

SPRINGFEST 2024

COMMUNITY SPIRIT

CONNECTION, EDUCATION,
AND ACTIVITIES AWAIT YOU!

APRIL 20-21, 2024

WE CANNOT WAIT TO WELCOME YOU AND
PROVIDE A SPIRITED SPRINGFEST AT THE
SHERATON ANN ARBOR HOTEL



SPRINGFEST2024

W E L C O M E

As we come together in person for SpringFest 2024, we are grateful for the camaraderie we share, learning from one another, and embracing both the joys and challenges. Let's appreciate this time of connection and renewal together.

SpringFest is a positive, community affirming event. Community members, hemophilia treatment center, and Hemophilia Foundation of Michigan staff involved in planning this event envision a conference brimming with constructive social engagement, education, and camaraderie. In the spirit of unity, we appreciate everyone involved in activities to demonstrate respect for diverse opinions and methods of self-care. Let's embrace our shared similarities, recognizing that we have more to unite us than to set us apart. Enjoy the company of your fellow community members!

This program is provided to facilitate your attendance at educational sessions and social opportunities tailored to your interests. We encourage you to carefully review the brief descriptions of each session, enabling you to make informed decisions about how to optimize and enjoy your time at the event.

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 to 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.

If you wish to have more conversations after SpringFest, you are free to share your contact information, but you are under no obligation. 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 Bleeding Disorders Foundation and the Hemophilia Federation of America leadership, agrees that industry has a place in supporting our efforts in Michigan. HFM believes SpringFest is a chance to share and receive information and education that is respectful of community members, always emphasizing that medical decisions should be physician-led.

A NOTE ABOUT THE ROLE OF INDUSTRY AT SPRINGFEST

SPRINGFEST

COMMUNITY SPIRIT

2024

LEARN MORE ABOUT HFM AT SPRINGFEST

We will have an HFM community table and an HFM camp table in the Conference Lobby. Stop by 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 summer camps, and learn how to obtain a medical ID bracelet. You can also find information about HFM's programs on the app under the Community Rooms heading.

OPPORTUNITIES TO WIN PRIZES!

In your registration materials, you will find bingo cards designed for a fun and interactive experience as you attend educational sessions, explore our sponsor tables, and connect with fellow community members. Ensure your card is stamped or initialed after participating in a session, visiting a booth, or completing any other designated task. Drop off your completed card at our registration table by noon on Sunday to be entered into a drawing, taking place during lunch. Winners must be present to claim their prizes.

For the first time ever, we will be hosting a raffle that features the talents of your fellow Community Members! Be sure to check out the items that you can win in the hotel lobby. This is a basket raffle, so for each ticket you purchase, you will have an opportunity to place it in a basket that coordinates with an item you wish to win. Tickets are \$2 each or 6 for \$10. We will draw the winners Saturday night and announce them at lunch on Sunday. You must be present to win.

ONSITE CHILD CARE

HFM has partnered with Corporate Kids to offer childcare services on Saturday from 10am to 5pm. Children ages 0-4 are eligible to participate.

On Sunday, there will be family sessions for everyone to enjoy together. Additionally, the Petit Ballroom will be available for parents to accompany their children ages 0-4 and their siblings, offering a comfortable space for relaxation or play during sessions if needed. Please note minors under 18 must be accompanied by a guardian to use this space.

OFFSITE YOUTH PROGRAMMING

Corporate Kids is also providing a Youth Program for children ages 5-12. They will be participating in games and activities such as balloon volleyball, a soccer shootout, and relay races all before getting to experience the Ann Arbor Hands-On Museum! Travis Miller, Associate Camp Director and Program Services Manager will be accompanying the youth program. If you need to reach him, please call 734-961-3510; this number does not accept text messages.



SPRINGFEST APP

HFM will be utilizing WebEx Events as our conference app. This will be your go-to source for accessing SpringFest sessions, speaker biographies, and HFM resources. A link to the WebEx app was sent the week of SpringFest. If you did not receive the link, use the QR code above. If you need assistance accessing the app, please find an HFM staff member to assist you.

OFFSITE TEEN PROGRAMMING

Ages 13-17 will be meeting across the parking lot at Hyatt Place. You will find their agenda in teal.

