



THE ARTERY

SPRING/SUMMER 2026



THIS ISSUE

10 2025 BY THE NUMBERS

15 WASHINGTON DAYS RECAP

20 COMMUNITY MEMBER SPOTLIGHT

DEAR FRIENDS,

Spring is the time of year we anticipate new beginnings, especially the beauty of our Michigan summers, as flowers blossom, leaves begin to fill out our trees, days grow sunnier, and we consider life's many possibilities. Just as HFM's VWD Symposium and SpringFest 2026, our multi-day conference for the bleeding disorders community, focused on taking flight, this Spring issue of The Artery invites you to continue uplifting the quality of life for our Michigan bleeding disorders community.

Joining your fellow community members at advocacy events, retreats, holiday gatherings, summer camp programs and other educational and social activities demonstrates the reach of our bleeding disorders community, through both challenges and opportunities. Whether you're providing your stories and life experiences to state or federal legislators or standing with your fellow community members during a difficult experience, we are grateful for the support and spirit this incredible community provides to one another.

Engagement and education within and across our community truly sets us apart!

In the coming months, HFM has wonderful activities for you and yours: Eagle Journeys' summer camp programs,

in-person community gatherings and retreats, and online Ruby Connection groups and Dinner Talks. We are here to come together, share experiences, and support one another with empathy and kindness.

We also congratulate our HTC colleagues who recently received well-deserved recognition: Kathi Sheldon, Volunteer of the Year; and Diana Mathis, Charles Stanley Hamilton Legacy Award, each from the Hemophilia Federation of America; Alice Cakebread, Michigan Medicine's Social Worker of the Year; and Dr. Roshni Kulkarni, World Federation of Hemophilia President's Award. The strength and dedication of our community as folks living with bleeding disorders, as well as those providing support and care, demonstrates the many ways we each show up for one another. You make all the difference.

Heartfelt appreciation,



Susan Fenters Lerch

HFM Executive Director

Regional Director, Great Lakes Federal HTC Network



The HFM team at the 2026 VWD Symposium and SpringFest. 2026. © Box of Light Photography

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THANK YOU
TO OUR
CONTRIBUTING
AUTHORS

15 2026 WASHINGTON DAYS

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*Denotes part-time

PAID CONSUMER OUTREACH INCLUDED
IN THIS NEWSLETTER

WE ARE PLEASED THAT OUR HFM MEMBERSHIP INCLUDES BOTH LIFETIME MEMBERS AND ANNUAL MEMBERS WHOSE GIFTS HELP SUPPORT HFM'S WORK EVERY DAY. EACH OF THESE INDIVIDUALS HAS MADE A SPECIAL COMMITMENT TO THE MICHIGAN BLEEDING DISORDERS COMMUNITY. WE ARE VERY APPRECIATIVE OF OUR NEW AND RETURNING 2025 ANNUAL MEMBERS AND WE ARE ESPECIALLY GRATEFUL FOR OUR LIFETIME MEMBERS. YOUR SUPPORT, INSIGHT, AND ENGAGEMENT TRULY MAKE A DIFFERENCE. THANK YOU! 💧

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Teresa, Brian, Kara & Kelly Tabel
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Robin Whitfield

*Deceased

REMEMBERING BILL SPARROW

November 20, 1945 – December 28, 2025

BY SUSAN LERCH, HFM EXECUTIVE DIRECTOR, REGIONAL DIRECTOR, GREAT LAKES FEDERAL HTC NETWORK

I have fond memories of Bill most especially during my early years on HFM's staff in the 1980s and 1990s. He was a dedicated leader of HFM's Board of Directors and a strong advocate for our bleeding disorders community during this devastating time at the height of the HIV/AIDS crisis. Bill would often connect with both Sally (Crudder) McAlister (then HFM's Executive Director) and me after hours to discuss issues affecting our community. At that time, calls were made via landlines. If my husband Dan answered and asked who was calling, Bill, of course, identified himself as Bill Sparrow. Before meeting Bill in person (following several calls to our home!) Dan asked, "Who is this Birdman?" Bill chuckled at the nickname and became Birdman to many of us. In the early 1990s in collaboration with HFM, Bill became the founding Executive Director of the Cascade Hemophilia Consortium which continues to make incredible contributions to the success of treatment centers and bleeding disorders organizations. I deeply respect Bill's dedication to people living with bleeding disorders and to our HTC network. Thank you, Birdman, for making a lasting difference and impact for so very many.



