



THE **ARTERY**

WINTER 2024



THIS ISSUE

**14 NATIONAL WOMEN AND
TEEN GIRLS CONFERENCE**

**16 AGING WITH A BLEEDING
DISORDER**

DEAR FRIENDS OF HFM



From Left: Carrie, Susan, and Cindy together at the 2024 National Women and Teen Girls Conference.



From Left: Karen Boyd, Susan Lerch, Dave Rushlow, and Samantha Carlson at the 2024 Regional Meeting.

It seems each year the days and months go by more quickly!

In 2024, our HFM team of leadership volunteers, staff, community members, treatment center colleagues, and various supporters have again come together to make a difference for those affected by bleeding disorders across Michigan and our region.

This year, in-person educational programs allowed many long-term HFM participants, together with others who are new to the many programs and services HFM provides, to meet one another. We are thrilled community members who previously only attended virtually, decided to join us in-person for SpringFest as well as our summer kick-off at HFM's office! New and experienced folks attended Eagles Nest family camp, as well as kids and teens taking part in our many other camp programs! HFM's annual Women's Retreat welcomed new faces and offered numerous fun and educational in-person activities!

HFM's 7th Annual National Conference for Women and Teens with Hemophilia and Rare Factor Deficiencies was held the first weekend of October. Among post-conference survey respondents, 97% would recommend it to a friend, 91% gained valuable information about their bleeding disorder, and 90% felt more supported by the bleeding disorders community. See the full synopsis on pages 14–15.

In early November, HFM as the federal regional core center, hosted the Great Lakes V-E HTC Network Regional Meeting with more than 140 HTC staff members participating from Michigan, Indiana, and Ohio. This robust meeting featured sessions on musculoskeletal ultrasound; setting up women and girls' clinics; new treatment therapies; advocacy and legislative updates; as well as numerous sessions specific to physicians and advanced practitioners, nurses, social workers, physical therapists, and data managers. With several new HTC staff across the region as well as long-term practitioners, this annual gathering provides opportunities for engagement with colleagues across our three states.

Given the vastness of our state and busy schedules, we continue to offer virtual programming for our Michigan bleeding disorders community. Educational opportunities are enhanced by continuing our online efforts, reducing the level of

time commitment and travel, which can be barriers for participation for some.

We truly delight in the renewed, as well as new, friendships and relationships that come about via community involvement with HFM programs and events. Spending time with people who also face the challenges of bleeding disorders, sharing with one another as well as health care providers and other educators, creates a sense of camaraderie and understanding. Community members whose paths wouldn't have crossed if it weren't for bleeding disorders become dear friends, often life-long friends, through involvement with both our in-person and virtual programs.

We recognize that each of us is more than a bleeding disorder, yet shared experiences often foster deeper connections. We are grateful to create opportunities that unite our community in friendship, love, and support.

As the new year approaches, I send my warmest wishes of peace and joy to you and your loved ones!

With Gratitude,

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

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THANK YOU TO OUR CONTRIBUTING AUTHORS

Front Cover: Daicia Price, PhD, LMSW, QMHP, speaks at the National Women and Teen Girls Conference, guiding attendees on using their unique superpowers to pursue healthcare justice through personal strengths and identities. ©Brian Sevald Photography

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*Denotes part-time

PAID CONSUMER OUTREACH INCLUDED IN THIS NEWSLETTER



HFM's Advocacy Committee, which includes staff from HFM, the National Bleeding Disorders Foundation, the Hemophilia Federation of America, hemophilia treatment center providers, patient advocates, and industry representatives, joined us for this important event.

Each attendee brought unique knowledge on health policy, insurance, and advocacy to contribute to a meaningful conversation. HFM shared updates on recent advocacy activities at the state and national level, and a recap of the 2024 general election, before leading a discussion on what lies ahead for 2025. The contributions from our stakeholders were very beneficial and this Summit continues to provide HFM with information to target advocacy priorities more effectively within the state in the coming year. 🩸

To close out the year, HFM hosts our annual Advocacy and Health Policy Summit to gather a variety of stakeholders familiar with patient advocacy, health policy, and insurance trends. Together, this group lends their voice to local and national issues impacting the bleeding disorders community with the goal of identifying current state policy and/or health care policy priorities and target advocacy efforts for the coming year.

In November 2024, HFM was pleased to return to Zingerman's Roadhouse for our eighth annual Summit.

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Tuesday 3:24 pm
Practicing yoga with her mom
Mariana, living with von Willebrand disease

Not an actual patient

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PAID CONSUMER OUTREACH



BACK TO SCHOOL EVENT

It was time to accept that the summer was coming to an end, but at HFM, we didn't consider this a bad thing. In fact, the start of school was a cause for celebration! On August 26th, we did just that when our friends on the West Side of Michigan joined us for our Back to School Day!

Families gathered at the Byron Center park pavilion for lunch and some treats from the famous Sandy's Donuts. There wasn't cider available quite yet, but we couldn't resist doughnuts as a nod to the fall. Once everyone had their fill, it was time to play some games, create some crafts, and learn about all of the ways that we can support each other through the school year.

Students were able to select a backpack and a variety of school items ranging from markers and notebooks to scissors and glue sticks. With the help of our magical volunteers, participants personalized their notebooks with

craft supplies before moving on to another activity: creating their very own adorable bookworm.

Everyone had the chance to mingle over lawn games and face painting, but we paused to focus on the task at hand: learning some tips and tricks for the school year. Parents and older students wrote down their best advice and these were shared with all. We also played a game created to foster connections with other students in the classroom. Finally, we were joined by staff from the HTC at the Helen DeVos Children's Hospital who shared the many services they can offer families to help students with bleeding disorders adjust to the classroom.

We would like to thank all our wonderful volunteers, sponsors, and the staff at Helen DeVos Children's Hospital for creating a warm and welcoming environment for our students to kick off a new school year! 🩸



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TO SEE HOW WE'RE CREATING
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LAUNCH



Brian Sevald, our event photographer, shares a headshot with an attendee during our inaugural interactive in-person career workshop, Launch Day, on November 2, 2024.



Community members discuss best practices in career building on Launch Day.

The Hemophilia Foundation of Michigan's (HFM) LAUNCH Vocational Job Training Assistance Program's goal is to provide education, vocational, and/or professional assistance to post-high school-aged individuals within the bleeding disorders community. We help individuals find jobs that accommodate their needs by offering support in obtaining certifications in select fields such as healthcare and information technology, as well as providing resume and cover letter reviews and mock interview skills coaching. We help individuals find jobs that accommodate bleeding disorders. In partnership with the ten hemophilia treatment centers in Michigan, HFM works to improve the quality of life for all members of the Michigan bleeding disorders community. 🩸

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Are you in need of career assistance through certification, education, or training? Please reach out to Travis Miller at tmiller@hfmich.org to see if LAUNCH can help you with your next steps. Learn more at hfmich.org/launch

BLEEDER AND A BUDDY

It can often feel isolating to grow up with a bleeding disorder, and it can be hard for people, even your friends, to grasp what it is like to live with a bleeding disorder. However, that doesn't mean they can't learn! HFM's Bleeder and a Buddy is a weekend retreat designed for teens aged 13-17 to educate their friends about bleeding disorders, share their unique experiences, and connect with the welcoming HFM community. By bringing a buddy, there is a stronger peer network at home and someone who can understand what it's like to have a bleeding disorder.