QUIET ROOM

The quiet room at Spring Fest is located in Michigan V and is available as a sanctuary for attendees seeking solitude from the bustling excitement. It provides a safe space to escape noise, allowing individuals to re-center themselves and find peace. This room can also be a place for attendees to uphold their religious practices, offering a respectful environment for prayer, meditation, or reflection. Overall, the quiet room offers a retreat within the conference setting, promoting mental clarity, relaxation, and a sense of well-being amidst the busy event schedule (Available Saturday 9:00am-6:00pm and Sunday 8:00am-12:00pm).

MEMORY SWAP

If you brought items to participate in the Memory Swap to support the community as memory keepers, please find Stephanie, located in the hotel lobby, Saturday 5:00-9:00pm and Sunday 9:00am-12:00pm.

She will assist community members in scanning photographs, negatives, and documents. She will also provide the option to share brief explanations about the personal significance of these items and the importance to our broader community history. All participants will receive digital scans of their materials and a recording of their oral history interviews. By participating, you are giving consent for these materials to potentially be showcased on the HFM website or in various print and digital media formats. Also, participants can donate physical artifacts to HFM for archival preservation, if desired.

SPRINGFEST WEEKEND MEDICAL SUPPORT

In the event of a life-threatening emergency, dial 911 immediately. For all other medical concerns during SpringFest weekend, please contact our on-call nurse, Sarah Spencer at 616-844-8479 (Available 24/7, starting from Saturday, April 20, 9:00am through lunch on Sunday, April 21).

For non-emergency medical inquiries, including information about local medical care, contact the front desk of Sheraton Ann Arbor Hotel at 734-996-0600.

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

SOARING EAGLE SPONSORS

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SPRINGFEST DISPLAY SPONSORS

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HFM does not endorse any specific product or company.

SPRINGFEST PROGRAM SUPPORTER



CHAPTER EDUCATION SUPPORTER



AGENDA

We invite you to visit our industry sponsors in the Conference Center lobby and meeting hallway, for information and resources throughout the day, including breaks between sessions.

SATURDAY, APRIL 20

9:00AM–5:00PM EXHIBITOR SPACE OPEN
Conference Lobby

9:00AM–1:00PM REGISTRATION OPEN
Hotel Lobby

9:00–10:30AM BREAKFAST
Michigan I-II Ballroom

10:00AM CHILDCARE AGES 0-4 DROP OFF
Petit Ballroom

**10:10-10:25AM YOUTH PROGRAMMING
AGES 5-12 DROP OFF**
Grande I

10:30-10:45AM WELCOME
Michigan I-II Ballroom

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

**10:45–11:40AM COMMUNITY SPIRIT
KICKOFF**
Michigan I-II Ballroom

Join us for an electrifying opening session led by the dynamic Michael Jay Garner that promises laughter, bonding, and interactive excitement! Prepare for an unforgettable experience as Michael Jay engages the audience with an interactive, musical introduction and some icebreaker warmups that will help set the stage for a weekend filled with excitement and connection.

Speaker: Michael Jay Garner, BA, Beyond Recreation

**11:45AM TEEN PROGRAMMING AGES 13-17
DROP OFF**

Walk to the Hyatt Place
3223 S State St, Ann Arbor, MI 48108
Ann Arbor Sheraton Hotel Lobby

11:50AM–12:40PM BREAKOUT SESSIONS

**a. Navigating a New Diagnosis with Bleeding Disorders - Insights from Healthcare Professionals
Michigan III**

Receiving a bleeding disorders diagnosis for you or your child can be a stressful experience. In this session, a nurse and social worker will provide valuable insights and guidance tailored for those navigating the initial stages of diagnosis. This session will provide practical strategies and support to empower individuals through the complexities associated with a newly diagnosed bleeding disorder.

Speakers: **Alice Cakebread**, LMSW, Clinical Social Worker, Michigan Medicine Hemophilia and Coagulations Disorders Clinic
Allan Kucab, RN, Michigan Medicine Hemophilia and Coagulations Disorders Clinic

**b. Factor up: Discover the Possibility of Higher Factor VIII Levels for Longer
Michigan IV**

Learn about the importance of Factor VIII levels and what a first-in-class treatment could mean for your management plan.