WITH SINCERE GRATITUDE

THANK YOU TO OUR INDIVIDUAL FINANCIAL DONORS. THIS LIST REPRESENTS CONTRIBUTIONS RECORDED FROM JANUARY 1, 2025, THROUGH DECEMBER 31, 2025, OUTSIDE OF PROGRAM OR REGISTRATION FEES. HFM IS GRATEFUL TO OUR MANY SUPPORTERS WHO MAKE OUR COMMUNITY PROGRAMS AND SERVICES AVAILABLE. WE WOULD LIKE TO ACKNOWLEDGE THE FOLLOWING INDIVIDUALS AND FAMILIES WHO SUPPORTED OUR EFFORTS THROUGHOUT THE 2025 CALENDAR YEAR. PLEASE CONSIDER MAKING A DONATION TO HFM IN 2026. YOUR SUPPORT TRULY MAKES A DIFFERENCE. 💧

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UP TO \$100

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CAMP HOLIDAY PARTY

Our Camp Holiday Party was held at the Hemophilia Foundation office this year. We had a full house, with a total of 27 camp alumni! We spent time cutting out snowflakes, making ornaments, pinning the hat on the director, and exchanging gifts. It was a night full of laughter, memories, and camp spirit. 🩸



BLOOD BUDS: MONSTER JAM



Did you know a six-ton monster truck can do a backflip? That was a new discovery at the in-person Blood Buds event! Blood Buds is HFM's monthly group for men 18+ in the community. It is a great opportunity to make new friendships and reconnect with familiar faces.

The spring in-person event kicked off at Ford's Garage with a funnel of onion rings and some of the best buffalo chicken dip around. From there, the

group headed to Monster Jam, where monster trucks delivered big jumps, backflips, and even a mid-air confetti blast. Safe to say this one was crushed!

Be sure to join the next Blood Buds event, either in-person or virtually. For more information, contact Travis Miller at tmiller@hfmich.org. 🩸

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END-OF-YEAR COMMUNITY GATHERING



Every year, the Hemophilia Foundation of Michigan (HFM) proudly partners with the Troy High School Project Lead the Way team to host a joyful end-of-the-year gathering for our community. This beloved tradition brings together families, volunteers, and partners to celebrate the season, and 2025 was no exception—though it did mark a meaningful transition.

Following the retirement of the longtime teacher who previously led the program, we were thrilled to welcome Christa Polan into this role. Christa worked diligently with her students to ensure the experience maintained the same warmth, creativity, and excellence our community has come to expect. To welcome her into the HFM family and thank her for carrying on this important tradition, HFM was proud to present her with HFM swag as a small token of our appreciation.

Together, the Project Lead the Way team and HFM created a vibrant and engaging event filled with activities for



all ages. Families enjoyed gingerbread house building using graham crackers, face painting, and a variety of arts and crafts designed to keep everyone entertained and immersed in the holiday spirit.



A key part of what makes this event so special each year is the continued partnership with Cascade. Year after year, the Cascade team generously donates toys and gifts to ensure every child leaves with something special. Behind the scenes, this involves thoughtful planning and intentional shopping—selecting items like LEGO sets, Squishmallows, dolls, art kits, and gift cards—to ensure children ages 17 and under have options they are genuinely excited about. Making sure every child feels seen and happy with their gift is no small task, and this care is felt throughout the event. “The staff at Cascade are more than happy to support HFM’s End of Year Party each year. It’s a truly joyful event that brings the community together, and we love knowing that the toys will put smiles on the children’s faces.” stated Colleen Joiner, Cascade Education and Outreach Manager.

This year’s gathering welcomed 168 attendees, including community members, HTC partners, and HFM

staff, all of whom were delighted by a visit from the ever-magical Santa Antonio. During the event, Antonio was also honored with his NBDF Volunteer of the Year award, making the celebration even more meaningful.

