



THE ARTERY

SPRING/SUMMER 2023



THIS ISSUE

- 05** LANSING DAYS
AND ADVOCATING
ON THE HILL
- 27** EMERGENCY
PREPAREDNESS



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DEAR HFM FRIENDS,

We're so grateful to offer SpringFest, HFM's annual educational conference for Michigan's community online and in-person.

The last few years we have considered and navigated how to best offer education, services, programs, and our many camping opportunities, to individuals and families living with bleeding disorders. HFM's staff team, together with HTC care providers and various supporters, have worked collaboratively to assure access to care and information.

The foundation's Board of Directors have been incredible partners as we pressed forward with decision making and responsibilities to best fulfill our mission. The Board voted to have colleagues remain past their usual tenure to assure steadfast, consistent organizational support during the pandemic. My deepest appreciation to Jim Mohnach and Dr. Kathy Fessler for their willingness to remain on HFM's Board of Directors. Through thoughtful, judicious conversations with the full board and staff colleagues we worked together to continue exceptional service in kind, supportive, and new ways.

There are so many ambitious, exciting (yet demanding!) opportunities impacting our bleeding disorders community. Research, clinical trials, newly approved treatment modalities, advocacy efforts, insurance barriers, education—sometimes it seems insurmountable to meet the possibilities already taking place while considering those on the horizon. Life has improved exponentially for many in our community, while we understand there remains so much yet to be accomplished. We strive each day to improve the quality of life for you and yours, mine, and ours. That's why we persist.

With friendship and love,

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



THE ARTERY

A MESSAGE FROM HFM'S BOARD PRESIDENT: JIM MOHNACH

This is one of those bittersweet moments in life for me. My privilege of serving as the President of the Board of Directors for the Hemophilia Foundation of Michigan (HFM) is coming to a close at the 2023 SpringFest annual conference. I'm sad to leave, yet excited to hand over the honor of being the Board President to another.

I joined the Board of Directors at HFM in 2014, wanting to get involved and give something back to the Michigan bleeding disorders community—probably the same reason many have joined the board. I didn't realize at the time that it was me who would be gaining so much—friendships, opportunities to learn and form amazing collaborations, and a community that supports each other every step of the way. It's that time to look back on the work that's been achieved and reflect with pride. This part is important; it's important to celebrate the wins, learn from the missteps, share my gratitude with my fellow board members and the incredible staff at HFM who go above and beyond each and every day, and celebrate the

community that has been built through each of your individual contributions.

When I joined the board, the foundation was in a difficult space. During my first meeting, we appointed Sue Lerch as the new executive director. I had no idea how lucky I was at that moment (more on that in a bit). The foundation was beginning its transformation to what it is today and will continue to evolve into in the future: the centerpiece of the bleeding disorder community in the state of Michigan and in our region. You could say that's always been the case, and you'd be right. But throughout the last few years during unexpected difficulty when the community needed a strong foundation, HFM was there to support each and every community member in any way needed. Whether it was quickly pivoting camp online (I'm still blown away at how the team not only created something virtual but created an experience that was just as impactful as going to camp), continuing and amping up advocacy, adjusting programming for a virtual

world, or expanding the programming for the unique challenges women and girls with bleeding disorders face, HFM has been there for the community with assistance, creativity, and flexibility.

The team at HFM is second to none. The breadth of the work the team tackles from huge undertakings like camp, programming, advocacy, grant and scholarship management, and international adoptions, to the day-to-day compassion and kindness they provide to the community will always leave me impressed. They never forget about the human beings on the other end of the work they're doing. This is not only because individually they're all wonderful people—they are—but also because of the steadfast and compassionate leadership of Sue Lerch. She's been one of the best collaborators, partner, friend, mentor, and leader I've had the privilege to work nearby. I can't thank her and the entire staff at HFM enough. And the entire community, thank you for allowing me to do this work. 💧

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PAID CONSUMER OUTREACH INCLUDED IN THIS NEWSLETTER

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THANK YOU TO OUR CONTRIBUTING AUTHORS



On Tuesday, March 21 and Wednesday, March 22, 2023, twenty-nine Michigan bleeding disorders advocates joined the Hemophilia Foundation of Michigan (HFM) for our legislative advocacy event, Lansing Days. On Tuesday evening at the Kellogg Hotel and Conference Center HFM staff provided legislative advocacy training, discussed our asks, and introduced a new role-playing skit to share tips and tricks for advocates during their legislative meetings.

On Wednesday, our group of bleeding disorders advocates traveled to the capital to visit with thirty-four state legislator offices to share bleeding disorders education and discuss issues important to the community. We were particularly excited to meet with several of the 60 newly elected legislators to introduce them to the community and our needs.

Advocates asked legislators to continue funding Children's Special Health Care Services (CSHCS), a program within the Michigan Department of Health and Human Services that provides coverage for bleeding disorders treatment when all else fails. Advocates shared support for Governor Whitmer's inclusion of an age eligibility increase for CSHCS in her FY2024 budget recommendation.

