



THE **ARTERY**

WINTER 2025

THIS ISSUE

08 UP RETREAT RECAP

19 JOINT REGIONAL MEETING

29 DETROIT COMMUNITY NIGHT



HAPPY NEW YEAR!

Hemophilia and Thrombosis Center, whose leadership strengthens our shared efforts.

HFM's programming is also made possible through the support of HTC's across the region, industry partners, and generous individuals and organizations that make consistent and new educational programming available. Together, along with you, our community members, we make this happen.

As we celebrate 70 years, thank you for making a difference as we navigate the future for those living with bleeding disorders.

With Gratitude,



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



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As we kick off the Hemophilia Foundation of Michigan's 70th year of serving those affected by hemophilia, VWD, and other bleeding disorders, our collective wish is for each of you to be positively impacted by HFM's devotion to outstanding service, healthcare, and education.

Our commitment to all affected by bleeding disorders remains steadfast as we strive to

effectively collaborate with our national partners, care providers, community members, and industry representatives to offer unbiased education and information to enhance care.

In this issue of The Artery, we reflect on the meaningful programs and services you helped make possible, and we're excited to share what's ahead in the year to come.

I am incredibly proud of the work our staff leads alongside care providers, community members, and partners across the state and region. This includes our much appreciated collaboration with the Cascade Hemophilia Consortium, Inc. (via HFM's responsibilities as the federal Great Lakes Region of the United States Regional Hemophilia Treatment Center Network, HFM serves as the sole member organization of Cascade); and our valued regional partner, the Indiana

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THANK YOU TO OUR CONTRIBUTING AUTHORS

Front Cover: A panelist shares insights during HFM's National Women's Conference.

PAID CONSUMER OUTREACH INCLUDED
IN THIS NEWSLETTER

2025 HFM ADVOCACY AND HEALTH POLICY SUMMIT



HFM Advocacy Summit attendees hear from staff from the Michigan Department of Licensing and Regulatory Affairs.

At the end of each year, the Hemophilia Foundation of Michigan (HFM) hosts our annual Advocacy and Health Policy Summit to gather a variety of stakeholders familiar with patient advocacy, health policy, and insurance trends, who can lend 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 2025, HFM was pleased to return to Zingerman's Roadhouse for our tenth annual Summit. HFM staff, the National Bleeding Disorders Foundation (NBDF), the Hemophilia Federation of America (HFA), Hemophilia Treatment Center providers, patient advocates, and industry representatives joined us for this important event.

Each attendee brought unique knowledge on policy, insurance, and advocacy to contribute to meaningful conversation. We first heard from the Michigan League of Public Policy regarding the work of the Protect MI Care Coalition, which advocated against the cuts to Medicaid and to permanently extend the Enhanced Premium Tax Credit. HFM and our national partners, NBDF and HFA, shared updates on recent advocacy activities at the state and national level. We were grateful to be joined by representatives of the Department of Licensing and



HFM Advocacy Committee members; Larry West and Suzan Higgins.

Regulatory Affairs, who shared the forthcoming regulatory changes that HFM worked on to make mental health and substance use disorder treatment facilities more accessible for people who use infusion medications.

Lastly, we were excited to have a discussion regarding the role of artificial intelligence (AI) in the healthcare space. To lead this discussion, we were joined by experts from the University of Michigan's Institute for Healthcare Policy & Innovation, and Representative Carrie Rheingans of Ann Arbor, who has introduced legislation regarding the use of AI by insurers. The contributions from our stakeholders were very beneficial and provided HFM information and resources to target 2026 advocacy priorities more effectively within the state. 💧



HFM Advocacy Summit attendees discuss the impacts of the changes to Medicaid.

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BLEEDER AND A BUDDY

Teens and their buddies gathered at North Star Reach this year for our annual fall teen retreat, Bleeder and a Buddy. This weekend provided teens an opportunity to share the connections of the bleeding disorders community with a loved one. Teens had the opportunity to teach their buddy what it is like to live with a bleeding disorder and how they advocate for their needs with their friends, at work, and at school. Their buddies learned how to best support their affected friends. It was a weekend full of learning, games, and plenty of karaoke! It was a great weekend, and we hope to see you there next year! 📌



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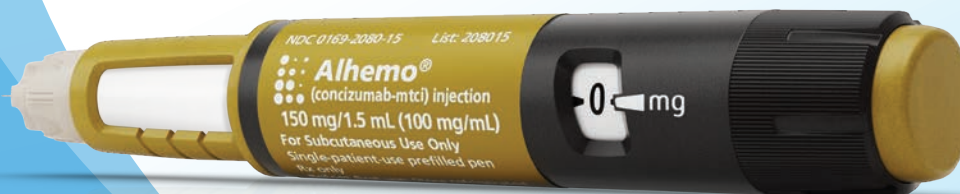
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WHAT'S NEXT? YOU DECIDE.

At Genentech, we're committed to supporting the hemophilia A community in ways that go beyond treatment and focus on you as a person. From sharing real stories and experiences from our Patient Ambassadors, to an educational rap anthem for a hemophilia A treatment, to one-on-one support from a team of experts, we're here to help you take on what comes next.

SCAN THE QR CODE TO SEE HOW
GENENTECH AND THE HEMOPHILIA
A COMMUNITY ARE EMBRACING
WHAT'S NEXT, TOGETHER.



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**GENENTECH IN
HEMOPHILIA**

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LAUNCH

On November 15, HFM held LAUNCH Day, an in-person workshop designed to assist community members in their job search. This event offered hands-on assistance with resume writing and helped community members create an impactful resume. Attendees also honed their interview skills with questions tailored to their career interests. Amidst the networking with fellow job seekers, community members had the chance to update their professional image and social media profiles with a complimentary headshot. HFM staff offered insights to help individuals find a job that fits their needs as well as the opportunity to join HFM's job training and certification program. 🩸

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READY TO LAUNCH YOUR CAREER?

Take the next step with the Hemophilia Foundation of Michigan's LAUNCH Vocational Job Training and Certificate Program — your pathway to opportunity in healthcare or information technology.