This end-of-the-year gathering continues to be a beautiful example of what’s possible when schools, nonprofit organizations, and community partners come together with a shared goal: creating joy, connection, and lasting memories for the families we serve. 🩸



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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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300

CAMPERS, FAMILY MEMBERS, AND STAFF AFFECTED BY BLEEDING DISORDERS PARTICIPATED IN THE EAGLE JOURNEYS CAMP PROGRAMS

36

TEENS PARTICIPATED IN THE BLEEDER AND A BUDDY AND SPRING TEEN RETREAT WEEKENDS

335

COMMUNITY MEMBERS JOINED HFM IN TROY, MICHIGAN FOR OUR ANNUAL PATIENT AND FAMILY EDUCATION CONFERENCE – SPRINGFEST!

IN 2025

215

INDIVIDUALS, INCLUDING 122 ATTENDEES, FROM ACROSS MICHIGAN AND THE UNITED STATES TRAVELED TO ATTEND THE NATIONAL CONFERENCE FOR WOMEN WITH HEMOPHILIA AND RARE FACTOR DEFICIENCIES

7

ADULTS WITH BLEEDING DISORDERS WERE PROVIDED WITH SUPPORT IN THEIR PURSUIT OF VOCATIONAL TRAININGS AND EMPLOYMENT VIA THE LAUNCH PROGRAM

75

MEN WITH BLEEDING DISORDERS TOOK PART IN HFM'S MONTHLY COMMUNITY EVENT, BLOOD BUDS

44

PEOPLE MADE 45 LEGISLATIVE
OFFICE VISITS DURING HFM'S
LANSING DAYS, A TOTAL OF 60
STATE LEGISLATIVE VISITS WERE
MADE THROUGHOUT 2025

64

PEOPLE ATTENDED HFM'S VIRTUAL
VWD SYMPOSIUM

137

COMMUNITY MEMBERS ATTENDED
ONE OF HFM'S 4 COMMUNITY
NIGHTS TO RECEIVE EDUCATION
AND CONNECTION

WHILE WE DON'T HAVE THE SPACE TO INCLUDE ALL OF HFM'S 2025
PROGRAMS OR EVERY SMILE CAPTURED ALONG THE WAY, HERE ARE
A FEW HIGHLIGHTS THAT YOU HELPED MAKE POSSIBLE!

140

WOMEN OF THE BLEEDING
DISORDERS COMMUNITY ATTENDED
6 VIRTUAL RUBY CONNECTIONS

33

PEOPLE ATTENDED HFM'S UP
RETREAT IN MARQUETTE FOR
A WEEKEND OF CONNECTION,
EDUCATION, AND FUN

2026 SPRING TEEN RETREAT AT CAMP COPNECONIC

Teen Retreat was a huge success in 2026. Along with our 12 teens we had the whole camp team including our newest staff addition Victor, our Camp Health Officer, as well as HTC staff and adult chaperones, at Camp Copneconic. This weekend was full of fun, team building, and learning about our bleeding disorders. Participating in a fun activity with Sam Cassisi from the Michigan State University HTC we learned how bleeding disorders are passed down through our genes. Through teamwork we built creatures made of Legos, built bridges, both literally and figuratively, and met a horse named Sugar. We wrapped up our weekend with karaoke and a movie night before departing and saying goodbye until next year! 🍷

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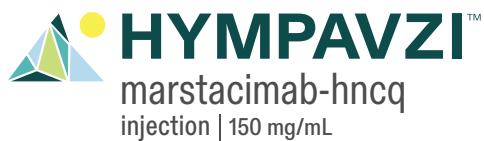
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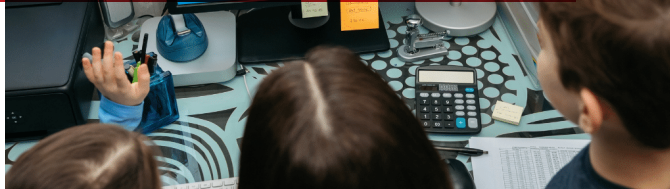
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MARCH COMMUNITY NIGHT



On the evening of March 20th, a secret mission took place with a few select bleeding disorders spies. Our mission? Simple. Come together to connect with others in the community and crack the secret code on meeting with physicians.