Bleeders and their buddies gathered October 25-27 at Camp Copneconic for this annual weekend retreat. Teens taught their friends about their life with a bleeding disorder and made stronger connections. This weekend was also

filled with fun activities such as a low ropes course, corn maze, visit to a planetarium, and a movie night. Join us next year for a weekend of fun and connection! 🩸

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THE ARTERY

BLOOD BUDS

Living with a bleeding disorder can be painful and pose an obstacle to participating in community events which can be isolating. Blood Buds strives to provide accessible events for men with bleeding disorders ages 18+. We hold virtual events every month, including game night, trivia, and even escape rooms. We also offer in-person events such as pub trivia, card nights, and bowling, just to name a few. Here is what some of our community members had to say about their experience with Blood Buds.

"HFM has a myriad of programs and services, and Blood Buds is one of my favorites! I like attending Blood Buds because I get to meet familiar faces from when I went to Camp Bold Eagle as a child. I like the convenience of Blood Buds because it happens after work hours. Whether it's attending in-person escape rooms or doing virtual trivia nights, I have a lot of fun hanging out with others in the hemophilia community. As a bonus, dinner is reimbursed with the participation in Blood Buds, and you can't go wrong with free food!" – Luke Luckey

"As a member of the Hemophilia Foundation of Michigan (HFM) living with a bleeding disorder, I am an active participant in many of the virtual and in-person events organized by HFM all year-round. The Blood Buds event, directed at 18+ adult men living with a bleeding disorder,

quite possibly a brainchild of the energetic organizing committee currently at the helm, is both a virtual and an in-person monthly event. This new program, started only a few months ago, has already attracted a sizable audience and is a lot of fun to be a part of. While I have only participated in virtual events thus far, I believe the in-person events are equally entertaining and fun-filled as well. Programs such as trivia nights, escape rooms, and game nights (live and virtual versions) keep us engaged and the camaraderie shared with fellow bleeders during these events is quite memorable as well. My sincere thanks to all those involved in putting these programs together and I look forward to participating in many more such events in the future." – Sundar Selvaraj

We hope you will join us for an upcoming program! To learn more about Blood Buds and to register, please visit hfmich.org/events, or contact Travis Miller at tmiller@hfmich.org. 🩸

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Learn more about our focus on the rare bleeding disorder community

Visit us online at hemabio.com



DENTAL IMPLANTS

ELLEN KACHALSKY, LMSW, ACSW, HEMOPHILIA AND THROMBOSIS CENTER, HENRY FORD HEALTH SYSTEM
 KAREN RIDLEY, MSDH, UNIVERSITY OF MICHIGAN CENTER FOR BLEEDING AND CLOTTING DISORDERS

It's hard to watch TV for any length of time without seeing an ad for dental implants. Many patients are contacting us with questions about the implant process and financial concerns. Can a person with a bleeding disorder have a dental implant? Implants are surgical procedures that can be successfully done with combined planning between the hematologist and the dentist. Persons who have health conditions that prevent bone healing may not be a candidate for implants.

When you lose a tooth, you may experience problems chewing and eating. Your appearance may change. If you lose all of your teeth, you may find it difficult to wear a denture. Implants can help correct all of those problems.

A dental implant uses a metal post to provide a new root for the missing tooth. An artificial tooth, looking like a real tooth, screws into the post. Another use of implants is to secure a denture, particularly a lower denture. These implants are little posts that snap into the denture, making it more secure. Before an implant can be done, additional oral surgery may be needed to provide a secure base for the implant. Implants can be done at the same time as an extraction or at a later time.

WHAT DO IMPLANTS COST?

Dental implant procedures are complex. Fees will range widely depending on the tooth, difficulty of the procedure, and even the area of the country. The implant is only the metal or ceramic

screw that goes into the jawbone. Other costs include the abutment (the part that attaches the crown to the implant) and the crown itself. All of these items have separate prices. Based on the American Dental Association's Health Policy Institute cost survey, the total cost of an implant, abutment, crown, and other necessary procedures ranges from \$3,100 to \$5,800 per tooth. While dental insurers have traditionally considered implants to be elective and haven't covered costs associated with them, some insurance is now covering a small part of implants. Medicaid and Medicare traditionally do not cover implants. Always discuss the cost with your dentist and get a prior authorization from your insurance. 🩸

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 Kaite Scott, LLMSW, Program Social Worker, at kscott@hfmich.org or 734.292.5267

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. 🩸



DO YOU HAVE A DENTAL QUESTION WEIGHING ON YOUR MIND? CONFUSED ABOUT YOUR DENTAL CARE? EMAIL KAITE SCOTT WITH YOUR QUESTIONS! [KSCOTT@HFMICH.ORG](mailto:kscott@hfmich.org)

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



Tara Dryer

Regional Account Manager
 Serves IN, KY and MI

"I am committed to being a resource for the bleeding disorders community via trust and educational partnerships."

✉ Tara.Dryer@hemabio.com

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Earlier this year, HFM sent Days for Girls (DfG) menstrual health kits and educational materials to Pakistan through Save One Life, marking the start of a collaboration with the Hemophilia Foundation of Pakistan (HFP). After a planning meeting in June, HFP conducted a workshop in August, educating 84 women and girls with bleeding disorders on menstrual health, reproductive well-being, and legal rights.

Discussions are ongoing about expanding kit distribution, with a focus on integrating educational workshops and training across provinces, supported by quarterly meetings. 🩸

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We invite you to read the Women and Girls with Bleeding Disorders Days for Girls Activity Report provided by the Pakistan Hemophilia Patients Welfare Society.



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2024 NATIONAL WOMEN AND TEEN GIRLS CONFERENCE

The National Conference for Women and Teens with Hemophilia and Rare Factor Deficiencies — Empowerment, Education, Policy: Hear Our Voices — took place in early October, with a diverse group of attendees. This year’s Alice in Wonderland theme encouraged participants to explore their identity by embarking on a journey of self-discovery and to reflect on the fluid nature of self. The conference was again held both in-person and virtually, with 209 eligible women registered from 34 states and Puerto Rico. To ensure accessibility, all mainstage and select breakout sessions were translated into Spanish, with tailored sessions for women of color and a three-part teen track.

Friday evening laid a solid foundation for the days ahead. Margaret Bridges from GutMonkey explored the Alice in Wonderland theme, encouraging attendees to reflect on their potential and to step outside their comfort zones through group activities. Dr. Daicia Price followed with a compelling call to view healthcare as a social justice issue, encouraging participants to use their power to drive change. The night concluded with a shared stories tea party, led by Kaite Scott and our newly named Leaders in Action group, where participants connected deeply in small groups, sharing personal experiences and reinforcing the importance of community support.

Moderated by Dr. Roshni Kulkarni and Dr. Ann-Marie Nazzaro, Saturday’s opening session featured a distinguished panel discussing the challenges and successes in educating healthcare providers about the unique needs of women and girls with bleeding disorders. Experts Dr. Meera Chitlur and Dr. Rebecca Jameson highlighted that women are the best advocates for their bodies, underscoring the need for better physician training in areas such as maternal and neonatal care. Dr. Andra James focused on collaboration between patients and healthcare providers to achieve improved outcomes and Dr. Kerry Funkhouser covered the necessity for interdisciplinary clinics to ensure comprehensive care across a woman’s life stages. This discussion emphasized the importance of self-advocacy in seeking proper diagnosis and treatment.