Speaker: **Shveta Gupta**, MD, Pediatric Hematologist, Haley Center for Children's Cancer and Blood Disorders, Orlando Health, Arnold Palmer Hospital for Children
This session is sponsored by Sanofi.

**c. Session for Men with Bleeding Disorders: A Nurse-Social Worker Collaboration
Grande I**

An HTC nurse and social worker come together to shed light on the unique challenges faced by adult men living with bleeding disorders encompassing the physical, emotional, and social aspects of managing these conditions. The session will provide practical strategies and support to empower individuals in navigating the complexities associated with bleeding disorders.

Speakers: **Dave Rushlow**, LMSW, Program Manager, Northern Regional Bleeding Disorder Center, Munson Medical Center
Kathi Sheldon, RNC, Nurse Coordinator, Northern Regional Bleeding Disorder Center, Munson Medical Center

**d. Aging Gracefully: Navigating Physical and Emotional Well-Being
Grande II**

Join us for an insightful session led by an HTC nurse and social worker, to explore the typical aging process, including its social and emotional aspects. Learn essential characteristics of aging, such as balance, mobility, and overall joint and cardiac health. Discover the importance of involving your HTC in regular aging tests and gain valuable insights into managing specific needs. This session aims to empower you with knowledge to navigate the journey of aging with grace and well-being.

Speakers: **Ellen Kachalsky**, LMSW, ACSW, Integrated Case Manager/Social Worker, Hemophilia and Thrombosis Center, Henry Ford Health System
Linda Mueller, MSN, RN, Nurse Coordinator, Hemophilia and Thrombosis Center, Henry Ford Health System

**e. Managing the Transition from Pediatric to Adult Hematology
Grande III**

This session will offer guidance to understanding the changes in healthcare dynamics, fostering self-advocacy, and building a collaborative relationship with adult hematology specialists. Whether you're a young adult managing this transition or a caregiver seeking valuable insights, our discussion will shed light on essential strategies for an empowered move to adult hematology care.

Speakers: **Kristen DePew**, CNP, MSN, Hemophilia and Thrombosis Center, Children's Hospital of Michigan
Laura Gusba, CNP, MSN, Hemostasis and Thrombosis Center, Henry Ford Health System
Rosanne Ososki, NP, Benign Hematology, Detroit Receiving Hospital Comprehensive Center for Bleeding Disorders and Thrombosis

12:00–12:15PM TEEN SESSION

Ice Breakers with Michael and HFM staff

12:15–1:00PM TEENS

Lunch

12:50–1:50PM LUNCH

Michigan I-II Ballroom

(Childcare, Youth, and Teens will have lunch with their groups)

Table Topic: Join community member Jim, as he discusses his recent experience going through the testing process to find out if he qualifies for gene therapy.

1:00–2:00PM TEEN SESSION JOURNEY THROUGH THE CLOTTING CASCADE WITH JILL FOLEY

Explore the wonders of the human body by learning about the clotting cascade. What happens when someone gets an injury, and the body needs to jump into action? In this session learn how proteins work together to heal an injury.

Speaker: **Jill A. Foley**, RDH, RN, BSN, Registered Dental Hygienist, Registered Nurse Clinician, Michigan State University Center for Bleeding and Clotting Disorders

2:00–2:50PM ALIGNING EFFORTS: NATIONAL & STATE UPDATES IN BLEEDING DISORDERS

Michigan I-II Ballroom

Learn about bleeding disorders initiatives with the National Bleeding Disorders Foundation, Hemophilia Federation of America, and Hemophilia Foundation of Michigan representatives. Gain insights into the collaboration between these organizations, dedicated to enhancing the lives of those affected.

Speakers: **Samantha Carlson**, MSW, LMSW, Senior Manager of Research Programs and Partnerships, NBDF

Dan Kelsey, President and CEO, Hemophilia Federation of America

Susan Fenters Lerch, Executive Director, HFM; Regional Director, Great Lakes Federal HTC Network

Zach Ryan, MPP, Government Relations and Communications Manager, HFM

2:00–4:00PM TEEN SESSION TASKMASTER GAME FOR TEENS

Michael Jay Garner will transform into his alter ego, The Taskmaster, to lead a teen program filled with creative, mental, and physical challenges played in a game show format - with an 80s twist! There will also be plenty of music from that decade, which The Taskmaster believes has the best music of any decade.