Whether you're seeking professional certification, need help polishing your resume and cover letter, or want to build confidence through mock interviews and coaching, LAUNCH is here to help you succeed.

Get started today!
Contact Travis Miller to
learn more or to enroll:
734.961.3510
tmiller@hfmich.org

SCAN TO LEARN MORE



SHINING TOGETHER IN THE UP: 2025 RETREAT RECAP



Angela Jaehnig and Jill Foley share a warm moment during HFM's UP Retreat.

The Hemophilia Foundation of Michigan was proud to welcome five families to Marquette for a weekend of connection, education, and fun at our bi-annual Upper Peninsula Retreat. Held August 1–2, this year's theme, Yooperlites: Find Your Shine, celebrated the rare glow within each of us and the power of community.

From our glow-themed icebreakers to the heartfelt conversations shared over meals, the weekend was filled with light, laughter, and learning. With curiosity and a dash of silly string, we explored the relationship between bleeding disorders and sleep, recreated the clotting cascade, learned how to travel safely, and how to communicate effectively with care providers. We even dipped our toes into the complex world of gene therapy, gaining insights into its promises and challenges.

Children 0-4 received one on one attention in onsite childcare, while school age children 5-12 spent time at the Upper Peninsula Children's Museum, played games, and interacted with reptiles. Teens hiked Presque Isle, interacted with animals at the Moosewood Nature Center, visited a bog, and engaged in meaningful conversations surrounded by nature.

Yooperlites are a type of igneous rock, specifically syenite, that contains the fluorescent mineral sodalite. They are known for glowing with bright colors like orange, pink, and yellow under ultraviolet (UV) light, making them a popular find for rock hunters, particularly along the shores of Lake Superior in Michigan. In natural light, they can look like ordinary granite.

Our Saturday evening family picnic took place on beautiful Presque Isle, right next to the Community Garden, lovingly overseen by our own Tina Taylor, who treated us to a wonderfully informative tour of the garden space. With a classic cookout, bingo scavenger hunt, and outdoor games, we ended the retreat with joy and connection.

We're deeply grateful to our community members, speakers, sponsors, and partners at the Michigan State University Center for Bleeding and Clotting Disorders and Cascade Hemophilia Consortium for making this weekend so special.



Ezra flashes a big smile while posing with Jonathan during the event.



Ellie smiles brightly while enjoying activities at the Retreat.

We hope everyone who attended left feeling seen, heard, and valued—because just like Yooperlites, we shine brightest together. We're looking forward to returning to the Upper Peninsula for another retreat in 2027.

If you're interested in joining the planning committee, please reach out to Shari Luckey at sluckey@hfmich.org. And if you know someone living in the UP who hasn't attended a retreat yet, feel free to share Shari's contact information with them.

This retreat is open to adults, families, and individuals of all ages living in the UP who are affected by a bleeding disorder.

Until next time—keep shining. 💧



Session facilitators, Karen Boyd and Dr. Chandra Gera, brought energy and insight to the Retreat.

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rare bleeding disorder community

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

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HFM'S AGING PROGRAMS

Thank you to Genentech for their generous support this year of programs serving the aging population with bleeding disorders. We were pleased not only to be able to integrate these programs into our larger events and meet the needs of those aging with hemophilia and other bleeding disorders but also to share programming ideas with other chapters across the country.

Throughout 2025, HFM developed and worked with expert speakers to share relevant information such as "Testing, Diagnosis, and Research Trials: Through the Lifespan," "Aging Affects: Longevity and Wellness with VWD," "You Are the Expert: Piecing Together Our Past," "Aging with a Bleeding Disorder," "Pre-Menopause and Menopause with Bleeding Disorders," and small group conversations for those ages 55+. Multiple yoga and aqua aerobics sessions were held to encourage movement activities for those of all ages.

HFM is here to meet the needs of all individuals in the Michigan bleeding disorders community, and we are so pleased to offer relevant and needed programming for everyone. 💧



We also appreciate Genentech's commitment to the Days for Girls initiative. Through this partnership, Genentech supports HFM's efforts to provide vital education and menstrual kits to women in developing countries, empowering families and promoting health and dignity worldwide. 💧

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ARE YOU UNINSURED OR UNDERINSURED WITH YOUR DENTAL COVERAGE? IF YOU ARE, WE MAY BE ABLE TO HELP.

We understand that even with insurance, our community faces challenges in obtaining dental care to meet our unique and individual needs. In partnership with Cascade Hemophilia Consortium, HFM can offer dental care coverage to those who need it.

TO BE ELIGIBLE FOR THIS PROGRAM YOU MUST MEET THE FOLLOWING CRITERIA:

- You must have a bleeding disorder
- Be a Michigan resident
- Have no dental insurance or only Children's Special Health Care Services
- If you have other coverage like Medicare, Medicaid or employer sponsored plans, you are not eligible unless you have special circumstances (ex: extensive dental

work) that will not be covered by your existing coverage.

- You **may** be eligible for time-limited coverage based on special circumstances — these exceptions are limited and determined on a case-by-case basis. Please call us for more information.

TO BE ELIGIBLE FOR THE FOLLOWING BENEFIT YEAR, YOU MUST VISIT THE DENTIST FOR TWO CLEANINGS DURING THE CALENDAR YEAR AS WELL AS COMPLETE THE RENEWAL APPLICATION. THE RENEWAL APPLICATION IS SENT OUT EVERY YEAR IN OCTOBER.

This program provides \$1,000 in dental coverage. Regular teeth cleanings (not extensive cleanings) and limited x-rays are included in addition to the \$1,000

coverage. There is currently no premium charged for this program.

It is **important** to always consult with your hematologist before getting dental work completed; and **always get a pre-treatment estimate** from your dentist before having any dental work done.

If you have an application or eligibility question, contact Dana Brendecke-Carrier, HFM Office and Database Manager, at dbrendeckecarrier@hfmich.org or 734-544-0015. 💧

You may have already submitted your 2026 application, if not please make sure to get them in before January 31, 2026!