Throughout the conference, speakers including Drs. Angela Weyand and Lynn Malec addressed gender inequity in diagnosis, urging a more proactive approach in screening female relatives for hemophilia. Dr. Mina Nguyen-Driver highlighted historical biases in women’s healthcare and called on attendees to engage in self-advocacy to improve their medical experiences. The emphasis on early diagnosis, patient registry participation, and the comprehensive management of bleeding disorders reinforced the ongoing need for systemic changes in women’s healthcare.

A highlight of the event was the live recording of the FLOW Podcast, where co-hosts Sarah Watson and Jessica Richmond facilitated a discussion about menstruation challenges faced by women with bleeding disorders. The candid conversation revealed common struggles like heavy menstrual bleeding and cultural taboos, resonating deeply with the audience. This session underscored the shared experiences within the community and reinforced the conference’s mission to create a supportive and informative space. During the podcast another space was available for conversation and support from Michigan HTC social workers, Dave Rushlow and Karen Boyd, and nurse Kathi Sheldon.

Breakout sessions spanned a wide array of topics, from emergency room advocacy and aging to financial management and self-care techniques. The “Body and Mind” workshops offered yoga, dance, and creative art, allowing participants to engage in holistic wellness practices. The National Bleeding Disorders Foundation (NBDF) presented “The Pain Palette: Exploring the Colors of Discomfort,” a session that explored innovative approaches to pain management, further enriching the attendees’ experience.

In a poignant session, Kathy Gerus-Darbison shared her personal story following a clip from *On the Shoulders of Giants* documentary, reflecting on the impact of HIV/AIDS on the bleeding disorders community. Her narrative brought attention to the strength of women advocating in the community, with many attendees sharing their connections to this legacy and expressing a collective sense of hope and solidarity.



© Sonja McGovern Photography

Saturday evening’s “A Very UnBirthday Pajama Party” infused the event with creativity and whimsy. Led by the Leaders in Action group, participants engaged in activities that included designing bookmarks, making friendship bracelets, games, and karaoke. The pajama party offered a lighthearted yet meaningful way for attendees to connect, relax, and celebrate the sense of community that the conference fostered.

Before the conference concluded, NBDF leadership, including President and CEO Phil Gattone, Director of Research Samantha Carlson, and Director of Education Lena Volland, provided updates on their national initiatives. They focused on strategic goals aimed at building strong, diverse communities, emphasizing the importance of including lived experience experts in research, and enhancing healthcare provider education. Their insights highlighted a commitment to fostering community connections and addressing the unique needs of women and girls with bleeding disorders.

Attendees departed the conference with a renewed sense of empowerment, education, and community. Advocacy emerged as a central theme, extending beyond individual healthcare needs to encompass broader systemic changes in the treatment and understanding of women with bleeding disorders. The emphasis on self-discovery, identity, and collective strength was woven into sessions, inspiring participants to push for equity and support within their communities. The weekend reinforced that while challenges remain, the strength of the bleeding disorders community lies in its shared commitment to change. The solidarity, exchange of stories, and collective voice of those present embodied the theme, Empowerment, Education, Policy: Hear Our Voices, promising to fuel ongoing advocacy, support, and progress for women and teens with hemophilia and rare factor deficiencies.💧

ATTENDEES JOINED US FROM THE FOLLOWING STATES:

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HFM programming is designed to meet the needs of all individuals in the Michigan bleeding disorders community — whether you are a family with a new diagnosis, a teen transitioning into adulthood, a caregiver, or a camp family. In order to address the needs of those aging with hemophilia and other bleeding disorders, HFM began a new aging series three years ago. These programs were designed to fill a gap in many of the community services and educational opportunities that have been offered in the past.

We have continued to integrate aging programs within our larger events, and we have also continued to provide stand-alone programs specifically for those who are older in our community. In order to make sure programs are accessible for those aging with hemophilia and other bleeding disorders, a mix of in-person and virtual programming is offered across the year.

In 2024, programming for older adults focused on medical issues (joint pathology and management strategies; reproductive health, bleeding disorders, and aging gracefully; pain management), physical wellbeing (foundational strength for injury prevention and vitality; tai chi; chair yoga; gentle mindfulness and movement), and the intersection of

AGING WITH HEMOPHILIA AND OTHER BLEEDING DISORDERS

these needs (navigating physical and emotional well-being for aging gracefully). We also highlighted practical considerations (advance directives, living wills, and durable power of attorney; life by design 50+) and emotional wellness (creative expressions workshops; mindful moments for serenity).

We were pleased to continue efforts to develop, facilitate, and offer programs this year for those aging with hemophilia and other bleeding disorders. With expert speakers from hemophilia treatment centers and other disciplines, we hope many of you joined us and other community members throughout the year. We look forward to continuing this programming in 2025 and most importantly, being alongside you on all steps of your journey. 💙

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*Average trough levels were 18% for adults 18 years and older, 9% for adolescents aged 12 years to under 18 years, 17% for children aged 6 years to under 12 years, and 11% for children aged 1 year to under 6 years.

†The half-life was 44.6 hours for adolescents aged 12 years to under 18 years, 42.4 hours for children aged 6 years to under 12 years, and 38 hours for children aged 1 year to under 6 years.

‡Data based on treated bleeds.

§159 adults and adolescents with severe hemophilia (aged 12 years and older) were enrolled in the XTEND-1 study; 133 people were in Group 1 and switched to ALTUVIIIIO prophylaxis from prior prophylaxis therapy. Efficacy of prophylaxis was evaluated in 128 of these patients. 74 previously treated male children under 12 years who switched to ALTUVIIIIO were studied over 1 year in the XTEND-Kids study. Efficacy was evaluated in 72 of these children.

INDICATION

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IMPORTANT SAFETY INFORMATION

What is the most important information I need to know about ALTUVIIIIO?

Do not attempt to give yourself an injection unless you have been taught how by your healthcare provider or hemophilia center. You must carefully follow your healthcare provider's instructions regarding the dose and schedule for injecting ALTUVIIIIO so that your treatment will work best for you.

Who should not use ALTUVIIIIO?

You should not use ALTUVIIIIO if you have had an allergic reaction to it in the past.

What should I tell my healthcare provider before using ALTUVIIIIO?

Tell your healthcare provider if you have had any medical problems, take any medications, including prescription and non-prescription medicines, supplements, or herbal medicines, are breastfeeding, or are pregnant or planning to become pregnant.

What are the possible side effects of ALTUVIIIIO?

You can have an allergic reaction to ALTUVIIIIO. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.

Your body can also make antibodies called "inhibitors" against ALTUVIIIIO. This can stop ALTUVIIIIO from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

The common side effects of ALTUVIIIIO are headache and joint pain.

These are not the only possible side effects of ALTUVIIIIO. Tell your healthcare provider about any side effect that bothers you or does not go away.

Please see full Prescribing Information.

Connect with your CoRe today

Sanofi Hemophilia Community Relations and Education (CoRe) Managers provide information about ALTUVIIIIO, living with hemophilia, and treatment options.