Speaker: **Michael Jay Garner**, BA, Beyond Recreation

3:00–3:50PM BREAKOUT SESSIONS

a. Joint Pathology and Management Strategies in Hemophilia (with a nod to the normal, aging joint) - Part One Michigan I-II Ballroom

In this two-part session, presenters will discuss management of joint pathology in hemophilia. A physical therapist will review common X-Ray findings of hemophilic joint disease, focusing on hips, knees, ankles, elbows, and shoulders. Discussion will include various management strategies including non-invasive and invasive approaches. Real-life post-surgical experiences from individuals with bleeding disorders will supplement the presentation. The intention is to provide participants with a better understanding of joint disease treatment, empowering them to make better-informed decisions about their healthcare management.

Speakers: **Erin Barnes**, Lived Experience Expert

Shelley Gerson, Lived Experience Expert
Steve Houghton, PT, FAAOMPT

Bill Polley, Lived Experience Expert, Senior Systems Analyst, Michigan Medicine

Tim Wicks, Lived Experience Expert, Camp and Youth Services Director, HFM

b. Ultra-Rares and Personal Advocacy

Michigan III

This interactive workshop will explore the lived experiences of the ultra-rare bleeding disorders community through a personal advocacy lens. This is a discussion-based workshop that will allow you to learn from fellow community members' experiences in addition to sharing your challenges, experiences, and perspectives.

Speaker: Natalia Winberry, MNLM, Senior Manager of Education, National Bleeding Disorders Foundation

This session is sponsored by the National Bleeding Disorders Foundation.

c. EmpowHer Health: Women's Wellness

Michigan IV

This session will provide a comprehensive discussion of the unique challenges and considerations women face in managing bleeding disorders. We will address menstrual health, pregnancy, and beyond for women living with a bleeding disorder and supportive allies. The purpose of this session is to foster understanding, resilience, and a sense of community.

Speaker: Laura Gusba, CNP, MSN, Hemophilia and Thrombosis Center, Henry Ford Health System

d. Chair Yoga: Intentionality for Breath,

Body, and Mind

Grande I

For those with bleeding disorders, yoga provides unique benefits. Research indicates that yoga practices can enhance joint health, alleviate pain, and improve physical function in individuals with bleeding disorders. Chair yoga's gentle nature reduces the risk of injury or bleeding episodes, making it a safe and effective exercise. This class invites individuals of all ages and abilities to experience the benefits of yoga while seated or using a chair for support. Participants will engage in breath-awareness, flexibility, and strength-focused poses, fostering an empowering atmosphere of inner calm and relaxation within our bleeding disorders community.

Speaker: Saydi Davis, LLMSW, Regional Program Manager, HFM

e. Enhancing Support for Students with

Bleeding Disorders: Bridging the Gap between HTC, School, and Home

Grande II

Join us for a dynamic panel discussion where a HTC social worker, school nurse, and parent share their insights and strategies for fostering collaborative care for students with bleeding disorders. The discussion will dive into essential topics such as 504 plans and accommodations, student and parent rights at school, self-advocacy, and overcoming barriers while promoting collaboration between HTC staff and schools. The session will conclude with a Q&A segment, providing audience members with an opportunity to gain a deeper understanding of the specific needs and supports required for students with bleeding disorders in the school environment.

Speakers: Rachel Cain-Kellman, LLMSW, Clinical Social Worker, Division of Hematology/Oncology, Children's Hospital of Michigan
Vanessa Long, BSN, RN, School Outreach Nurse, Wayne RESA

f. Navigating Trauma: Strategies for Coping with PTSD in the Context of Bleeding Disorders

Grande III

This session will provide a comprehensive understanding of post-traumatic stress disorder (PTSD) within the unique context of individuals with bleeding disorders. We will explore the intricate interplay between physical health challenges and mental well-being, offering valuable insights into managing and mitigating PTSD symptoms. Join us as we discuss effective coping strategies, resilience-building techniques, and supportive resources tailored to empower those navigating the intersection of bleeding disorders and traumatic experiences. Together, let's foster a community of understanding, strength, and healing.