Constituents also shared information on copay accumulator adjustment

programs and the financial impact they have on Michigan patients who rely on copay assistance to access their necessary medications. After stalling in the Senate Health Policy Committee during 2022, we asked legislators to support reintroduction in the 2023-2024 session. One day after our meetings, an office emailed HFM staff to express their interest in cosponsoring legislation. This is a true testament to the skill of our advocates and the importance of sharing our stories to enact change.

We were also excited to discuss our support for House Bill 4167, legislation to establish a Rare Disease Advisory Council. Serendipitously, the bill was called for a vote during our event on Wednesday! HFM staff and advocates gathered in the House gallery and were introduced to the House floor by HB 4167 sponsor, Jason Morgan. We are thrilled to share that the bill passed by a vote of 88-20. We look forward to continuing our work with Representative Morgan as the legislation moves to the Senate.

Lansing Days 2023 was an incredible success. We are so thankful to the support of our sponsors and the participation and passion of our community advocates.

Together, we are making a difference! ♦

ADVOCATING ON THE HILL

In early March, HFM staff and patient advocates traveled to Washington, DC to participate in the National Hemophilia Foundation's (NHF) annual legislative event, Washington Days.

The bleeding disorders community attended meetings with federal legislators to share education on bleeding disorders, the importance of funding for hemophilia treatment centers and research, and the need to pass federal copay accumulator legislation through the HELP Copays Act.

Michigan advocates met with the offices of Representatives Dingell, Huizenga, Kildee, and Senators Stabenow and Peters. We were proud to represent the Michigan bleeding disorders community and look forward to continuing strong advocacy work via both national opportunities as well as in Michigan.

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Not listed are the many individual supporters who donated less than \$100 or those foundations and companies who also support the work of HFM. Thank you for your generosity; every gift makes a difference.



THANK YOU FROM THE HFM STAFF!

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After two years away, HFM's End of the Year Community Gathering had a joyous return to Troy High School to celebrate the Michigan bleeding disorders community! In collaboration with Project LEAD, a community service club for students, the cafeteria was transformed into a winter wonderland. Families engaged in a variety of fun and festive activities including decorating cookies and gingerbread houses, designing ornaments, and face painting. Mrs. Claus made a special appearance, reading us a holiday story, and was joined by our infamous Santa Antonio! Families got their picture taken with Santa and every youth had the opportunity to go home with a gift, many of which were generously donated by our friends at Cascade Hemophilia Consortium. The atmosphere was truly merry and bright as laughter and conversation filled the space. Families reunited with old friends, new connections were made, and together we celebrated the holidays and the end of 2022! We send our gratitude to the families who joined us along with Project LEAD, Cascade, and our sponsors. Thank you all for a warm and cheerful afternoon! 💧

2022 END OF YEAR COMMUNITY GATHERING

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H-Fit

with Dolvett Quince

Regular exercise is important. But moods vary. No two days are exactly the same. So we asked celebrity trainer Dolvett Quince to create a series of exercise videos called H-Fit. Each video features a different **hemophilia-friendly workout**. And each workout is built around a different mood. How are you feeling today? H-Fit has got you covered.

Always talk to your health care provider before starting any new exercise routine.



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Please accept our apologies for any errors or omissions.
Please contact Carrie McCulloch at cmcculloch@hfmich.org or at 734-544-0015 to correct our records.



ADVOCACY AND HEALTH POLICY SUMMIT

In November 2022, HFM was pleased to gather again for HFM's Annual Advocacy and Health Policy Summit. HFM staff, NHF representatives, HTC providers, patient advocates, and industry representatives joined us for this important event intended to identify current state policy and/or health care policy priorities and target advocacy efforts for the coming year. We were also pleased to welcome a special guest, newly elected Ann Arbor representative, Jason Morgan, who shared his personal connection to patient advocacy and his expectations for the coming year in Lansing.

Each attendee brought unique knowledge on policy, insurance, and advocacy to contribute to a meaningful conversation. HFM shared updates on recent advocacy activities at the state and national level before inviting attendees to share their thoughts

and insights during our threats and opportunities analysis. The contributions from our stakeholders were invaluable and provided HFM information to target 2023 advocacy priorities more effectively within the state. 🩸

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TOOTH TIME

JENNIFER KERNS, BS, RDH

Hello Jennifer,
I have been hearing more and more of this black stuff people are putting on their teeth that cures cavities! Can you explain? I cannot understand why someone would want to put this on their teeth!
Signed,
Curious in Grand Rapids

Absolutely! The product is called Silver Diamine Fluoride (SDF). It has been around for about 80 years in other countries with the US receiving FDA approval for off-label use around 2016.

Yes, it will turn black but let me explain.