Sign up to connect and learn more today!

Patient Information

Rx Only

ALTUVIIIIO® (al too'vee oh)

[antihemophilic factor (recombinant), Fc-VWF-XTEN fusion protein-ehtl] for intravenous use after reconstitution only

Single-dose vial

Please read this Patient Information carefully before using ALTUVIIIIO and each time you get a refill, as there may be new information. This Patient Information does not take the place of talking with your healthcare provider about your medical condition or your treatment.

What is the most important information I need to know about ALTUVIIIIO?

Do not attempt to give yourself an injection unless you have been taught how by your healthcare provider or hemophilia center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for injecting ALTUVIIIIO so that your treatment will work best for you.

What is ALTUVIIIIO?

ALTUVIIIIO is an injectable medicine that is used to control and reduce the number of bleeding episodes in people with Hemophilia A (congenital Factor VIII deficiency).

Your healthcare provider may give you ALTUVIIIIO when you have surgery.

Who should not use ALTUVIIIIO?

You should not use ALTUVIIIIO if you had an allergic reaction to it in the past.

What should I tell my healthcare provider before using ALTUVIIIIO?

Talk to your healthcare provider about:

- Any medical problems that you have or had.
- All prescription and non-prescription medicines that you take, including over-the-counter medicines, supplements or herbal medicines.
- Pregnancy or if you are planning to become pregnant. It is not known if ALTUVIIIIO may harm your unborn baby.
- Breastfeeding. It is not known if ALTUVIIIIO passes into the milk and if it can harm your baby.

How should I use ALTUVIIIIO?

You get ALTUVIIIIO as an injection into your vein. Your healthcare provider will instruct you on how to do injections on your own and may watch you give yourself the first dose of ALTUVIIIIO.

Contact your healthcare provider right away if bleeding is not controlled after using ALTUVIIIIO.

What are the possible side effects of ALTUVIIIIO?

You can have an allergic reaction to ALTUVIIIIO. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash or hives.

Your body can also make antibodies called "inhibitors" against ALTUVIIIIO. This can stop ALTUVIIIIO from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

The common side effects of ALTUVIIIIO are headache and joint pain.

These are not the only possible side effects of ALTUVIIIIO. Tell your healthcare provider about any side effect that bothers you or does not go away.

What are the ALTUVIIIIO dosage strengths?

ALTUVIIIIO comes in seven different dosage strengths with 3 mL sterile water for injection (sWFI). The actual number of international

units (IU) of Factor VIII activity in the vial will be imprinted on the label and on the box. The seven different strengths are as follows:

Strength	Cap Color
250 IU	Yellow
500 IU	Red
750 IU	Garnet
1000 IU	Green
2000 IU	Royal Blue
3000 IU	Mist Grey
4000 IU	Orange

Always check the actual dosage strength printed on the label to make sure you are using the strength prescribed by your healthcare provider.

How should I store ALTUVIIIIO?

- Keep ALTUVIIIIO in its original package.
- Protect it from light.
- Do not freeze.
- Store refrigerated 2°C to 8°C (36°F to 46°F) up to 48 months or at room temperature [not to exceed 30°C (86°F)], for a single period up to 6 months. Do not use ALTUVIIIIO after the expiration date printed on the label and carton of each vial.
- When storing at room temperature:
 - Note on the carton the date on which the product is removed from refrigeration.
 - Use the product before the end of this 6-month period or discard it.
 - Do not return the product to the refrigerator.

After mixing with the diluent:

- Do not use ALTUVIIIIO if the mixed solution is not clear and colorless to slightly yellowish.
- Use mixed product as soon as possible.
- You may store mixed ALTUVIIIIO at room temperature, not to exceed 30°C (86°F), for up to 3 hours. Protect the mixed ALTUVIIIIO from direct sunlight. Discard any mixed ALTUVIIIIO not used within 3 hours.

What else should I know about ALTUVIIIIO?

Medicines are sometimes prescribed for purposes other than those listed here. Do not use ALTUVIIIIO for a condition for which it was not prescribed. Do not share ALTUVIIIIO with other people, even if they have the same symptoms that you have.

This Patient Information has been approved by the U.S. Food and Drug Administration.

Manufactured by:
Bioverativ Therapeutics Inc.
Waltham, MA 02451
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Revised: MAY 2024

AHF-PPI-SL-MAY24

sanofi

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COMMUNITY MEMBER SPOTLIGHT

LUKE LUCKEY



Hello everyone! My name is Luke, and I am excited to share with you my story in the bleeding disorders community. My first involvement was through HFM's Camp Bold Eagle. At Camp Bold Eagle I met many people with hemophilia, and I immediately bonded with the bleeding disorders community. I learned not only how to self-infuse, but also that hemophilia doesn't need to limit me from doing the things I am most passionate about. I immediately got involved with HFM's advocacy program in 2010. I remember going into the capital in Lansing and seeing so many community members having a common goal: to improve access to healthcare for people in the bleeding disorders community. Flash forward to today, I am still actively involved in HFM's advocacy during Lansing Days. I am proud to be part of the team that is fighting to eliminate Copay Accumulator Adjustors and urging legislators to continue to support Children's Special Health Care Services.

In 2022, I was honored to be selected to be a member of the National

Youth Leadership Institute through the National Bleeding Disorders Foundation (NBDF). Through this program, I attended NBDF's Bleeding Disorders Conferences, the National Research Blueprint Summit, and Washington Days. During the Bleeding Disorders Conferences, I had the opportunity to speak at several sessions regarding my personal experiences with hemophilia. I also had the chance to educate younger community members about hemophilia and the experiences that come along with it. During Washington Days, I used skills from HFM's annual Lansing Days to my advantage. I spoke with legislators and representatives regarding the current issues surrounding access to treatment.

Currently, I work at Michigan Medicine as a clinical research assistant on two longitudinal studies: the Adolescent Brain Cognitive Development study and the Maturing Out study. Receiving my certification in phlebotomy helped me a lot during my time at Michigan Medicine. I'm very grateful that I had the opportunity to gain this certification through HFM's LAUNCH Vocational

Job Training Assistance Program, which aims to provide education, vocational, and professional assistance to post-high school-aged individuals, like me, within the bleeding disorders community. I am also excited to share that I will attend medical school at Central Michigan University College of Medicine in August 2025. I am grateful that I get to pursue my dream of becoming a physician. I am hoping to become an Adult Hematologist at Michigan Medicine in the future. My long, exciting journey with this strong community has encouraged me to continue to be involved with it for the rest of my life.

I am thankful for my family for their tremendous support of my academic journey. Without them, I wouldn't be where I am today. I would also like to thank HFM for making me the person I am today. Not only have I learned to be independent with self-infusion, but I have also learned the importance of lifelong advocacy for the community that needs it the most. I will forever be grateful for all the programs and opportunities that HFM has offered me. ♡

MEDICARE 101

On Thursday, September 19, HFM was pleased to partner with the Michigan Medicare Assistance Program (MMAP) to provide a thorough overview of Medicare. As we know in the bleeding disorders community, insurance is a lifeline for patients with chronic conditions who rely on consistent care and treatment; unfortunately, it can be extremely complex to navigate.