Speakers: Kathy Gerus-Darbishon, MA, Sociology Professor, Macomb Community College
Kaite Scott, LLMSW, Program Social Worker, HFM
Lisa Taton-Murphy, LBSW, Clinical Social Worker, HIV Treatment Program, Michigan Medicine

4:00–4:50PM BREAKOUT SESSIONS

a. Joint Pathology and Management Strategies in Hemophilia (with a nod to the normal, aging joint) - Part Two Michigan I-II Ballroom

In this two-part session, presenters will discuss management of joint pathology in hemophilia. A physical therapist will review common X-Ray findings of hemophilic joint disease, focusing on hips, knees, ankles, elbows, and shoulders. Discussion will include various management strategies including non-invasive and invasive approaches. Real-life post-surgical experiences from individuals with bleeding disorders will supplement the presentation. The intention is to provide participants with a better understanding of joint disease treatment, empowering them to make better-informed decisions about their healthcare management.

Speakers: Erin Barnes, Lived Experience Expert

Shelley Gerson, Lived Experience Expert

Steve Houghton, PT, FAAOMPT

Bill Polley, Lived Experience Expert, Senior Systems Analyst, Michigan Medicine

Tim Wicks, Lived Experience Expert, Camp and Youth Services Director, HFM

b. VWD: Finding Strength Through the Struggle Michigan III

As a person with a bleeding disorder, you have individual struggles and triumphs. There are many people – even some you haven't met – who care deeply about the challenges you face. Join us for this interactive workshop that will focus on you, your hopes, and your empowerment. You will learn how to harness frustration and turn it into positive action. You will walk away feeling energized and ready to face a new day!

Speaker: Natalia Winberry, MNLM, Senior Manager of Education, National Bleeding Disorders Foundation

This session is sponsored by the National Bleeding Disorders Foundation.

c. Understanding Gene Therapy Research and Its Potential Application to Hemophilia Michigan IV

Overview of genetics. In-depth review of investigational gene therapy, including history, past research, and challenges. Considerations of gene therapy research for those living with hemophilia.

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

d. Tai Chi Harmony: Cultivating Relaxation, Flexibility, and Joy Grande I

The benefits of Tai Chi have continued to resonate within this community. Through this form of meditation in motion Master Wasentha Young, in her playful way, will help you to reconnect with relaxation, flexibility, whole body awareness, and the strength of physical and energetic alignments. By the end of this session, you will have a sense of the connection between mind and body and feel a sense of calm and joy as you continue to "spring forward" towards your sense of well-being.

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

e. Creative Expression: How Art Can Help You Connect to Your Emotions Grande II

Join us in exploring how engaging in creative art making can be a powerful tool for understanding your emotional self. Discover the therapeutic benefits of creativity as we discuss how art offers a unique language for processing emotions. Whether you're a person with a bleeding disorder or someone touched by chronic illness, this presentation sheds light on the healing potential of artistic expression.

Speakers: Amar Haidar, BFA
Sarah Watson, LPC, CST and Art Therapist

f. Emotional Challenges in Ultra-Rare Bleeding Disorders Grande III

Join us for an intimate session where seasoned social workers convene to help attendees navigate the emotional landscape of living with ultra-rare bleeding disorders. These experts will share insights, strategies, and empathetic approaches aimed at fostering emotional well-being within this unique community.

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

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

4:00–4:50PM TEEN SESSION MENTAL HEALTH FOR TEENS

Mental Health issues are not just for adults, but also affect younger generations. It is important to recognize and understand the mental health challenges impacting teenagers in the bleeding disorders community. This workshop will equip you with greater knowledge, innovative strategies, skills, and resources to tackle these challenges.

Speaker: Lucy Ramirez, MS, LCSW, Rush Hemophilia and Thrombophilia Treatment Center, Rush University Medical Center

This session is sponsored by the National Bleeding Disorders Foundation.