SDF comes as a clear/blue liquid that is applied to cavities (hole in your tooth that is decaying and has bacteria) with a small applicator brush. SDF attacks the bacteria in the hole and "kills" it, a

process that turns that decaying hole a black color and then rock hard. The rest of the tooth and all other teeth in the mouth will not be discolored because the SDF only turn cavities black, it does not affect the healthy parts of your mouth and teeth—which also means that if you have a tiny cavity starting somewhere else that no one knew about that tiny little cavity will also turn black because the product travels through your spit over the next 24 hours and will find any areas starting to become cavities, turning those tiny areas black as well.

It is a great product to use in areas where you want to stop a cavity and prevent it from getting worse but can't have a traditional restoration yet. It can buy you time to save up money for a new crown, help eliminate dental anxiety in small children with cavities, and stop a cavity that is getting too close to the

nerve while you determine your treatment options. This product cannot be used once a cavity reaches the nerve of the tooth, so it does have limits and it's not a final definitive treatment.

And yes, SDF will leave black spots. If you do not like the black spot on the tooth, you can easily do a tooth-colored filling material over it when you are ready. I've included some photos of patients I've treated; you can see the before and after with a cavity, SDF treatment, and then how fillings can look after the SDF.

If you are interested in SDF, please talk to your provider to see if it is a good treatment option for your unique dental situation. 🩸

Contact Jennifer
231-721-5337
jkerns@nmhsi.org



Primary incisors before SDF treatment.



Primary incisors after SDF treatment.



Primary incisors after SDF treatment and with filling.

A ONCE-WEEKLY TREATMENT OPTION FOR HEMOPHILIA B.

HOW DOES THIS FACTOR IN?

To find out about a prescription option, talk to your doctor or visit [OnceWeeklyForHemophiliaB.com](https://www.OnceWeeklyForHemophiliaB.com)

NEED DENTAL INSURANCE?

If you are uninsured or underinsured with your dental coverage, we may be able to help. We understand that our community faces challenges obtaining dental care to meet unique and individual needs. HFM has partnered with Cascade Hemophilia Consortium to offer free dental insurance to those who need it.

QUESTIONS?

Contact Lisa Clothier, LMSW, ACSW, LCSW, Outreach and Community Education Manager, at lclothier@hfmich.org or **734.961.3512**

You can find the application here: www.hfmich.org/dental-health

In order to be eligible for this program you must:

- Have a bleeding disorder
- Be a Michigan resident
- Have no dental insurance or only Children's Special Health Care Services
- However, if you have Medicare, Medicaid, or an employer based private insurance plan you may be eligible for limited-time coverage based on special circumstances – these exceptions are limited and determined on a case-by-case basis. Please call us for more information.

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DELTA DENTAL

hfm

DO YOU HAVE A DENTAL QUESTION WEIGHING ON YOUR MIND? CONFUSED ABOUT YOUR DENTAL CARE? LOOK HERE IN OUR NEXT ISSUE FOR ANSWERS TO COMMUNITY MEMBER QUESTIONS!

**To maintain your coverage, you must visit the dentist two times during the calendar year for regular teeth cleanings.*

CENTER OF CARE BRINGING CARE TO THE PATIENT: AN OUTREACH STORY

LAURA CARLSON, BS, RN, NURSE MANAGER, MICHIGAN STATE UNIVERSITY CENTER FOR BLEEDING AND CLOTTING DISORDERS

Thank you to contributing authors: Roshni Kulkarni, MD, Director Emeritus, Michigan State University Center for Bleeding and Clotting Disorders; Sue Adkins, BSN, RN, Regional Program Manager, Hemophilia Foundation of Michigan; Karen Ridley, MSDH, Dental Hygienist, University of Michigan Center for Bleeding and Clotting Disorders



Access to specialty/comprehensive care is often challenging for patients with bleeding disorders who live in rural areas. Although Michigan has nine federally funded hemophilia treatment centers (HTCs) throughout the state, they are mostly located in large urban areas leaving portions of the state underserved or requiring rural patients to travel long distances to obtain care.

Over 40 years ago, Dr. John Penner, an adult hematologist, recognized the need for an expansion of services to this population and started the first outreach clinics in the state. He and Dr. Roshni Kulkarni, a pediatric

hematologist, and their team began traveling across the state to provide comprehensive care services including education and support to patients and their local providers. Some of his initial outreach locations later became federally funded HTCs; others remain outreach locations served by the Michigan State University HTC. MSU has continued this amazing tradition of service to remote locations of Marquette, Mt. Pleasant, Alma, Houghton Hancock, Iron Mountain, Escanaba, Harrison, and even to an Amish home. The entire team (adult and pediatric hematologists, nurse practitioner, clinical nurses, medical assistant, lab services, physical therapy, social work, dietitian, dental hygienist, genetics counselor, and research nurse) travels to provide comprehensive care to patients with bleeding disorders of all ages and genders including family visits where both adult and pediatric hematologists attend.