Our guest speaker from MMAP, Peggy Kahn, joined us to help make this large and intricate topic more manageable for members of the community. She started by explaining what Medicare is and the different parts and plans available. We learned how to enroll, when to enroll, and what to look for in your Medicare plan choices. Thank you to Peggy and MMAP for volunteering their time to make sure members of the bleeding disorders community understand and feel comfortable with Medicare.

If you need assistance with Medicare, please reach out to the Michigan Medicare Assistance Program. MMAP can help you solve problems, find answers, and understand your options. This assistance is unbiased and free of cost. ♡



LEARN MORE ABOUT THE MICHIGAN MEDICARE ASSISTANCE PROGRAM

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YOU CAN COUNT ON

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NOVO NORDISK

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For 30 years, Novo Nordisk has been a driving force for people living with rare bleeding disorders. We take pride in striving for innovative solutions to help improve patients' lives. This motivates us to uphold the highest standards in our product research and development. This vital research is just the beginning of our commitment in hemophilia.

We will continue our research and connect with people with hemophilia and health care professionals to ensure we understand and respond to the specific needs of the hemophilia community.

With a rich history, Novo Nordisk remains at the forefront of discovery. We are poised to continue to develop innovative solutions that can help improve the lives of people with hemophilia in the future.

Please visit www.rarebleedingdisorders.com or find us on Facebook at www.facebook.com/cpih.us.

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WE'RE IN THIS TOGETHER.

Sunday 2:16 pm
Jogging in the park with his girlfriend
Ben, living with hemophilia A

Not an actual patient

BOARD OF DIRECTORS UPDATE

HFM IS HAPPY TO WELCOME TWO NEW MEMBERS TO HFM'S BOARD OF DIRECTORS. WE APPRECIATE THEIR DEEP COMMITMENT TO THOSE IMPACTED BY BLEEDING DISORDERS AND THEIR ENGAGEMENT WITH HFM'S PROGRAMS AND SERVICES.



DAVE RUSHLOW, MSW
MUNSON MEDICAL CENTER NORTHERN REGIONAL BLEEDING DISORDERS CENTER
CLINICAL SOCIAL WORKER

"I bring 31 years of experience as the social worker and manager of our HTC. I feel I can add value to the Board with my experience, patient knowledge, and knowing the pulse of the community."



MICHELLE HYDE, RN, BSN
CHILDREN'S HOSPITAL OF MICHIGAN HEMOSTASIS AND THROMBOSIS CENTER NURSE COORDINATOR

"I want to serve on the HFM Board of Directors to help ensure the mission of HFM. I believe one of the most important duties of a board member is to listen to what the community is expressing, (understand) their needs, and help brainstorm ideas on how to address those needs."



Every fall, HFM hosts a weekend retreat at Pioneer Trails for Eagle Journeys alumni to gather and reconnect. Camp Old Beagle is open to any previous camper and/or counselor of HFM's camping programs.

This year, Camp Old Beagle had 33 alumni join us September 13-15 at the home. at the home of Camp Bold Eagle for a weekend full of bonding and traditional camp activities. Attendees participated in scavenger hunts that tested their knowledge of the campgrounds, an evening of karaoke, a kickball tournament, and plenty of time on the dock and in the lake. Of course, we can't forget about the camp classics, making s'mores around the campfire, singing camp songs, and making lanyards and friendships bracelets. We even had a Euchre tournament on the waterfront! Our group had a wonderful weekend sharing laughter, memories, and good times.



No matter how long you have been away, Camp Bold Eagle stays in the hearts of all who experience it. Camp Old Beagle will always welcome you back. 🍷

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Let's make today brilliant.

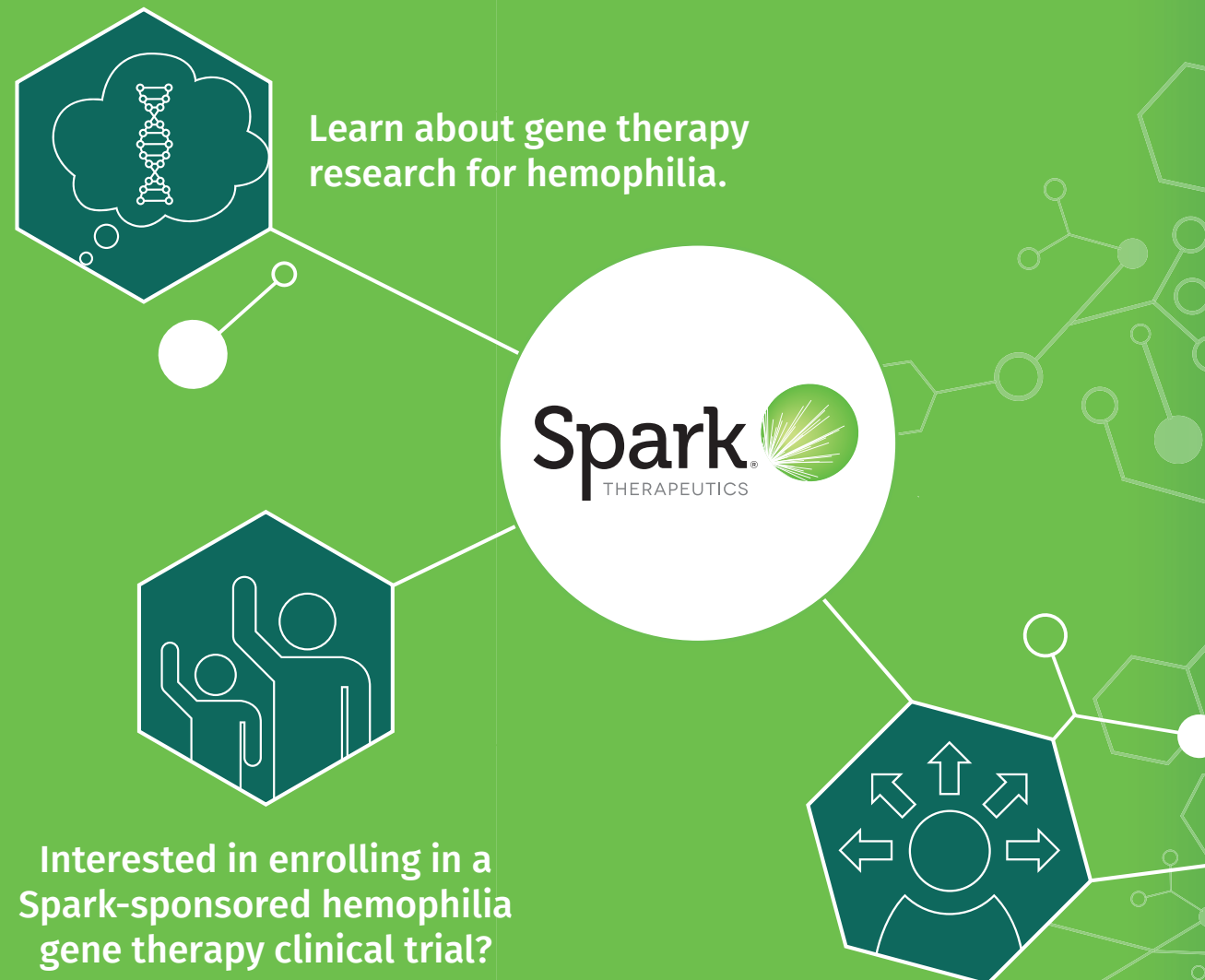
Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world is stronger than ever.