5:00PM CHILDCARE AGES 0-4 PICKUP YOUTH AGES 5-12 AND TEEN AGES 13-17 PICKUP
Coach’s Room and Courtyard

5:15–6:00PM HFM ANNUAL MEMBER MEETING AND RECEPTION
Club Lounge

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 and an acknowledgment of our outgoing Board members. Light refreshments will be provided.

Interested in learning more about HFM membership? Stop by the community tables on Saturday to learn more and to see an updated agenda.

6:00–7:30PM TAILGATE DINNER
Michigan I-II Ballroom

7:30–9:00PM COMMUNITY PEP RALLY
Michigan I-II Ballroom

Join us for an evening filled with community spirit and entertainment! Enjoy a dazzling performance by the EMU Dance Team, meet beloved EMU mascot Swoop, and join in a lively session of camp songs to set the mood. Unleash your inner rock star with karaoke, savor delicious snacks, and experience an unforgettable night of camaraderie, laughter, and community pride that you won’t want to miss!

8:00–9:00pm TAILGATE GAMES
Grande I

Engage in friendly competition with tailgate games.

SUNDAY, APRIL 21

8:00AM–1:00PM EXHIBITOR SPACE OPEN
Conference Lobby

9:00–10:00AM BREAKFAST
Michigan I-II Ballroom

9:30–10:00AM HFM SCHOLARSHIP AWARDS
Michigan I-II Ballroom

9:00AM-12:00PM
Petit Ballroom

This designated space is available for respite breaks for parents with children ages 0-4 who are looking for a comfortable space to relax or play near conference activities. All minors must be accompanied by a guardian.

10:00–10:50AM BREAKOUT SESSIONS

a. Michael Jay's Solo Spectacular Show Michigan I-II Ballroom

Prepare to be mesmerized by Michael Jay Garner's captivating solo show, where he seamlessly blends jaw-dropping tricks with everyday objects, mesmerizing juggling feats, and enchanting music. After the show, don't miss the opportunity to engage with Michael during a short Q&A session, where he'll share insights, stories, and behind-the-scenes anecdotes from his life touring the world with Cirque du Soleil and Britney Spears. Get ready for a morning of spectacle, skill, and sheer entertainment!

Speaker: Michael Jay Garner, BA, Beyond Recreation

b. Emerging Therapies for Hemophilia Michigan III

Discussion of targets for emerging therapies in hemophilia, including a discussion of Pfizer investigational agents in development. If time allows, a discussion of patient-centered shared decision making for hemophilia will follow.

Speaker: Tim Riddell, PA-C, MMSc, Field Medical Director, Rare Hematology, Pfizer
This session is sponsored by Pfizer.

c. Hemophilia and Academic Success: Tools for Success in College Michigan IV

Do you know how to define your adult identity and take ownership of your health management in college? We'll discuss powerful tools to make the transition to college easier, successful, and exciting—let's hit the ground running! This program is also great for parents to help transitioning students.

Speaker: Michelle Leona Cecil, MPA, Rare Bleeding Disorders Liaison, Novo Nordisk
This session is sponsored by Novo Nordisk.

d. Karate: Philosophy and Fundamentals for Adults Only Grande I

Join 3rd-degree Karate black belt and bronze medal-winning World Champion from

our community, Parker, as we explore the philosophy of karate and learn fundamental movements. This exclusive session is tailored specifically for adults. Please dress comfortably for a light workout. Limit 30 individuals.

Speaker: Parker Higgins

e. Aging: Advance Directives, Living Wills, and Durable Power of Attorney Grande II

Navigating the complexities of aging requires thoughtful planning and understanding of legal frameworks. In this informative session, we will discuss the crucial topics of Advance Directives, Living Wills, and Durable Power of Attorney. Explore the importance of making informed decisions about your healthcare preferences, ensuring that your wishes are honored in times of incapacity, and designating a trusted individual to act on your behalf. Join us for a comprehensive discussion that empowers you to proactively shape your future and embrace the peace of mind that comes with strategic planning during the aging process.

Speaker: Saydi Davis, LLMSW, Regional Program Manager, HFM

f. One Family-World Hemophilia Day 2024 Grande III

Join us for a World Hemophilia Day 2024 generation celebration.