Alice Cakebread, LMSW, Social Worker at the University of Michigan Hemophilia Treatment Center provided secret intel and top-secret spy strategies on how to work hand in hand

with providers to accomplish the mission. Alice taught us the "Ask Me 3" strategy — "What is my main problem? What do I need to do? Why is it important for me to do this?" We also learned how to utilize the PQRST Pain Assessment Scale for patients when discussing pain management strategies.

After Alice sharpened our skills, we jumped into Codenames — with the Spymasters dealing out clues and the Operatives trying to crack them. Let's just say, some of the teams were luckier than others. 🍀

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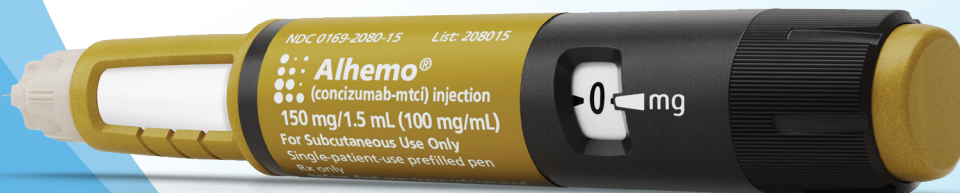
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2026 WASHINGTON DAYS



At the beginning of March, HFM was excited to be able to be a part of the National Bleeding Disorders Foundation's (NBDF) Washington Days Conference in our nation's Capital. HFM's Executive Director, Susan Lerch; Associate Director, Gwyn Hulswit; and Government Relations & Communications Manager, Zach Ryan represented HFM along with Michelle Cecil, Ken Martin, Jason Rogers, and his son Ben, Seth Furr, and Dan Lerch. NBDF's programming encompassed advocacy and issues training, legislative visits, and an Advocates' Recognition dinner.

During Washington Days HFM's group met with the offices of Rep. Haley Stevens (MI-11), Rep. Debbie Dingell (MI-06), Rep. Tom Barrett (MI-07), Rep. Lisa McClain (MI-09), Sen. Gary Peters, and Sen. Elissa Slotkin and focused the discussion on patient protections against copay accumulator adjusters and maximizers and asked lawmakers to support the national HELP Copays Act. Our advocates also shared that federal bleeding disorders programs at HRSA, CDC, and NIH provide critical funding to HTC's and help support research, care, and public health monitoring for bleeding disorders. We asked the Michigan delegation in the House to support these programs by signing onto a "Dear Colleague" letter and asked Senators Peters and Slotkin to lead a "Dear Colleague" letter in the Senate. Additionally, we discussed the barriers faced by women and girls with bleeding disorders and asked for support of the Fostering Effective Diagnosis and Treatment for Underserved Populations (FED UP) with Bleeding Disorders Act to address these concerns.

Overall, our discussions with the Congressional offices were productive. Many wanted to hear personal stories from individuals about how having a bleeding disorder has impacted their way of life, and others were interested in hearing how they could help our community.

But the advocacy didn't stop there. HFM's Lansing Days were only three short weeks away, providing additional opportunities for the Michigan bleeding disorders community to share their stories with legislative decision makers. 🩸





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**SCAN TO HEAR STORIES
FROM OUR COMMUNITY**

First approved in 2017* | Over 9,000 people in the US treated with HEMLIBRA†

*November 2017: FDA approval for adults and children with hemophilia A with factor VIII inhibitors.

†Number of people with hemophilia A treated with HEMLIBRA in the US as of November 2025.

INDICATION & IMPORTANT SAFETY INFORMATION

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. People who use activated prothrombin complex concentrate (aPCC; Feiba®) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots.

These serious side effects include:

- **Thrombotic microangiopathy (TMA)**, a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs
- **Blood clots (thrombotic events)**, which may form in blood vessels in your arm, leg, lung, or head

Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. If aPCC (Feiba®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (Feiba®) total.

Your body may make antibodies against HEMLIBRA, which may stop HEMLIBRA from working properly. Contact your healthcare provider immediately if you notice that HEMLIBRA has stopped working for you (eg, increase in bleeds).