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ADVOCACY UPDATE

After missing a constitutional deadline for the first time in 16 years to pass an annual budget before the October 1 start of the fiscal year, Michigan lawmakers finalized the Fiscal Year 2025-26 (FY 25-26) budget in the early morning hours of October 3, 2025. Governor Gretchen Whitmer then signed the \$75.9 billion spending plan with an additional \$5 billion held in contingency funds on October 7, 2025.

Within the spending plan, the Department of Health and Human Services (DHHS) received \$30.03 billion with \$7.62 billion coming from the General Fund, which represents a 20.2% decline overall due to \$5.87 billion in lost federal funds from H.R. 1 (the One Big Beautiful Bill Act). We knew that Michigan would need to make cuts to address the budget deficit created by the federal cuts included in H.R. 1, but despite these cuts, HFM was grateful to see that Children's Special Healthcare Services (CSHCS) received \$430.3 million in continued funding. The CSHCS budget for FY 25-26 amounts to a 36% increase compared to the \$315 million allocated in the previous year's budget.

The robust CSHCS program will help ensure all Michiganders with bleeding disorders maintain access to life-saving medication and treatment. Families of all incomes are eligible to join, including those with other

health insurance including Medicaid — though there may be a yearly fee to join CSHCS based on family income and family size. Visit www.michigan.gov/cshcs or call the CSHCS Family Phone line at 800.359.3722 for more information.

We invite you to join us at HFM's annual advocacy day, Lansing Days, to talk to elected officials about the value of the CSHCS program. Lansing Days will be held March 24 and 25, 2026. You can learn more at www.hfmich.org/lansingdays. 📍

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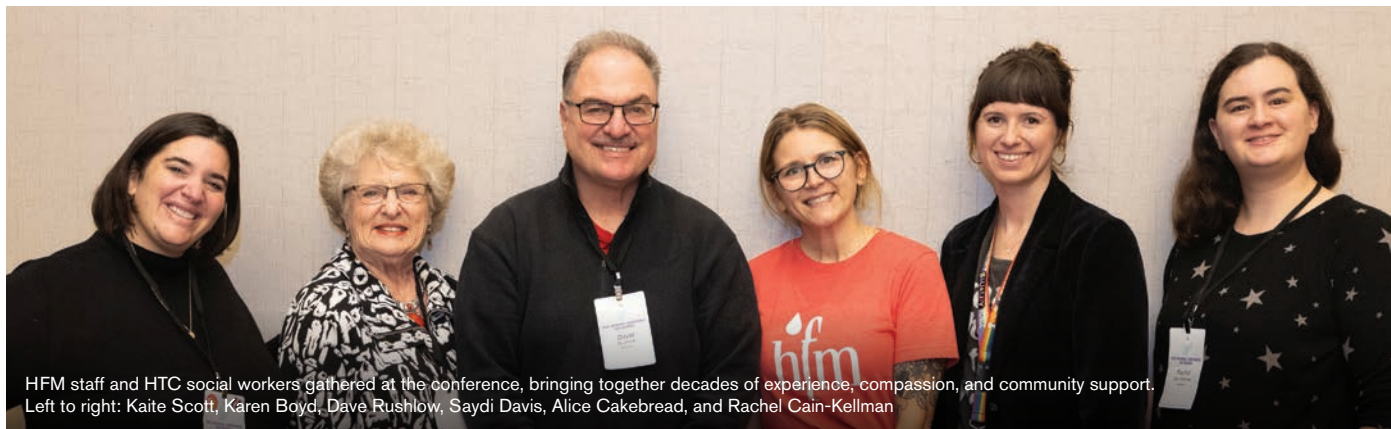


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SOCIAL WORKERS STRENGTHEN COMMUNITY AT HFM'S NATIONAL WOMEN'S CONFERENCE



Social workers offer unique value to any atmosphere, but particularly at HFM's National Conference for Women with Hemophilia and Rare Factor Deficiencies. The 2025 National Women's Conference welcomed the support and collaboration of several HTC social workers. From the intentional planning of sessions to the execution of facilitating and moderating these sessions, these HTC social workers made a lasting impact on conference attendees. ♦



"I found that the women were engaged and lively during our session on self-care. It was wonderful to see the interactions among attendees as they shared dilemmas, perspectives, hints, and tips [on self-care in managing their bleeding disorder]."

Ellen Kachalsky, LMSW, ACSW
Hemophilia and Thrombosis Center
Henry Ford Health System



"I feel absolutely honored to be invited and a part of the National Women's Conference. The sessions are informative, engaging, and supportive. You can feel the incredible community and presence of all the women attending and their knowledge and experiences. Participating as a social worker has greatly informed my [social work] practice for the better!"

Alice Cakebread, LMSW
Hemophilia and Coagulation Disorders
University of Michigan



"As one of the few males attending, I gained insight as an HTC social worker into the unique challenges women with bleeding disorders experience. The experience can only help me be a better clinician in working with women with bleeding disorders."

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



"See Me! Hear Me! Believe Me! That's what women experience at the HFM National Women's Conference. The National Women's Conference continues to be one of the most meaningful and empowering gatherings for women in the bleeding disorders community."

Karen Boyd, LMSW
Clinical Social Worker, Michigan State
University Center for Bleeding and Clotting
Disorders



KALAMAZOO COMMUNITY NIGHT

On August 15, HFM families gathered at **Revel & Roll in Kalamazoo** for an evening that blended meaningful conversation with good food and plenty of fun. Community Nights are one of HFM's favorite ways to bring people together, and this one was no exception.

As participants shared pizza around the tables, **Jason Wong, LLMSW of Bronson, and Kaite Scott, LLMSW, HFM Social Worker**, led an engaging discussion titled "*Mental Health Effects of Chronic Health Conditions*." The presentation opened the door to honest conversations about how chronic health challenges can affect emotional well-being.

Once the discussion wrapped up, it was time to start bowling! Families and friends cheered each other on,

celebrated strikes, and laughed off the gutter balls. The night was a reminder of the strength and joy found in community.

