JOIN US IN THE BALLROOM Wilbanks Ballroom

# CAMP REGISTRATION IS OPEN!

## **Eagles Nest Family Camp:** June 28-July 1

Open to the immediate families of children with bleeding disorders ages 5-9 who are new to the Camp Bold Eagle experience.

## **Eagle Quest:** (open to adults): June 10-16

### **Camp Bold Eagle:**

- Session 1 (ages 6-9): July 9-13
- Session 2 (ages 10-12): July 15-21
- Teen Camp (ages 13-17): July 23-29

## **Eagle Outpost:** (ages 14-17): August 6-12

## **Eagle Expedition:** (ages 16+): August 14-21

## **Old Beagle:** (open to adults and their families): September 8-10



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Registration closes on May 26, 2023! For more details and to register, **visit [www.hfmich.org/camp](http://www.hfmich.org/camp)**

Please see HFM's COVID policies for more information about all HFM in-person programs, including camp.



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