Please see Brief Summary of Medication Guide on following page for Important Safety Information, including **Serious Side Effects**.

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Medication Guide
HEMLIBRA® (hem-lee-bruh)
(emicizumab-kxwh)
injection, for subcutaneous use

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
 - confusion
 - weakness
 - swelling of arms and legs
 - yellowing of skin and eyes
 - stomach (abdomen) or back pain
 - nausea or vomiting
 - feeling sick
 - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
 - swelling in arms or legs
 - pain or redness in your arms or legs
 - shortness of breath
 - chest pain or tightness
 - fast heart rate
 - cough up blood
 - feel faint
 - headache
 - numbness in your face
 - eye pain or swelling
 - trouble seeing

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

Your body may make antibodies against HEMLIBRA, which may stop HEMLIBRA from working properly. Contact your healthcare provider immediately if you notice that HEMLIBRA has stopped working for you (e.g. increase in bleeds).

See “What are the possible side effects of HEMLIBRA?” for more information about side effects.

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I use HEMLIBRA?

See the detailed “Instructions for Use” that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.

- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. **Do not** give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

What are the possible side effects of HEMLIBRA?

- See “What is the most important information I should know about HEMLIBRA?”

The most common side effects of HEMLIBRA include:

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 86°F (30°C).
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

Keep HEMLIBRA and all medicines out of the reach of children.

General information about the safe and effective use of HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048

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For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised: 07/2025



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LANSGING DAYS



HFM was pleased to welcome fifty-five community members to Lansing Days at the Kellogg Hotel and Conference Center on Tuesday, March 24 and Wednesday, March 25, 2026. On Tuesday evening, we were excited to welcome Amber Bellazaire, a Senior Policy Analyst from the Michigan League for Public Policy, to help our group understand the state budget process and the impact that H.R. 1 is having on this process. Amber was fantastic in explaining the difficulty that state lawmakers face as they try to

deal with a \$1.8 billion shortfall from a reduction in federal money coming into the state. She also touched on the impending work requirements that will need to be implemented to comply with H.R. 1. Amber graciously answered questions following her remarks, and our advocates were able to gain better insight into the thinking of the legislature and the Governor in terms of how they make up the shortfall in the upcoming budget. Following her presentation, we welcomed Matt Delaney, Government Relations Manager from the National Bleeding Disorders Foundation (NBDF), who shared a recap from NBDF's Washington Days and focused on HFM and NBDF's shared push for the removal of Copay Accumulator Adjustment Programs at the state and federal levels. HFM staff provided legislative advocacy training, discussed



our asks, and invited several patient advocates to share their understanding of the issues, and provide helpful tips that their fellow advocates could take into meetings to feel more prepared and ready for a successful meeting.

On Wednesday, our group of bleeding disorders advocates traveled in small groups to the capital to visit 45 state legislator offices to provide bleeding disorders education and discuss issues important to the community.

Advocates asked legislators to continue funding Children's Special Health Care Services (CSHCS), a program within the Michigan Department of Health and Human Services that provides coverage for bleeding disorders treatment when all else fails.

Constituents also shared information on copay accumulator adjustment programs and the financial impact they have on Michigan patients who rely on copay assistance to access their necessary medications. Our advocates met with several offices who offered





support for this issue as we work to reintroduce the legislation in Michigan. Throughout the day we were happy to hear that several offices were already well-versed in the topic, which is indicative of the advocacy work HFM and our coalition partners have done.

New this year, was our ask for legislators to support House Bill 5254 and Senate Bills 449, 450, 451, 701, and 702. These bipartisan bills would establish clear guidelines for hospitals to offer financial assistance programs for patients struggling with medical expenses and seek to expand consumer protections around medical debt.

Our advocates were able to share how crucial modifying step therapy coverage would be to removing barriers to accessing critical medication, and we heard from legislators and staff the importance of maintaining the relationship between patients and



We were excited to discuss our support for House Bill 4169, legislation to establish a Rare Disease Advisory Council, which Representative Jason Morgan has been championing this session. We look forward to continuing our work with Representative Morgan as the legislation moves back through the House and Senate before being signed by the Governor.