HFM thanks everyone who joined us for this special evening and looks forward to seeing you at future gatherings! To explore upcoming opportunities to connect and our 2026 Community Nights schedule, visit www.hfmich.org/events. 🍷

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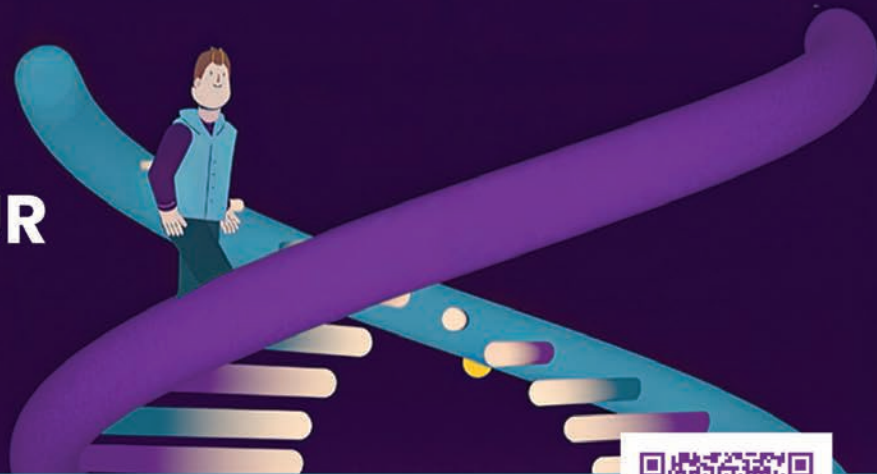
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BREAKING BARRIERS: SELF-REPORTED DIAGNOSIS DELAYS IN BLEEDING DISORDER PATIENTS BY BIRTH SEX

MARIA E SANTAELLA, PHD(C), MSN, RN-BC; SAMANTHA A CARLSON, LMSW; PAXTON MILLS; MARISSA JOHNS; CYNTHIA NICHOLS, PHD

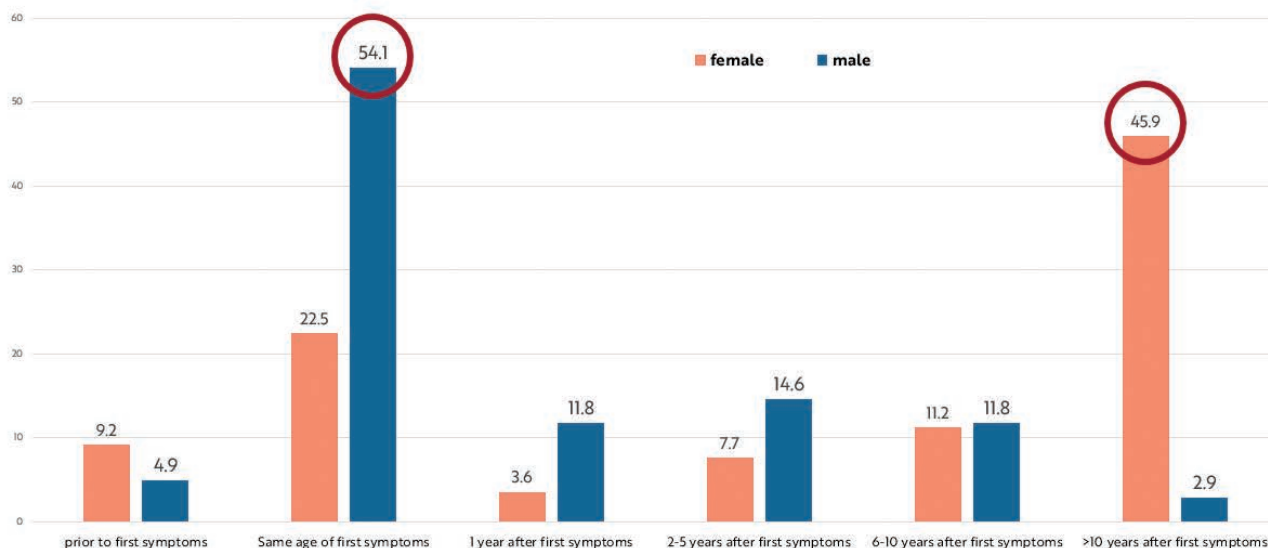
Community Voices in Research (CVR) is a community-powered registry that collects information directly from people who have inherited bleeding disorders and their family members (parents, spouses, grandparents, and siblings). The goal is to better understand your day-to-day experiences and identify important research questions that matter to the bleeding disorders community. Information is collected through electronic surveys with answers coming directly from you.

Women and girls often face unequal treatment in healthcare, and research shows they often experience more challenges and delays in getting proper care. Learning about their

experiences can help reduce health differences and improve outcomes for everyone with bleeding disorders.

This analysis looked at how long it takes from the time someone first has symptoms until they are diagnosed — called **time to diagnosis (TTD)** — and compared this by sex at birth and type of bleeding disorder. Data were collected between 2019 and 2022 from **442 participants** (196 female at birth and 246 male at birth) who self-reported having **Hemophilia A, Hemophilia B, Von Willebrand Disease, or other bleeding disorders (includes platelet disorders, Ehlers Danlos, and other factor deficiencies)**. 🩸

**Time between symptoms and diagnosis:
males vs. females (sex at birth)**



N = 442

Time between first symptoms and diagnosis	Hemophilia A (n=224)				Hemophilia B (n=94)				VWD (n=69)				Other (n=55)			
	female (n=67)	male (n=157)	P (main effect)	P (time period)	female (n=20)	male (n=74)	P (main effect)	P (time period)	female (n=63)	male (n=6)	P (main effect)	P (time period)	female (n=46)	male (n=9)	P (main effect)	P (time period)
	n (%)	n (%)			n (%)	n (%)			n (%)	n (%)			n (%)	n (%)		
Prior	8 (11.94)	6 (3.82)	<0.001	0.32	4 (20.00)	5 (6.76)	<0.001	0.093	none		0.375		6 (13.04)	1 (11.11)	0.007	1.000
same time	9 (13.43)	89 (56.69)		<0.001	5 (25.00)	38 (51.35)		0.044	16 (25.40)	2 (33.33)		1.000	14 (30.43)	4 (44.44)		0.454
within 1 year	3 (4.48)	20 (12.74)		0.090	0	7 (9.46)		0.339	2 (3.17)	1 (16.67)		0.245	2 (4.35)	1 (11.11)		0.421
2-5 years	4 (5.97)	17 (10.83)		0.322	1 (5.00)	16 (21.62)		0.109	9 (14.29)	0		1.000	1 (2.17)	3 (33.33)		<0.001
6-10 years	6 (8.96)	22 (14.01)		0.053	2 (10.00)	6 (8.11)		0.677	8 (12.70)	1 (16.67)		1.000	6 (13.04)	0.00		0.574
>10 years	37 (55.22)	3 (1.91)		<0.001	8 (40.00)	2 (2.70)		<0.001	28 (44.44)	2 (33.33)		0.687	17 (36.96)	0.00		0.044