In 2022, we expanded our services to include a mobile dental clinic to serve the Amish population. MSU also provides comprehensive telemedicine care to many of these locations due to the barriers of inclement weather. The outreach clinics provide a direct connection for specialty care for rural patients and providers to receive education, support, and guidance while removing the financial barrier of travel. This relationship ensures patients in rural areas are provided



the same information, opportunities (such as participation in clinical trials), and state of the art medical care regardless of location.

MSU is continually reviewing areas in the state where outreach may be necessary to provide access to bleeding disorders care and collaborates with other Michigan HTCs to assist in providing care where needed. MSU believes no patient with a bleeding disorder, or their providers, should be left without access to specialty comprehensive care services and support. 🩸



BLEEDER AND A BUDDY



Last fall, HFM was delighted to host our annual fall teen retreat, Bleeder and Buddy, in-person again! Teens from the bleeding disorders community invited 'buddies' to join them for the retreat for connection, education, and fun! The group got to know each other with ice breakers and "get to know you" games,



then learned more about bleeding disorders through a live action recreation of the clotting cascade!

No retreat would be complete without time to relax and enjoy each other's company with activities including swimming, games, and a movie night. 🩸



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GETTIN'



IN

THE

Each year, CSL Behring hosts the Gettin' in the Game Junior National Championship to promote education and physical fitness for children in the bleeding disorders community. The children receive instruction on the fundamentals of golf, baseball, and swimming, learn about the importance of physical fitness, and participate in friendly competition.

HFM was excited to have Miles Boahene represent our Michigan chapter as one of the 50 children who participated in the 2022 Annual Championship.

We encourage all interested and eligible participants to apply for the 2023 Gettin' in the Game program. HFM will share details on social media when information is available. 📌



GAME

INSPIRING SHOTS GOLF CLINIC

HFM is happy to be partnering with CSL Behring and the Wingmen Foundation again to host the Inspiring Shots Golf Clinic, a series of clinics for beginners to advanced players in the bleeding disorders community to receive hands on golf instruction and community connection. Following the clinics, selected individuals will be invited to attend the 2023 Wingmen National Championship. This is held at the same time as the Gettin' in the Game Junior National Championship, promoting friendship, mentorship, and physical activities for all ages.

The 2023 clinics will be on the west side of the state. Stay tuned for more information. We would love for you to participate! Thank you to CSL Behring for offering these opportunities to the Michigan community.

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Exploring the science behind gene therapy research

Gene therapy research has the potential to bring an entirely new option to people with specific genetic conditions. Many gene therapies are in clinical trials to evaluate the possible risks and benefits for a range of conditions, including hemophilia. HemDifferently is here with gene therapy education, providing accurate information on the basics and beyond.

What questions do you have? Get them answered. Explore gene therapy at **HemDifferently.com**

No gene therapies for hemophilia have been approved for use or determined to be safe or effective.

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STATE OF THE STATE

In December 2022, HFM partnered with Matt Delaney, Government Relations Specialist with the state policy team at the National Hemophilia Foundation, to host a special State of the State webinar to recap the results on the 2022 midterm elections and what those results mean for the Michigan bleeding disorders community and our policy priorities.

The 2022 midterm elections decided the makeup of the 118th Congress, control of the US House and US Senate, several gubernatorial races, and state legislature makeups throughout the country.

The Michigan governorship, all 110 state House seats, and all 38 state Senate seats were up for election in 2022. In a historic shift, Democrats retained control of the governorship and took control of the State House and State Senate with small majorities. This is called a 'trifecta.'

Prior to the 2022 midterms, Michigan had what is called a divided or 'split' government where Democrats controlled the executive branch while Republicans controlled both branches of the legislature. Legislation tends to move more slowly in divided governments as both parties must come to agreements on policy and language. However, it does happen!

The shift in majority power will influence policy priorities in the state with Democrats now able to appoint committee chairs, control hearing schedules and the floor agenda, as well as the ability to call floor votes.

Democrats have not controlled the government in 40 years and have expressed ambitious plans for policy change and reform.

Due to Michigan's term limits on legislators, and the redistricting process that caused open seats, the election results also welcomed 60 freshman lawmakers. A large percentage of Michigan legislators now have little to no experience in state government and likely are unfamiliar with the needs of the bleeding disorders community resulting in a large advocacy need.

The change in representation in Lansing will require additional advocacy needs to pass copay accumulator reform—a policy priority for the bleeding disorders community. We hope Michiganders impacted by bleeding disorders join HFM in our work to educate these new lawmakers throughout the year. 📌

HFM and the bleeding disorders community are nonpartisan and do not endorse candidates from either party. We look forward to working with all legislators to impact change for the community.

THANK YOU TO OUR SPONSORS



CAN YOU ANSWER THESE POLITICAL TRIVIA QUESTIONS CORRECTLY?