Lansing Days 2026 was an incredible success. We are so thankful for the support of our sponsors and the participation and passion of our community advocates. 🩸



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CHAPTER EDUCATION SUPPORTER



HFM does not endorse any specific product or company.

COMMUNITY MEMBER SPOTLIGHT

MATT BUURMA

Before takeoff, every pilot prepares for the journey ahead by mapping the route, checking systems, and getting ready for the unexpected. Parenting a child with a bleeding disorder can feel much the same. In this interview, Matt Buurma, a Delta pilot and father of five, shares how the principles of aviation, including preparation, communication, and trust, have helped guide his family's journey. From navigating diagnoses to building a strong care team, Matt offers a powerful perspective on what it means to stay grounded while helping your family take flight.

Can you introduce yourself and tell us a little about your family?

I am Matt Buurma. I am a father of 5 ranging in ages from 12 – 21. I have been married to my wonderful wife Mindy for 25 years. She was diagnosed with VWD Type 3 at the age of 6 months.

How long have you been a pilot with Delta, and what first inspired your interest in aviation?

I was inspired by my Dad. He used to talk about flying but never did. We

would make model airplanes together. We were a farm family, and I could often watch the crop dusters work. I decided to start flying in 2000 and attended the Western Michigan University College of Aviation. At first, I became an in-flight instructor and then worked a small regional job. Then I started at Delta and have been a pilot there ever since.

When did you first learn that your child had a bleeding disorder?

Because my wife had VWD Type 3, we knew that the kids would have VWD Type 1. I wasn't overwhelmed because we started talking to the staff at Children's Hospital of Michigan (CHM) as soon as Mindy was pregnant with our first. They were involved and watching out for our family before he was even born.

What helped you navigate the uncertainty in the beginning?

I was able to lean on my mother-in-law quite a bit because she had experience as a parent. She helped us deal with insurance, factor, and other issues. She was a calming presence. Mindy was the first in her family to

be diagnosed, but several of her siblings followed, so there is a lot of experience in their family.

As a pilot, you're trained to prepare for the unexpected. Do you see any parallels between flying and parenting a child with a bleeding disorder?

100%! As a pilot we are prepared for "abnormals and emergencies." We handle these with checklists. We have a checklist for almost every situation, but sometimes you can run into a situation that doesn't have a checklist.

As a parent, you can have your own checklist for emergencies. You can also take the time to learn about the diagnosis. By doing this work, you can be prepared and really understand what is happening at the HTC or Emergency Department.

In aviation, trust and teamwork are essential. Where do you see those same themes in the bleeding disorders community?

Teamwork is vital in aviation. I have a 2 person crew airplane. We have to trust each other that we are making

the right decisions and trust the flight attendants to do their job. I think that with a bleeding disorder there is a lot of trust that has to occur with your doctor, nursing staff, social workers, etc. You have to trust that they are making the best and most educated decisions for you and your family.

What does “safety” mean to you in the cockpit — and at home?

I typically fly with the same pilot for the whole trip, often over the course of 3 days. Our number one theme of our pre-trip briefing is safety. Another theme is communication. It is more than talking. It is also listening. We address that ahead of time. There is a prescribed way that Delta wants us to fly the plane and I work really hard to follow that plan.

Your doctors will give you a plan and it is really important to follow that plan as closely as possible, but it is important to speak up when needed so that you can solve the problems together.

This year’s VWD Symposium and SpringFest conference have an

aviation theme. What does the idea of “taking flight” or “navigating the journey” mean to you as a parent?

I think that if you look at it as going on a trip, you would plan by getting out your suitcase, laying out all of your clothes, and making an itinerary. Similarly, it is important to ask yourself, “What should I bring with me for my child with a bleeding disorder?” (For example: A letter to get factor through security.)

One of the first calls we make when we travel is to CHM to ask them where we should take our kids in case of an emergency, especially when we travel abroad. When we went to India recently, we were prepared with information on where to go during an emergency.

If you could share one lesson from aviation with other families in the bleeding disorders community, what would it be?