KEY FINDINGS

- Although females are more symptomatic, they often experienced longer delays before getting diagnosed compared to males.
- 46% of females reported waiting more than 10 years between their symptoms and diagnosis (especially for conditions other than Von Willebrand's Disease) while almost 60% of males were diagnosed within the first year of showing symptoms.

Understanding and reducing delays in diagnosis is critical to addressing disparities in the bleeding disorders community. These delays can limit access to treatment, affect education/work, and lead to poor health outcomes. More research is needed to find ways to close these gaps and ensure fair and equitable care for everyone in the bleeding disorders community.

YOUR EXPERIENCES MATTER — AND YOU CAN DRIVE REAL CHANGE.

Join **Community Voices in Research (CVR)** and share your story through quick, confidential surveys. Whether you're living with a bleeding disorder or supporting someone who is, your voice helps researchers better understand the real-life impact — and paves the way for better care, treatment, and support. Every voice adds to a powerful, community-driven effort to improve care, influence research, and build a better future for all generations.

Be part of the progress. Share your voice. Shape the future of bleeding disorders research.

 **Community Voices in Research**
National **Bleeding Disorders** Foundation



Visit www.bleeding.org/cvr or scan the QR code for more information! If you are already a CVR participant, we thank you for your help in shaping the future of bleeding disorders research!



We had a weekend filled with opportunities to connect, starting with a campfire where participants shared personal updates, met new friends, and cooked some delicious s'mores. We had other camp classic activities like tie-dying, canoe trips, friendship bracelets, and lanyard making. Campers also had a chance to show off their skills in a euchre tournament, karaoke, and team trivia. We had 31 attendees come to Old Beagle and make it a weekend worth remembering. We hope to see you next year! 🍷



Old Beagle, HFM's camp alumni retreat, welcomed past campers and staff (ages 18+) to come together at Pioneer Trails and reunite, share old camp stories, and make great new memories. Many brought their families to share this magical place and camp connections with their loved ones. After many years away, several camp alumni made their return to Pioneer Trails and were warmly welcomed.



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GREAT LAKES & NORTHERN STATES JOINT REGIONAL MEETING 2025



Each year, HFM's Regional Team hosts a meeting inviting attendees from various Hemophilia Treatment Centers (HTC) disciplines from across the Great Lakes Region (Indiana, Michigan, Ohio). For the first time, in November 2025, the Regional Team co-hosted a joint Regional Meeting with the Northern States Region (NSR) which consists of Illinois, Minnesota, North Dakota, South Dakota, and Wisconsin.

To encourage maximum participation, the meeting was hosted in Chicago, IL given its centralized location for both regions. The meeting offered a virtual attendance option as well.



In recent years, the Great Lakes Region (GLR) has welcomed an average of 140+ participants, in-person and virtually, to the annual Regional Meeting. This year, in conjunction with the NSR, attendance was more than 275 participants both in-person and virtually, the majority being from our region. These participants included HTC nurses, nurse practitioners, social workers, data managers, physical therapists, pharmacists, hematologists, business administrators, dietitians, and agencies supporting the success of HTCs nationally.



The Regional Meeting provided attendees information regarding innovative research studies, diversified best practices, and collaborative efforts. Notable topics of discussion at the 2025 Regional Meeting included iron deficiencies and the impact on women's health, surgical procedures, gene therapy, and program updates from organizations operating at a national level.

An additional session at the meeting was a patient panel featuring HTC patients. The intended purpose of this session was to welcome patient voices from the regions and to gauge the most



memorable moments experienced during their comprehensive visits. Through this unique session, attending disciplines were acknowledged and applauded for their strengths and successes. Additionally, the panel session encouraged professional attendees to explore potential methods for improvement to enhance the quality of patient care suggested by the patient panelists.

In addition to the exemplary general sessions, each discipline dedicated at least two hours to participate in educational sessions relevant to their profession. These breakout sessions offered an opportunity for collaborative problem solving and exposure to pertinent information. The sessions also awarded attendees the necessary continuing education units (CEUs) to maintain professional licensure. The 2025 Regional Meeting offered the highest number of CEUs, more than any previous GLR Regional Meeting, for social workers, nurses, and pharmacists.

In addition to a plethora of learning opportunities, there were moments of comradery, networking, and rest woven into the agenda, as well. This first-time collaboration was a resounding success for everyone involved in the Great Lakes Region and the Northern States Region. We greatly appreciate everyone's participation! 💧



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LAUNCHING A NEW CHAPTER: CHM INTRODUCES A HEMOPHILIA B GENE THERAPY PROGRAM

CHARITY STADLER, RN, BSN, DIRECTOR OF NURSING, HEMOPHILIA TREATMENT CENTER, CHILDREN'S HOSPITAL OF MICHIGAN

On July 8, 2025, Children's Hospital of Michigan's Hemophilia Treatment Center (HTC) infused the first commercially available gene therapy infusion, Hemgenix®, to a 26-year-old patient diagnosed with severe Hemophilia B. The patient had been researching gene therapy treatments since the age of 15. Finally, his wish came true after a rigorous screening process, implemented to assure safety and to promote the best possible outcome, confirmed that he was a good candidate for gene therapy.