1. The MI Senate has not flipped parties since what year?
2. How many state legislatures are bicameral? (meaning the legislature is divided into two parts usually a Senate and House)
3. How many nonvoting delegates are there in congress?
4. What year was March designated Bleeding Disorders Awareness Month (originally titled Hemophilia Awareness Month)?

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Bri Vieke

Phone | 551.502.7007

E-mail | briana.vieke@octapharma.com

"I have a passion for making a difference. As a Patient Experience Manager at Octapharma, I get to do that every day! I am dedicated to providing education and support for people living with bleeding disorders and their families. I'm proud to work for a company that shares the same mission and commitment to making a difference in the bleeding disorders community."

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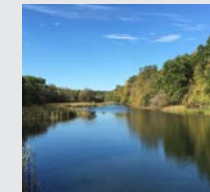
HFM IS ADDING 2 NEW EVENTS THIS YEAR!

REGISTER AT: WWW.HFMICH.ORG/EVENTS

ALL COMMUNITY REUNION & CAMP SEASON KICK-OFF



JUNE 3, 2023
11AM-2PM



Let's kick off the summer together! This event is for EVERYONE in the community! Join us for a picnic by the lake at beautiful Kensington Metropark and bring your family and friends along. The event will feature:

- Hot dog cart
- Fun
- Games
- Summer tips, tricks, and presentations and the chance to kick back and socialize with your fellow community members.

Campers will especially want to be there as this will be a chance for campers (and their parents) to meet some other campers and camp staff ahead of time!

This event is COST FREE. Kensington is yours to enjoy for the full day after the picnic. The beach and the water park will be open!

Kensington Metropark – Martindale Beach
4570 Huron River Pkwy.
Milford, MI 48380

THANK YOU TO OUR SPONSORS

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sanofi

HAPPY CAMPER SPONSORS:

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FRIENDS OF HFM SPONSORS:

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EVENT SPONSORS:

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HFM'S BACK TO SCHOOL DAY



AUGUST 26, 2023
10:30AM-12:30PM



Back to school time is meant for celebration! Let's meet at Robinette's to prepare for what is going to be a GREAT school year! This is our chance to have some fun and enjoy the sunshine one last time! Together, we will gather in the orchard at Robinette's AppleHaus. Our day will include:

- School supplies to take home
- Doughnuts (Allergy friendly available by request)
- Crafts
- Information that might help with those school jitters!

Robinette's AppleHaus
3142 4 Mile Rd NE
Grand Rapids Charter Township, MI 49525

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)



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PAID CONSUMER OUTREACH

COMMUNITY NIGHT: LET'S BAKE!



HFM kicked off our 2023 Community Nights with a virtual event for adults in the Michigan bleeding disorders community! Lisa Profera, MD, a certified medical marijuana doctor, joined us to speak about the use of CBD and cannabis as tools for coping with chronic pain, mental wellness, and other ailments. Dr. Profera educated the group on the human endocannabinoid system and how our body is impacted by the ingestion of phytocannabinoids, such as THC, CBD, and CBN. Attendees learned about the importance of utilizing the appropriate dosage and strain for their individual body and

about the multitude of ways plant medicine can be ingested including tinctures, edibles, and inhalation, as well as topical ointments.

After the evening's educational component, we transitioned to the kitchen, where our baking instructor, Emily Meade, guided us through the process of making homemade scones. No eggs? No problem! Our recipe utilized flaxseed meal as an egg substitute which also serves as a great addition of fiber. While this batch of scones was inspired by a Michigander favorite, cherries, we also learned how to adapt the recipe to please everyone's individual taste palates. Some attendees added a hint of orange zest and juice to their scones while others incorporated a dash of vanilla. For a savory twist, our baking instructor recommended trying roasted cauliflower, onion, and curry scones. Not only were the scones delicious fresh from the oven, but we learned how to freeze them so they could be reheated and served as a tasty homemade treat on a day when there isn't enough time to bake from scratch.

Thank you to all the community members who joined us, our presenters, and our sponsors who helped make this sweet evening possible! 🍷

THANK YOU TO OUR SPONSORS

SOARING EAGLE SPONSOR:



HAPPY CAMPER SPONSORS:



FRIENDS OF HFM SPONSORS:



EVENT SPONSORS:



HFM does not endorse any specific product or company.

HFM WILL BE HOSTING FOUR ADDITIONAL COMMUNITY NIGHTS IN 2023!