This community shares a connection that spans generations. Our 2024 One Family program is a celebration of the bond that comes from living with hemophilia: young and old, near and far, where we are now and where we want to be. Join us for hands-on activities like:

- Personal time capsule kits
- Selfie stations and DIY photo frames
- Wish ribbons for the global community
- Space to share your story and voice

It's all happening on World Hemophilia Day.

Speaker: Angel Guess, RN BSN, Community Relations & Education Manager (CoRe)

This session is sponsored by Sanofi.

11:00–11:50AM BREAKOUT SESSIONS

a. Should I Attend a Women and Girls Clinic at a Hemophilia Treatment Center?

Michigan III

This informative discussion is designed to provide clarity on the significance of Women and Girls Clinics at hemophilia treatment centers. We will explore the essential aspects of these clinics, offering valuable insights into the unique healthcare support they provide for females in the bleeding disorders community. Gain a deeper understanding of normal menstruation versus heavy menstrual bleeding and discover the educational resources available to empower informed decisions about attending these specialized clinics.

Speakers: Meera Chitlur, MD, Director, Hemostasis and Thrombosis Center, Children's Hospital of Michigan

Charity Stadler, RN, BSN, Nurse Coordinator, Hemostasis and Thrombosis Center, Children's Hospital of Michigan

b. Von Willebrand Disease: A-Z

Michigan IV

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: Maria Rohan, BSN, RN, Takeda

This session is sponsored by Takeda.

c. Karate: Philosophy and Fundamentals for the Family

Grande I

Join a 3rd-degree black belt in Karate and a bronze medal-winning World Champion from our community, as we explore the philosophy of karate and learn fundamental movements. This exclusive session is tailored specifically for families. Please dress comfortably for a light workout. Limit 30 individuals.

Speaker: Parker Higgins

d. Your Play Book for Dental Procedures and Prevention

Grande II

Join us for an informative and interactive session designed exclusively for families navigating the challenges of bleeding disorders and dental procedures. We will delve into the crucial intersection of oral health and bleeding disorders, offering practical insights and expert guidance to empower you and your loved ones on the path to optimal dental well-being.

Speaker: Jill A. Foley, RDH, RN, BSN, Registered Dental Hygienist, Registered Nurse Clinician, Michigan State University Center for Bleeding and Clotting Disorders

e. The Healing Powers of Touch and Writing

Grande III

Explore the profound impact of positive touch on mental, emotional, and physical well-being. Learn evidence-based strategies for incorporating healthy touch into daily life for improved overall health combined with the concept of brain dumping. Writing offers a cathartic release for the mind. When you're feeling overwhelmed or anxious, taking the time to jot down your thoughts can be incredibly therapeutic. Together, gathering the skills to soothe the mind and body in this session.

Speaker: Starlet Lee, LMT, Workshop Creator/Facilitator

12:00–1:00PM LUNCH BUFFET, EVALUATION, RAFFLE DRAWING AND PRIZES

Michigan I-II Ballroom

CAMP REGISTRATION IS OPEN!



Eagle Quest: (ages 18+): June 8-14

Eagles Nest Family Camp: June 26-29

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

Camp Bold Eagle:

- **Teen Camp:** (ages 13-17): June 30-July 6
- **Session 1:** (ages 6-9): July 14-18
- **Session 2:** (ages 10-12): July 20-26

Eagle Outpost: (ages 14-15): August 4-10

Eagle Expedition: (ages 16+): August 9-17

Old Beagle: (open to adults and their families): September 13-15



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Registration closes on May 24, 2024! For more details and to register, **visit www.hfmich.org/camp**



**SAVE THE DATE
SPRINGFEST 2025**

APRIL 26-27, 2025
DETROIT MARRIOTT TROY
200 W. BIG BEAVER RD.
TROY MI, 48084

SPRINGFEST WEEKEND MEDICAL SUPPORT

In the event of a life-threatening emergency, dial 911 immediately. For all other medical concerns during SpringFest weekend, please contact our on-call nurse, Sarah Spencer at 616-844-8479 (Available 24/7, starting from Saturday, April 20, 9:00am through lunch on Sunday, April 21).

For non-emergency medical inquiries, including information about local medical care, contact the front desk of Sheraton Ann Arbor Hotel at 734-996-0600.



www.hfmich.org



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