The HTC had been preparing their center to administer gene therapy to patients diagnosed with Hemophilia B for over a year, creating a well thought out and structured program. This careful planning was pertinent to the seamless execution of a series of events leading up to the

infusion day, the overall success of the infusion, and the patient's satisfaction with the experience.

Now, three and a half months later, the patient's Factor 9 levels are ~38%, and he has been off of prophylactic factor treatments since week two. He reports that he feels better than when he was on factor replacement treatments and is happy! The success of this infusion has inspired Children's Hospital of Michigan to create partnerships and offer Hemophilia B gene therapy for patients whose own HTCs are unable to offer gene therapy, while the patient continues their primary hematologic care with their primary HTC. Children's Hospital of Michigan HTC is committed to supporting every patient with Hemophilia B as they explore whether gene therapy is the right path for them. 💧

TRAVERSE CITY COMMUNITY NIGHT

Traverse City Community Night delivers connection, learning, and laughter!

On November 7, families, local Hemophilia Treatment Center staff, and HFM team members gathered at Incredible Mo's in Traverse City for an evening of connection, great food, and plenty of fun! The atmosphere was warm and lively as participants of all ages came together to learn, laugh, and build community.

The evening featured an engaging and informative session about the importance of good oral health, led by Melissa Hoxie, Registered Dental Hygienist. Her presentation offered practical tips and sparked meaningful conversation among attendees.

After dinner, complete with pizza, salad, and a sweet treat, families hit the bowling lanes and arcade for friendly competition and shared laughter.

As the evening wrapped up, families left looking forward to the next opportunity to connect. Nights like these continue to highlight the power of community and the joy found in coming together. 💧



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TINY CLOT CHRONICLES

This season's Tiny Clot Chronicles is filled with fun and creative ways for children to engage with HFM. From a Fall Spot the Difference challenge to a Winter Coloring Page and Winter Word Search, there's something for everyone to enjoy. Kids can also let their creativity shine with our Design Your Own Camp Shirt activity, a great way to get excited for summer camp. Encourage your kids to join in the fun and share their creations with us.

WINTER WORD SEARCH

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

HOLIDAY

GINGERBREAD

ICESKATING

HOTCOCOA

SLEDDING

SNOWBALL

SNOWMAN

PENGUIN

MITTENS

SHOVEL

WINTER

SCARF

FROST

COLD

SPOT THE DIFFERENCE

Can you find the **7** differences between the two pictures? *Bonus point: find the baby eagle!*



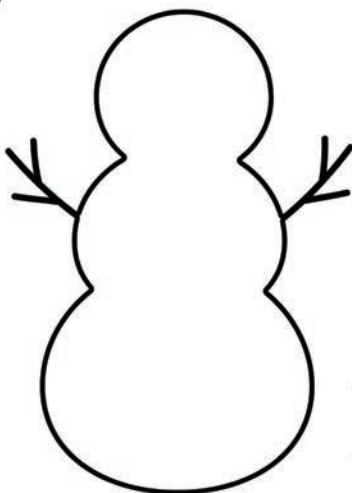
WINTER COLORING PAGE

Color in and decorate the snowman!

Do you like winter? What is your favorite part? _____



Winter is a great time to give thanks. Who and what are **you** thankful for? _____



DESIGN YOUR OWN CAMP SHIRT!

Have you ever wanted to design the Camp Bold Eagle t-shirt? **Use the template to give it a try!**

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Send the camp team your creations at CampBoldEagle@gmail.com!

WE KNOW HOW IMPORTANT IT IS FOR COMMUNITY MEMBERS TO HAVE MEDICAL ID TAGS. DID YOU KNOW THAT YOU CAN GET THEM FREE OF CHARGE?

Having a Medical ID bracelet or necklace helps in so many ways. Whether a small child or an aging senior and everyone in between, having your medical information readily available can be a life saver. A Medical ID provides first responders with critical information about your medical conditions, allergies, and medications, allowing them to treat you more effectively. This is especially important if you are unable to speak for yourself as a result of a medical crisis or accident. Wearing a Medical ID bracelet or necklace can provide peace of mind for you and those who care about you, knowing you are prepared for any emergency.

Ellen Kachalsky, LMSW, ACSW, a clinical social worker from Henry Ford Health shares, "It's extremely important. In the event there is a medical emergency and EMT or paramedics are called, they look for Medic-alert jewelry. They don't necessarily go through wallets, and they can't if a wallet is missing. In addition to Ellen, Suzanne Rogers, LMSW, a social worker from Karmanos Cancer Institute/DMC, has been having great success with patients ordering and wearing their ID tags.

Emily Valentino, BSN, RN, a nurse coordinator from Bronson Hemophilia, has patients who have rare, unique, and complex needs. It is vital that first responders and physicians are promptly alerted to their condition. Medical IDs help coordinate the treatment that patients need, especially in the event they cannot speak for themselves.

Thanks to support from Cascade, HFM offers a one-time medical identification tag free of charge, with updates available if your information changes. Contact your HTC social worker and they will be more than happy to assist you with your order.

A Medical ID tag could help save your life! 💧

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Briana McLaughlin

Patient advocate

About Briana

Briana is a Novo Nordisk Rare Blood Community Liaison (RBCL) whose daughter's diagnosis first brought her into the community, but whose passion for making a difference soon made her an advocate for families affected by rare bleeding disorders everywhere. When she's not diving deep into health education, she's camping, traveling, or cheering her daughter on at a basketball game.

Hobbies

- Reading
- Traveling
- Hiking/Camping

"We are such a close community, it's like one big family. They're so supportive, you go to events, and you feel like you are home. It's a safe space—it's like none other."

Connect with Briana

IBMG@novonordisk.com

(317) 430-4536

Rare Blood Community Liaison

IN, MI, KY

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BREATHE, STRETCH, HEAL: YOGA FOR PEOPLE WITH BLEEDING DISORDERS

For folks living with bleeding disorders, maintaining joint health, flexibility, and strength is a vital piece of managing pain, and promoting overall wellbeing. Yoga offers a gentle yet effective way to support physical and emotional wellness, making it an increasingly popular modality of exercise within the bleeding disorders community.