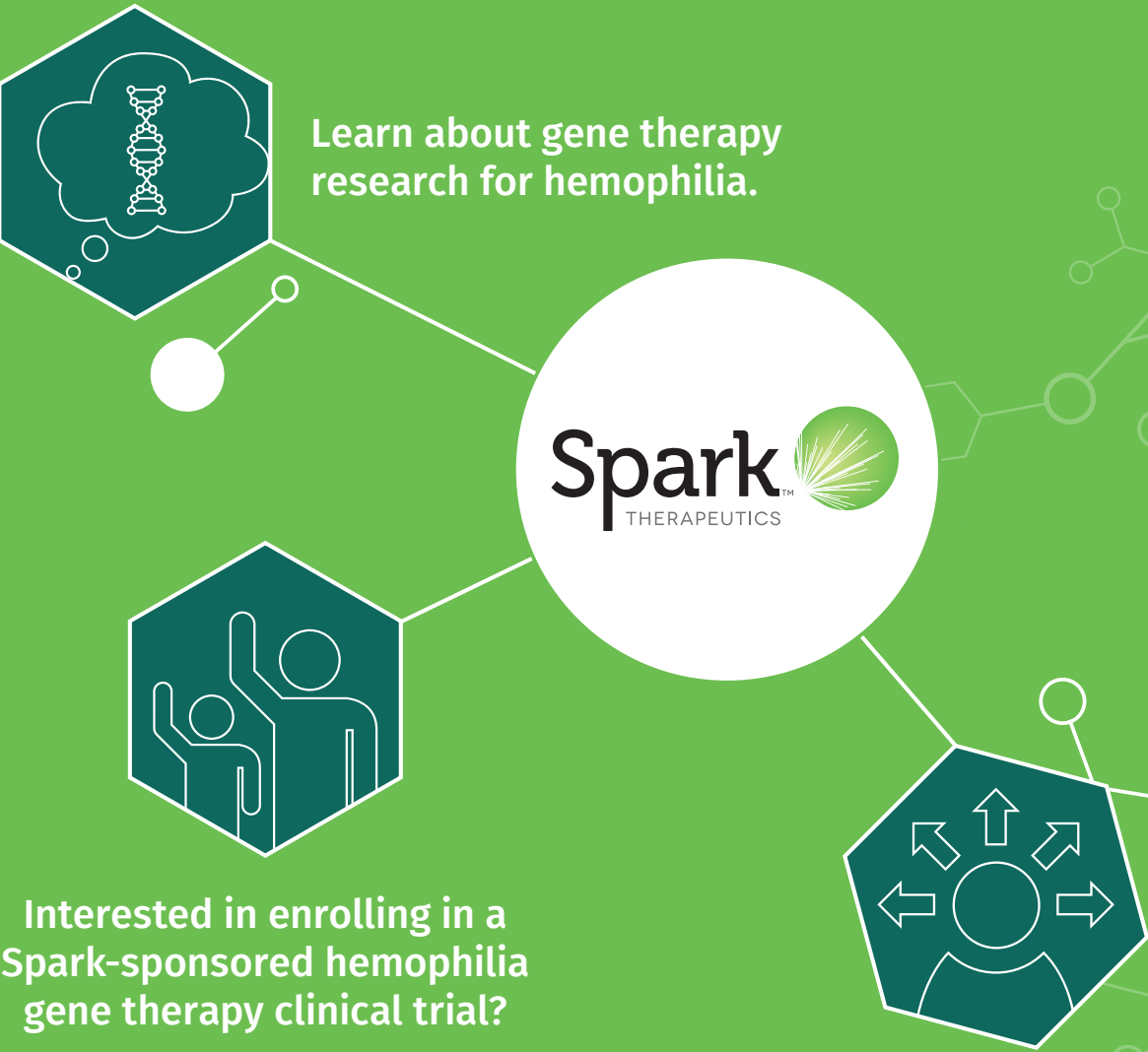
Join us in-person in **June at Craig's Cruisers in Grand Rapids**, in **August at Revel & Roll West in Kalamazoo**, and in **November we'll be at Incredible Mo's in Traverse City**! To ensure folks from across the state of Michigan can participate, we'll be hosting an additional **virtual family fun Community Night in October**.

VISIT [HFMICH.ORG/EVENTS](https://hfmich.org/events) TO LEARN MORE AND REGISTER.

OUR VISION: A WORLD WHERE NO LIFE IS LIMITED BY GENETIC DISEASE

At Spark® Therapeutics, we are committed to discovering, developing and delivering gene therapies.

We believe investigational gene therapy has the potential to be transformative in the treatment of hemophilia and we understand the importance of developing gene therapies that meet the needs of the hemophilia community. Our priority is the safety and well-being of clinical trial participants.



Discover more about gene therapy research

Want to know more about gene therapy clinical trials?