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

At Spark® Therapeutics, we're working to unlock the power of gene therapy to accelerate healthcare transformation.

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.



Learn about gene therapy research for hemophilia.

Interested in enrolling in a Spark-sponsored hemophilia gene therapy clinical trial?

Discover more about gene therapy research



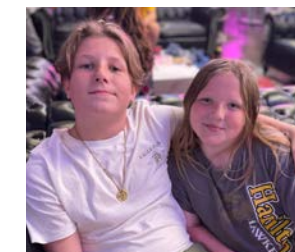
Want to know more about gene therapy clinical trials?

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KALAMAZOO COMMUNITY NIGHT



The Revel and Roll Community Night in Kalamazoo was bursting at the seams with fun, food, friends, bowling, and excitement! We were thrilled to invite Bronson HTC staff to share education on traveling with a bleeding disorder. Nurses Jenn and Emily gave so many fantastic tips including getting a travel letter from your HTC and even bringing a special bag with your needed supplies. We were also pleased to welcome Samantha Carlson, National Bleeding Disorders Foundation Social Worker and Director of Research who joined us for our event.

If you want to learn more about the event from several of our youth attendees, check out what Ben Lawson (13), Sammy Lawson (11), and Shawn Lawon (16) had to share about their experience at Revel and Roll.

WHAT WAS YOUR FAVORITE PART OF THE REVEL AND ROLL COMMUNITY NIGHT?

Ben: The pizza.
Sammy: The bowling.
Shawn: Free bowling and free food!

WHO WON YOUR BOWLING GAME?

Ben, Sammy, Shawn: Our dad!

DID YOU SEE ANY OF YOUR HFM FRIENDS AT THE EVENT?

Ben, Sammy, Shawn: Yes!

WHAT WOULD YOU SAY TO SOMEONE WHO HASN'T BEEN TO A COMMUNITY NIGHT BEFORE WHO IS THINKING OF COMING?

Ben: Just go, I guess.
Sammy: You should go, it is so fun!
Shawn: Go, you make lots of fun memories at events.

WHAT DID YOU LEARN DURING THE EDUCATION SESSION ON TRAVELING WITH A BLEEDING DISORDER THAT NURSES JENN AND EMILY FROM THE BRONSON HTC PRESENTED?

Shawn: That when traveling, you should have a bag with most, if not all of what you would need, if a bleed would occur. 🩸

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TINY CLOT CHRONICLES

Welcome to the Tiny Clot Chronicles! Enjoy solving the word search and challenge a friend in a game of tic-tac-toe. We've also included some inspiring quotes from campers at Camp Bold Eagle! ♡

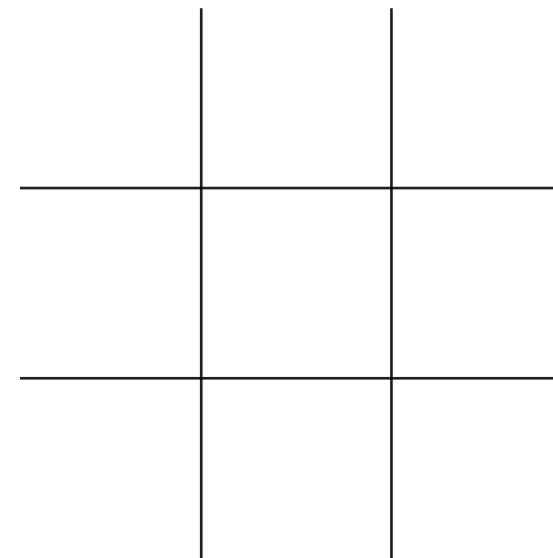
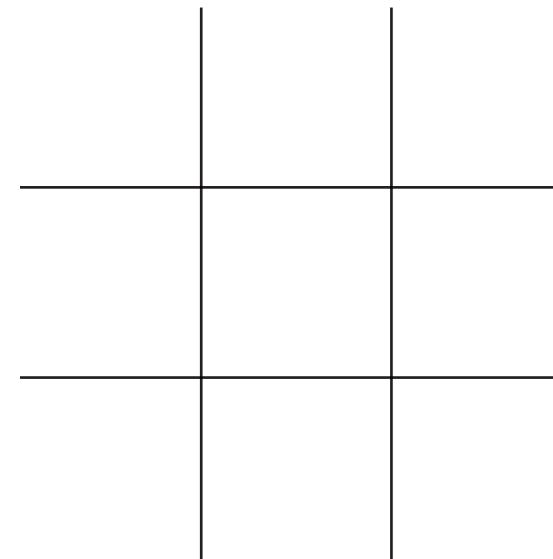
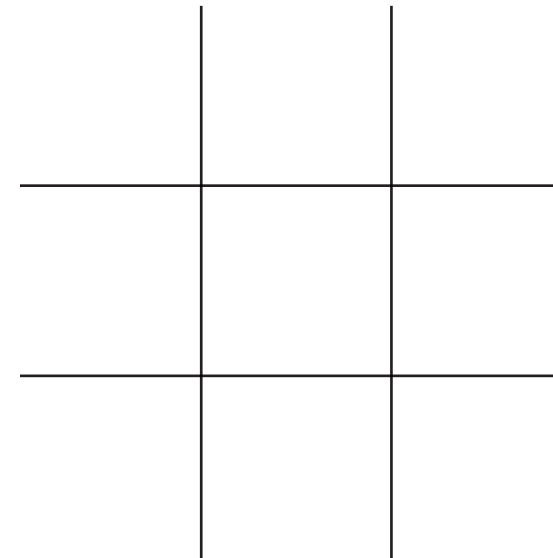
WORD SEARCH

P N P N X S H H O M C D O D R
 O X L E X P L O R E U D C U B
 C K N T J I W N L U Q X P W G
 Q C R S B R I W I J I R D K N
 H V O N W I L L E B R A N D S
 E I B U T T E R F L Y Q U C A
 M P O N D D B K E W E K F L W
 O P C S G B N O P P K Q A O B
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 I D B S W I M M I N G B G G A
 A I O G G W B G Q G D I F L D
 L P U B A F P L Y I H N K N E

VonWillebrands
 Butterfly
 Explore
 Cascade
 Cabin

Hemophilia
 Platelets
 Artery
 Factor
 Camp

BoldEagle
 Swimming
 Clotting
 Spirit



CBE SESSION 1 – JOSEPH MAYWOOD

Hi, my name is Joseph and camp is amazing! You can do my favorite, archery. You can also do arts+crafts, fishing, and lunch. Lunch is amazing, like so good. You can also swim in the lake. Next, let's talk about pins. You get them when you have the night at the campfire and after doing activities, and then you trade them, so cool. If you can get your factor together, poke by yourself, and answer a few questions, then you get my best badge: The Butterfly Award. Don't be scared about leaving your parents because you have a family at camp.

CBE SESSION 1 – GENE WISEMAN

I had a real good time at camp!! It was really fun. I loved the lake also.