According to Johns Hopkins Medicine, a few benefits of routine yoga practice include pain reduction, increased flexibility, strengthened muscles, and improved circulation. These physical benefits are especially meaningful for those with bleeding disorders, where joint bleeds, mobility challenges, and pain can be a daily concern. Alongside the physical benefits of yoga, the positive emotional impact is of great appreciation, as well. Studies show that yoga's emphasis on intentional movement, breathwork, and body awareness supports one's mental well-being. Yoga has the potential to reduce stress, aid in mood management, and enhance self-care rituals by practitioners. With this knowledge, HFM has initiated yoga programming in multiple ventures, including at SpringFest, the National Conference for Women with Hemophilia and Rare Factor Deficiencies, and the 2025 Michigan HTC Social Worker's Retreat.

HFM is thrilled to expand access to this transformative practice at forthcoming gatherings and is eager to utilize yoga mats generously donated by Gaiam Yoga. With their support, HFM will continue to curate tailored yoga practices that focus on the unique needs of those with bleeding disorders.

HFM extends immense gratitude to Gaiam Yoga for their generosity and commitment to health and wellness. This contribution makes a great difference — one breath, one posture, and one mat at a time. 💚



FINANCIAL ASSISTANCE

In 2025, HFM provided financial assistance to 238 individuals 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 for their contributions to our program, which allows HFM 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 through the Hemophilia Alliance Foundation grant process, enabling 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 2025.

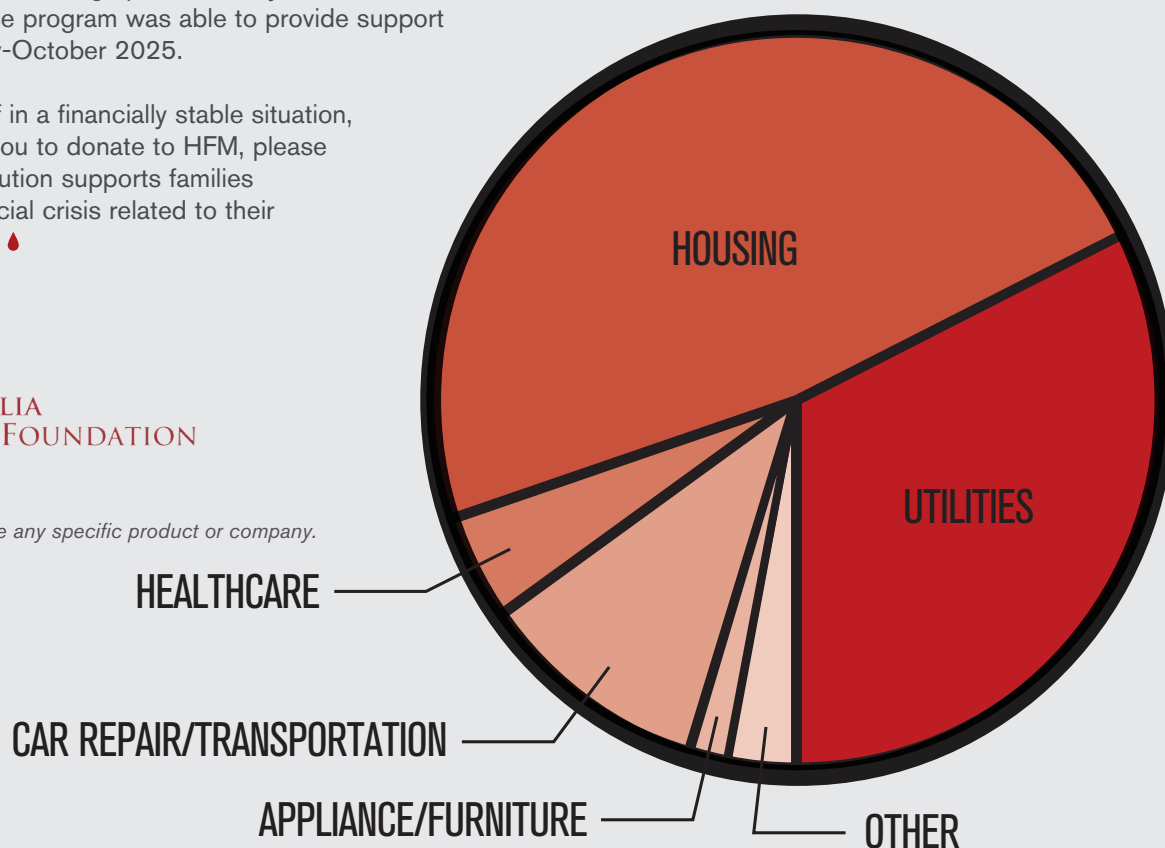
If you find yourself in a financially stable situation, and this inspires you to donate to HFM, please know your contribution supports families impacted by financial crisis related to their bleeding disorder. 💧

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



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DETROIT COMMUNITY EVENT



The Detroit Community Event, held on June 21 at the Detroit Outdoor Adventure Center, was filled with energy, laughter, and connection! The afternoon brought together families, youth, and healthcare partners for a fun-filled day of education and adventure.

Participants explored hands-on exhibits, enjoyed time together, and learned valuable information from the Detroit HTC team, who led an engaging educational session on transitioning from pediatric to adult HTC care. Their presentation helped families better understand what to expect during this important stage and how to make the process smoother.

In attendance were several new families to the HFM community, making this gathering even more special as they connected with others and learned about the resources and support available through HFM.

This marked HFM's first community event in the city of Detroit in more than 15 years — and it was well worth the wait! Between climbing walls, interactive nature displays, and meaningful conversations, attendees left with new insights, connections, and smiles that stretched from ear to ear.

With such an enthusiastic response — and buzz from our Detroit HTC partners — it's clear that the Detroit bleeding disorders community is ready for more events in the area! 🩸



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2025 HFM SUPPORT GROUPS

HFM provides multiple opportunities each month for members of the Michigan bleeding disorders community to come together, virtually and in-person, for support and connection. Through each of HFM's three monthly support groups, participants are provided education and connection, along with a time to share personal experiences and provide support to one another. 💧



Ruby Connection, HFM's women's group, provides a space for women in the bleeding disorders community to come together for online social experiences that include an educational speaker or activity and connection with other women in the community.