WE ARE SO PLEASED THAT OUR HFM MEMBERSHIP INCLUDES BOTH LIFETIME MEMBERS AND ANNUAL MEMBERS WHOSE GIFTS HELP SUPPORT HFM’S WORK EVERY DAY. EACH OF THESE INDIVIDUALS HAS MADE A SPECIAL COMMITMENT TO THE MICHIGAN BLEEDING DISORDERS COMMUNITY. WE ARE VERY APPRECIATIVE OF OUR NEW AND RETURNING 2022 ANNUAL MEMBERS AND WE ARE ESPECIALLY GRATEFUL FOR OUR LIFETIME MEMBERS. YOUR SUPPORT, INSIGHT, AND ENGAGEMENT TRULY MAKE A DIFFERENCE. THANK YOU! 💧

2022 ANNUAL MEMBERS

Henry Abel
Susan Adkins
Lynn and Kim Allen
Gregory Baustian
Dawn and Mark Bowles
Sherrilyn and Patrick Brown
Kathleen Bungart
Sharon and Sylvester Ceci
Lisa and Corey Clothier
Ronia Cole
Meghan Crosslin
Sandra and William Derman
Donald R. Fox
Ashley Fritsch
Laura Gusba
Suzan and Mark Higgins
Cheryl and Richard Holland
Shannon and Elliot Jones
David Kaumeyer
Shari and David S. Luckey

Mary A. and John May
Carrie and Mick McCulloch
Lauren and Jim Mohnach
Caitlyn and Patrick Monks
Siva Nadarajah
Laura and Mike Olson
Sarah Procaro
Karen and Bill Ridley
Stephanie and Jason Rogers
David Rushlow
Lakshmi Narayanaswamy and
Sundar Selvaraj
Jennifer Teper
Patrice and Craig Thomas
Jennifer and Jason Wakefield
Jennifer Warda
Sarah L. and Marty Watson
Larry West II
Jenna and Tim Wicks
James Wilson, Jr.

LIFETIME MEMBERS

Dr. Judith Andersen and
Dr. William Berk
Kathleen Donohoe
Shelley and Gary Gerson
Dean M. Hindenlang, PhD
Gwyn Hulswit and Jay Sennett
Susan and Dan Lerch
Dr. Deanna Mitchell and
Dr. Gary Rich
Laura and Bill Sparrow
Jeanne White-Ginder
Robin Whitfield

YOU CAN MAKE AN
IMPACT!

HFM MEMBERS ENJOY PRIVILEGES SUCH AS:

- Voting for the HFM Board
- Member reception at SpringFest
- Special recognition in print, online, and more!



Register at:
www.hfmich.org/membership
Scholarships Available



REGISTER FOR HFM’S CAMPING PROGRAMS



Registration closes on May 26, 2023! For more details and to register, **visit 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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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

10

ONLINE GATHERINGS FOR SOCIAL SUPPORT AND CONNECTION FOR WOMEN, THROUGH HFM'S RUBY CONNECTION, WITH MORE THAN 181 COMMUNITY MEMBERS JOINING ACROSS THE YEAR

224

COMMUNITY MEMBERS ATTENDED 14 VIRTUAL EDUCATIONAL DINNER TALKS

158

COMMUNITY MEMBERS ATTENDED 5 COMMUNITY NIGHTS AT LOCATIONS ACROSS THE STATE AND ONLINE

266

COMMUNITY MEMBERS, HTC STAFF, SPEAKERS, AND INDUSTRY SUPPORTERS ATTENDED VIRTUAL SPRINGFEST

31

COMMUNITY ADVOCATES JOINED US IN LANSING FOR OUR ANNUAL LEGISLATIVE ADVOCACY EVENT

184

AFFECTED WOMEN FROM ACROSS THE COUNTRY ATTENDED A HYBRID NATIONAL CONFERENCE FOR WOMEN WITH HEMOPHILIA AND RARE FACTOR DEFICIENCIES

IN 2022

AS HFM TRANSITIONED BACK TO IN-PERSON PROGRAMMING IN 2022, WHILE ALSO KEEPING ONLINE OPTIONS AVAILABLE, WE WERE SO PLEASED TO SEE THE MICHIGAN BLEEDING DISORDERS COMMUNITY ACROSS A NUMBER OF EVENTS AND PROGRAMS. WHILE WE DON'T HAVE THE SPACE NECESSARY TO LIST ALL OF HFM'S 2022 PROGRAMS – OR ALL THE SMILES THAT WERE CAPTURED AS WE GATHERED TOGETHER – HERE ARE SOME OF OUR HIGHLIGHTS THAT YOU MADE HAPPEN! 💧

35

COMMUNITY MEMBERS ATTENDED A VIRTUAL VON WILLEBRAND DISEASE SYMPOSIUM

32

COMMUNITY MEMBERS PARTICIPATED IN AN IN-PERSON AND ONLINE HYBRID WOMEN'S RETREAT

30

PATIENT ADVOCATES ATTENDED HFM'S FIRST COALITION WIDE EVENT TO SUPPORT COPAY ACCUMULATOR REFORM LEGISLATION IN LANSING

88

CAMPERS AND 25 CAMP STAFF ATTENDED AN IN-PERSON TRADITIONAL SUMMER CAMP EXPERIENCE DURING 5 WEEKS OF EAGLE JOURNEY'S CAMPING PROGRAMS AND STARTED OUR FIRST EAGLE'S NEST FAMILY CAMP

918

MEDICAL TAGS TO COMMUNITY MEMBERS SUPPLIED



SPRING TEEN RETREAT

What's spring in Michigan without a snowstorm? While teens from the community were ready and excited to return to our first in-person Spring Teen Retreat since 2020, Michigan weather had something else in mind in early March with a big snowstorm across the state. Luckily, we have all learned to be flexible and HFM's Spring Teen Retreat was easily rescheduled for later in the month. Camp Henry was able to accommodate our change in plans and our group of teens had a great time together over the weekend of March 24-26.