CBE SESSION 2 – LOGAN JANKENS

There's a lot of activities to do. Swimming is fun. Jumping off the floatable dock is fun. This year I got a pin and a hat for being in the Polar Bear Club, where we wake up early and jump in the cold water. They have good food. I love to eat possum on a stick, which is sausage wrapped in pancakes. It's fun and I feel happy when I'm at camp.

CBE TEEN SESSION – MAYA SELVARAJ

My name is Maya Selvaraj, and I am 15 years old. I've been attending Camp Bold Eagle since I was 9 and since then, it has been the highlight of my summer. I've made many lifelong friends at camp and I'm always excited to make more! Camp feels like a second home to me and I feel the most comfortable when I'm around everyone at camp. I will never forget the memories I've made and the amazing people who have fun with me at camp!

CBE TEEN SESSION – JORDAN JANKENS

I liked getting to meet new people who shared interests with me and hang out with them and make friends because it felt like I could just really be myself. I just really like the environment of camp. It's very friendly and welcoming. I really enjoyed arts and crafts, chilling in the art tent, and just talking to people. I have gone to camp like five times, and I love seeing my friends that are there year after year.



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GETTIN' IN THE GAME

BETSY BOAHENE, MILES' MOM AND COMMUNITY MEMBER

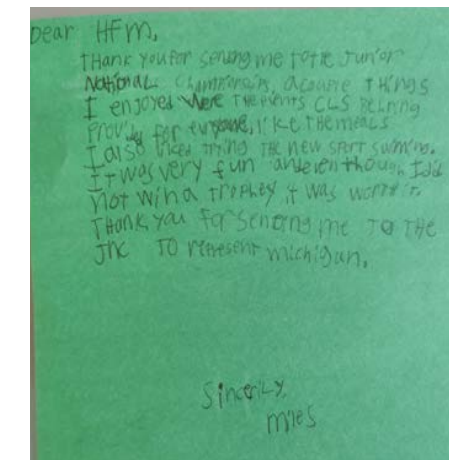
CSL Behring's Gettin' in the Game Junior National Championship offers a weekend for children and teens with bleeding disorders to come together for education, competitive fun, and physical fitness focused on golf, baseball, swimming, or basketball. HFM was pleased to send two Michigan families to Henderson, Nevada this year. One family was excited to share their experience, and to encourage other families to apply for the 2025 program. HFM will share details on social media when information is available.



We had an absolutely wonderful experience at Gettin' in the Game. From the seamless transportation and accommodations to the well-organized activities, everything ran so smoothly, making the weekend truly memorable.

Miles, who had been inspired by the Olympics this summer, was especially excited to dive deeper into swimming. On Saturday, they hosted a three-part swim competition focusing on controlled breathing, sprinting, and power & efficiency. Each kid had the opportunity to run through these skills multiple times, and it was amazing to see how eager they were to compete and challenge themselves. Miles wasn't sure how he'd feel about the sprint initially, but it quickly became his favorite, and he jumped at the chance to race as many times as possible.

One of the most meaningful moments was a special session where the coaches and athletes shared their experiences. Miles mentioned how each coach shared the most adventurous place they had to infuse their medicine, and it was truly inspiring.



WATCH THE RECAP VIDEO



While it was incredible to watch Miles grow in his swimming abilities, what stood out even more was the positive and encouraging community he was surrounded by—a place where bleeding disorders were normalized, experiences were shared openly, and everyone left feeling inspired and empowered.

Thank you so much for giving Miles the opportunity to attend the Junior National Championship. It was a weekend filled with growth, joy, and inspiration—one we will never forget. 💧

THANK YOU TO CSL BEHRING FOR OFFERING THESE OPPORTUNITIES TO THE MICHIGAN COMMUNITY.

CSL Behring

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TRAVERSE CITY COMMUNITY NIGHT BRINGS LAUGHTER, LEARNING, AND FUN!

On November 1, Incredible Mo's in Traverse City buzzed with excitement as community members, dedicated staff from the Munson Hemophilia Treatment Center, and HFM staff gathered for a night filled with education, fun, and food! This special Community Night brought together families and healthcare professionals for an evening designed to nourish both body and mind.

The highlight of the night was an interactive educational session on nutrition, presented by Melissa Goodchild, RD. With colorful visuals, participants learned which foods acted as superheroes—like leafy greens, whole grains, and lean proteins—and which ones take on the role of villains, including sugary snacks and overly processed foods.

Families shared laughter and conversation over a delicious dinner. With everyone refueled, the real action began with bowling and arcade games.

The night ended with smiles and promises of more moments like these—an unforgettable reminder that community and shared experiences are the true heroes of well-being. 💧



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FLINT COMMUNITY NIGHT



Community Nights offer a fantastic opportunity for families to connect and create lasting memories. This October, we gathered at the Longway Planetarium in Flint for a fun-filled evening. This was our first ever Community Night in Flint, and we were so excited to bring the Flint area community together on October 25. Families enjoyed dinner, Halloween crafts, trick or treating, musical chairs, and an opportunity to connect before experiencing a captivating planetarium show. We also hosted an educational session led by our very own Saydi Davis, Regional Program Manager and Travis Miller, Associate Camp Director and Program Services Manager. A special highlight of the night was welcoming the 'Bleeder and a Buddy' teen retreat group, who joined us in bringing new community members together! 💧



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FINANCIAL ASSISTANCE

In 2024, HFM provided financial assistance to 172 individual community members, and we would like to express our overwhelming gratitude to our many community partners who partner with our financial assistance program (these numbers reflect assistance provided January-October). We would like to first thank the Hemophilia Alliance Foundation and Cascade Hemophilia Consortium for their contributions to our program, allowing us to provide direct assistance to families who find themselves in emergency situations. Additionally, we owe gratitude to the University of Michigan Hemophilia and Coagulation Disorders and the Children's Hospital of Michigan Hemostasis and Thrombosis Center for partnering with us to write the Hemophilia Alliance Foundation grant which allowed us to distribute additional funds to their patients in financial crisis.

As we all know, bleeds happen, and the bills don't stop when they do. Below is a graph of the ways that HFM's financial assistance program was able to provide support to families January-October 2024.

If you find yourself in a financially stable situation, and this inspires you to donate to HFM, please know that your contribution supports families impacted by financial crisis directly related to their bleeding disorder. 🩸