Blood Buds, which meets both online and in-person, provides an opportunity for men 18+ with bleeding disorders to come together and share experiences living with bleeding disorders.



The **Men's Monthly Group** is facilitated by two Hemophilia Treatment Center social workers and creates an online space for men with bleeding disorders to share thoughts and ideas on daily living and challenges.

IF YOU ARE INTERESTED IN LEARNING MORE ABOUT ANY OF HFM'S SUPPORT GROUPS PLEASE VISIT WWW.HFMICH.ORG/EVENTS

You can learn more about each group, see upcoming topics and activities, and register to attend. We would love to have you join us!

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2025 NATIONAL WOMEN'S CONFERENCE



The 8th annual National Conference for Women with Hemophilia and Rare Factor Deficiencies was held in Detroit, Michigan at the Westin DTW over the first weekend of October. This year's theme, "See me. Hear me. Believe me." was inspired by a comment that Dr. Roshni Kulkarni made at the conference last year. The theme shaped many of our sessions and educational offerings throughout the conference by emphasizing the power of storytelling, advocacy, collaboration, and engagement to create lasting change.

HFM embraced a wide and comprehensive approach to educational programming through more than 40 unique programs across the weekend. Program selection was based on previous conference evaluations, application information, and input from previous attendees. Sessions were designed to provide education and to inspire participants to create a personal plan of action. The conference began on Friday evening with a showing of the new documentary, *Dismissed*, highlighting meaningful stories of women with hemophilia and their challenges accessing care and recognition by medical professionals.

Themes of storytelling continued throughout the weekend. The FLOW podcast was present for live recordings of women sharing their stories and for the first time, small conversation



groups were created that met four times over the weekend. The small groups were facilitated by the Leaders in Action group (affectionately referred to as the LIAs). Conference attendees broke out into affinity groups based on their specific bleeding disorder or life stage. Every woman had a space to share her insights and had the opportunity to get to know other attendees better. The discussions in these small groups were robust, reflective, and beneficial, allowing women to feel more fully seen, heard, and believed through more engaged and intimate conversations than are typically available during conference sessions.

We were honored to have several staff members from the National Bleeding Disorders Foundation (NBDF) in attendance, such as Phil Gattone, Maria Santaella, and Ryan Sarshuri. All of NBDF's staff addressed the conference either in the ballroom or by offering breakout sessions.

The 2025 National Conference for Women with Hemophilia and Rare Factor Deficiencies was a weekend that fostered hope and action through increased awareness and commitment to meaningful change. This impact will be felt throughout the year as women return to their home states, empowered to share their stories and a commitment to see, hear, and believe the stories of other women with hemophilia and rare factor deficiencies. 💧

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ARKANSAS	INDIANA	NEBRASKA	OREGON
CALIFORNIA	IOWA	NEVADA	PENNSYLVANIA
COLORADO	KANSAS	NEW HAMPSHIRE	RHODE ISLAND
CONNECTICUT	KENTUCKY	NEW JERSEY	TENNESSEE
DISTRICT OF COLUMBIA	LOUISIANA	NEW MEXICO	TEXAS
FLORIDA	MARYLAND	NEW YORK	VIRGINIA
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HIGHER FACTOR LEVELS FOR LONGER

Above 40% for most of the week (near-normal to normal range).^{*†}

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BLEEDS PER YEAR[‡]

Mean annual bleed rate observed in 128 people previously treated with prophylaxis therapy.[‡]

In people taking ALTUVIIIIO in the XTEND-1 study, 21% of people had headache, 16% had joint pain, and 6% had back pain

^{*}Average trough levels were 18% for adults 18 years and older, 9% for adolescents aged 12 years to under 18 years, 10% for children aged 6 years to under 12 years, and 7% for children aged 1 year to under 6 years.

[†]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.

[‡]Data based on treated bleeds.

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

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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, joint pain, and back 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](#).

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COMMUNITY MEMBER SPOTLIGHT

MICHIGAN WOMEN AT THE NATIONAL WOMEN'S CONFERENCE

© Brian Sevald Photography

This year, the National Conference for Women with Hemophilia and Rare Factor Deficiencies hosted 33 individuals from Michigan!

Of these 33 amazing attendees, 10 of them attended the women's conference for the first time.

Of our amazing Michigan women, Shianne Nocerinni shared her thoughts on what the conference means to her. "I feel incredibly lucky that I've been able to attend the women's conference for the past three years. This conference gives women in the bleeding disorders community a chance to share their own experiences, knowledge, laughter,

tears, and friendship. For me, this conference gives me a chance to step out of the caretaker role and focus on myself. Each year I walk away from the conference with gratitude for HFM for hosting this conference each year."

We were also fortunate to have two Michigan women serving as Leaders in Action (LIA) at the conference, Amar Haidar, pictured after speaking on a panel and Allie McComber, pictured left of Amar. We thank Allie and Amar for their efforts in assisting with the conference planning and implementation!

Lastly, we're thrilled to host medical providers from across Michigan

including physicians, social workers, nurses, physical therapists, and genetic counselors who come from every corner of the state to enhance the programming and education provided at the women's conference.

Jesse Lawson shared a sweet and powerful sentiment regarding her thoughts on the women's conference, "I'm never alone and there's always more to learn." We are excited to continue to provide a conference for our Michigan women and beyond that creates community and educates and empowers all patients. 💧



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UPCOMING 2026 EVENTS

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January 5
Men's Support Group  

January 15
Blood Buds: Virtual Night  

January 27
Ruby Connection  

February 19
Blood Buds: Virtual Night  

March 2
Men's Support Group  


March 19
Blood Buds: Virtual Night  

March 20
Virtual Community Night 


March 24
Ruby Connection  

March 24-25
Lansing Days
Lansing Capitol 

April 17
VWD Symposium
Kalamazoo, MI 

April 18-19
SpringFest
Kalamazoo, MI 

May 4
Men's Support Group  

 Virtual
 In-person
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