The theme of the weekend was "Facing Your Fears." During our kickoff program, teens were introduced to a number of small animals, insects, and reptiles and given the opportunity to interact with them, ranging from cute and cuddly to those with scales and multiple legs. While this was a fun icebreaker, we used this experience together to go deeper and to discuss fears and what it was like to step outside our individual comfort zones. Whether it's meeting new people, talking about our bleeding disorders, or embracing other things that we are initially fearful of, by stepping outside our comfort zone our zone expands and we can experience new people and new ideas with greater ease, and surprise ourselves by doing so!

The rest of the weekend was focused on spending time together reconnecting, playing modified basketball, talking, watching movies, and even playing a few rounds of pickleball (a new favorite for many!). When it came time to leave, everyone was glad to have had the chance to spend time with one another, face our fears, and take supportive steps outside of our comfort zone, with the encouragement of the HFM bleeding disorders community! 🩸

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EMERGENCY INTERVENTION PACKS: ESTABLISHING STANDARDS FOR CAMP EMERGENCY PREPAREDNESS



The Hemophilia Foundation of Michigan (HFM) Eagle Journeys' Camping Programs Health Officer Sarah Spencer, MPA, RN, BSN, EMT and Emergency Preparedness Advisor Matt Sterling, BA, CCP-C, I/C presented at the 2023 Arizona Bleeding Disorders specialized annual conference fondly referred to as NACCHO (North American Camping Conference for Hemophilia Organizations). NACCHO focuses on the work of bleeding disorders summer camps by bringing together presenters and leaders from the bleeding disorders community to share useful camp resources and techniques. Participants exchange ideas, resources, best practices, and successful endeavors with representatives from camps across the US and internationally.

Sarah and Matt's presentation titled "Emergency Intervention Packs" detailed the process of their onsite research and assessment of the HFM's camping programs' emergency response capabilities, resources, and health center staff to determine what equipment is necessary to respond to a variety of potential camp emergencies. Sarah and Matt presented examples of emergency packs they developed to cater to the specific needs of HFM's camping programs. The overarching goal in their development was to assure confidence, consistency, and competency when responding to any emergency that could occur at camp or in a wilderness setting. During their presentation, Matt and Sarah walked attendees through the included supplies and the policies and protocols developed to ensure all medical staff were trained to appropriately and effectively use the packs.



The presentation received all five-star reviews with attendees sharing specific feedback about the usefulness of the information. "This was a really helpful, practical presentation," said

Emily Bisson from the New England Hemophilia Association.



HFM is excited about the development of high-quality medical preparedness and proud of HFM's Eagle Journeys' continued leadership in establishing bleeding disorders camping program standards.

Thank you to Sarah and Matt for representing HFM camping programs at NACCHO and for their work to ensure Eagle Journeys' camps remain the best in the nation. 🩸



734. 544.0015

www.hfmich.org

1921 West Michigan Ave.
Ypsilanti, Michigan 48197

UPCOMING 2023 EVENTS

FOR MORE INFORMATION AND
OTHER UPCOMING HFM EVENTS,
PLEASE VISIT HFMICH.ORG/EVENTS

May 20-21

Women's Retreat   

Sheraton Ann Arbor Hotel,
Ann Arbor, MI

June 3

**All Community Reunion
and Camp Season
Kickoff** 

Kensington Metropark,
Milford, MI

June 9

**Community Night:
Craig's Cruisers** 


Wyoming, MI

June 10-16

Eagle Quest  

North Manitou Island
in Lake Michigan

June 28-July 1

**Eagles Nest
Family Camp** 
Pioneer Trails, Holton, MI

Camp Bold Eagle 

July 9-13

Session 1 (ages 6-9)

July 15-21

Session 2 (ages 10-12)

July 23-29

Teen Camp (ages 13-17)

August 4-5

UP Retreat 

TBD

August 6-12

Eagle Outpost Camp 

(ages 14-16)
Various Michigan
state parks

August 14-21

Eagle Expedition

(ages 16+) 

Northern California

August 25

**Community Night:
Revel and Roll West** 


Kalamazoo, MI

August 26

**Back to School
Gathering** 
Robinette's Apple Haus,
Grand Rapids, MI

 Virtual

 In-person

 18 and older

 www.hfmich.org

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 www.hfmich.org/facebook

 www.hfmich.org/camp

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