THANK YOU TO



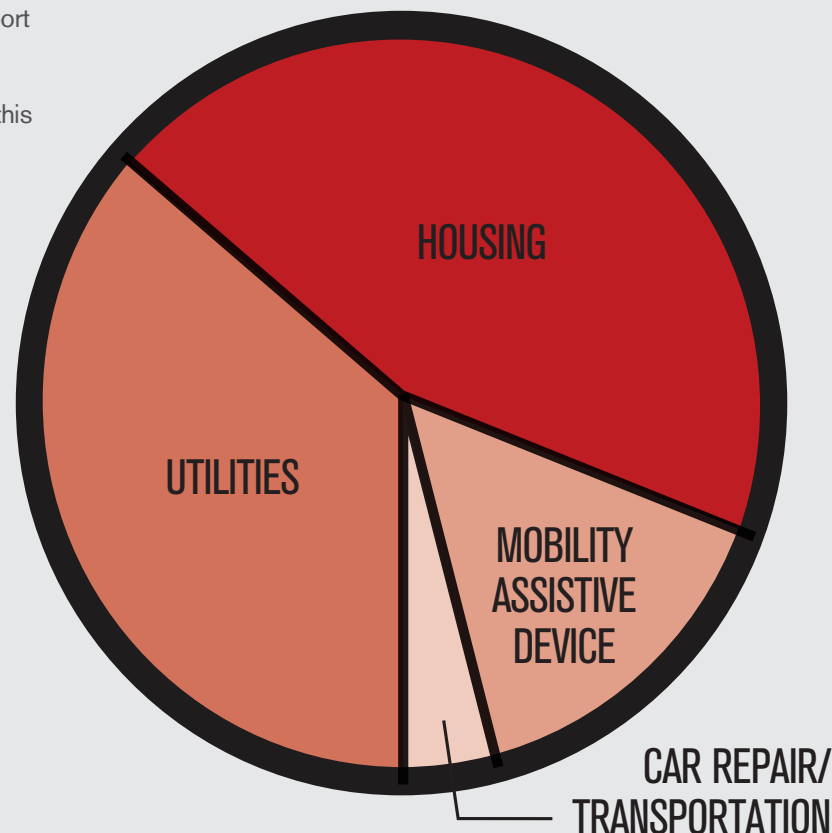
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FOR THEIR SUPPORT OF HFM'S FINANCIAL ASSISTANCE PROGRAM

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WAYS IN WHICH HFM'S FINANCIAL ASSISTANCE ADDRESSES NEEDS IN THE COMMUNITY



SPRINGFEST 2025

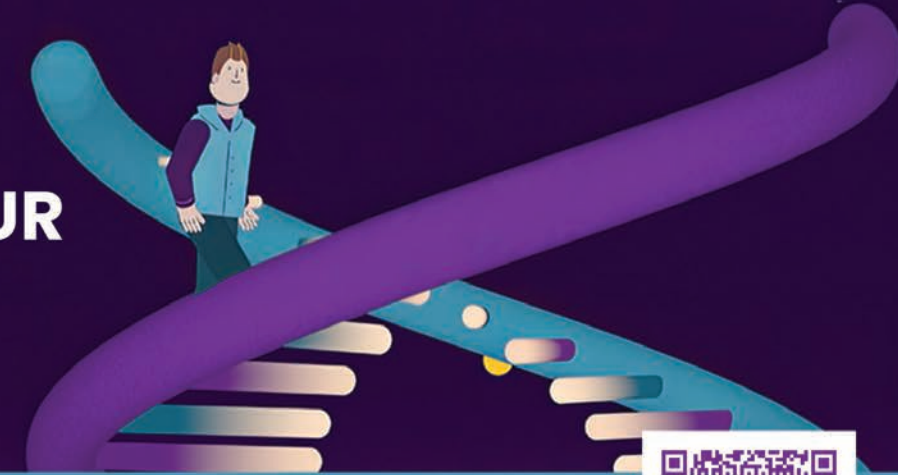
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APRIL 26 – APRIL 27 • 2025

DETROIT MARRIOTT, TROY MI

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PAID CONSUMER OUTREACH



NUTRITION AND RECIPE

TINA WILLIS, MA, RDN, INDIANA HEMOPHILIA & THROMBOSIS CENTER

Eating healthy during the winter can be challenging for several reasons. The number of daylight hours are fewer, and the weather is cooler which may mean less time outside resulting in us being less active. We may tend to hunker down and hibernate during those long, dark, cold months and our cravings for high calorie “comfort” foods is often higher.

Our nutrition is still important, so what do we do to make sure we are still getting all the nutrients that our body needs? First, include seasonal produce in your daily diet. Choose from brussels sprouts, cabbage, pumpkin and other types of squash, sweet potatoes, and turnips — just to name a few. Don’t forget that this is also the time of year that citrus fruits such as oranges and grapefruit are in season. You may also eat pineapple, cranberries, apples, and pears.

Broth-based soups are especially satisfying, filling, and delicious this time of year. There’s nothing like a bowl of vegetable soup to warm you up on a chilly day!

Make sure to also drink plenty of water to stay hydrated. Less outside humidity in the winter plus dry air in heated homes make getting the proper amount of fluid especially important.

Lastly, if you still feel you aren’t getting the nutrients you need, include a daily multivitamin. A multivitamin may act as an insurance policy on those days you aren’t able to get the nutrients you need in your diet. ♦

EASY VEGETABLE SOUP

- 1 pound ground beef, ground turkey, or ground chicken
- 1 medium onion (chopped)
- 28 ounces canned tomatoes (diced, undrained)
- 16 ounces frozen vegetables
- 1 can kidney beans (undrained) (may substitute black beans, pinto beans, etc.)
- 2 cups beef broth
- Taco seasoning to taste

Cook the meat in a stock pot and drain. Add the remaining ingredients and cook until the frozen vegetables are tender. Feel free to also add any other vegetables you’d like — cauliflower, broccoli, cabbage, potatoes, or even an additional can of beans!

ROASTED WINTER VEGETABLES

- 16 ounces carrots (chopped)
- 2 parsnips (peeled and chopped)
- 1 medium turnip (peeled and chopped)
- 1 onion (peeled and chopped)
- Garlic cloves, chopped
- Olive oil

Place the prepared vegetables on a shallow baking pan. Drizzle a small amount of olive oil over the vegetables. Add salt and pepper. Place in an oven that has been preheated to 425 degrees. Bake until the vegetables are soft — about 20 minutes depending on the size of the vegetables. After cooking, you may top the vegetables with shredded parmesan cheese or balsamic vinegar for added flavor.



Your support brings hope and creates connections in all the ways our community comes together.

88 cents of every dollar raised supports programs and services delivered to families living with bleeding disorders.



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ADVOCACY UPDATE

When you think of HFM’s advocacy efforts you likely think of our work with the Legislature on many issues, but we also work closely with state agencies to ensure that our community maintains coverage under Children’s Special Health Care Services, and more recently to ensure that our community has equitable access to mental health and substance use disorder treatment facilities.

In October of 2023, Michigan became one of five states that are a part of the Bleeding Disorders Substance Use and Mental Health Access Coalition (BD SUMHAC). BD SUMHAC advocates for access to appropriate substance use disorder and mental health treatment facilities for all individuals with a bleeding disorder, with a focus on inpatient and residential facilities. Since joining

the coalition, we have had several meetings with state agencies, specifically with the Department of Health and Human Services (DHHS) and Licensing and Regulatory Affairs (LARA). We have had the opportunity to submit comments and suggestions to the regulations for mental health and substance use treatment facilities during LARA’s process of rewriting the regulations. This is a unique opportunity, and we look forward to working with LARA on implementing changes that will protect members of the bleeding disorders community who need inpatient or residential substance use disorder treatment. Additionally, we will be submitting further suggestions for mental health treatment facilities’ regulations. HFM remains committed to ensuring equitable access to mental health and substance use treatment for everyone. ♦



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UPCOMING 2025 EVENTS

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

February 22
VWD Symposium 




March 14
Community Night 

March 18-19
Lansing Days
Lansing Capitol 

March 25
Blue Bridge Lighting
Grand Rapids 

April 26-27
SpringFest
Troy, MI 

May 17-18
Women's Retreat
Muskegon, MI  

 Virtual
 In-person
 18 and older

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