The most important thing is: be prepared. Take the extra time to be sure that you are successful in what you are doing. If you aren’t prepared,

speak up and get the help you need. Don’t be embarrassed.

What would you say to a parent who is just beginning this journey?

Find a care team that will break down walls for you! For example, my daughter had to have some dental surgery. I called CHM after selecting our surgeon and nurse Charity Stadler insisted on talking to the surgeon herself just to make sure they were prepared.

They are always looking out for us, and they never take “no” for an answer.

Is there anything else you’d like the HFM community to know?

Look for opportunities to have your kids around others with the same issues. Others can give them ideas on how to handle things. Camp Bold Eagle is an example of this. Our kids love it, and it gives them an opportunity to be around others with the same challenges. The most important thing is to be your child’s best advocate and teach them to advocate for themselves. 💧

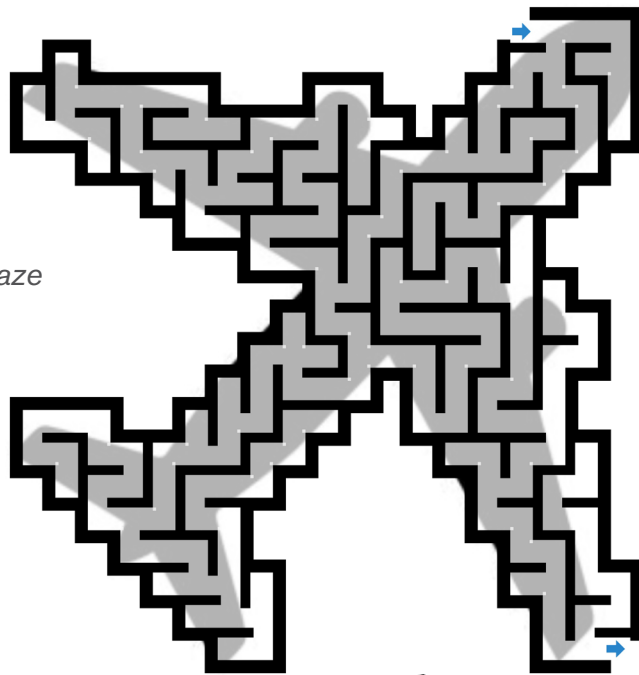


TINY CLOT CHRONICLES

Welcome to this Spring/Summer edition of Tiny Clot Chronicles! These pages are packed with high-flying fun, featuring an airplane-themed word search, a winding airplane maze, and a chance for kids to design their very own aircraft. It's the perfect way to spark creativity, build problem-solving skills, and enjoy a little adventure along the way! ✈

AIRPLANE MAZE

Help guide the airplane through the maze to reach its destination! Watch out for twists and turns along the way.



DESIGN YOUR OWN AIRCRAFT

Let your creativity take flight! Draw and design your own unique airplane, complete with colors, shapes, and special features.

WORD SEARCH

*Search high and low to find all the hidden airplane-themed words!
See how many you can spot as you scan across, down, and diagonally.*

Airplane
Clouds
Landing
Takeoff

Airport
Flight
Passport
Wings

Boarding
Fly
Pilot

Captain
Gate
Sky

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

2026 YETI RECAP

Gelli Kelley, HFM's Associate Camp Director, and HFM's new Camp Health Officer, Victor Vasquez, took a trip out to Portland, Oregon to the YETI Conference hosted by the Pacific Northwest Bleeding Disorders Chapter in February. YETI stands for Youth Effectively Transitioning to Independence. Gelli and Victor attended valuable sessions on how to empower our youth staff and how to better our teen programming while connecting with bleeding disorders chapters throughout the country. They participated in activities such as the Chopped Challenge, Project Runway, and Tie Dyeing! There were several Eagle Journeys alumni in attendance who will be bringing new skills to our 2026 camping programs as well. We extend our thanks to the PNWBD chapter and the YETI staff for the valuable insights. We are looking forward to implementing all that we learned into 2026 youth programming and Eagle Journeys camping programs! 🩸



Gelli Kelley and Victor Vasquez with Eagle Journeys alumni came together at the YETI Conference, highlighting partnership, connection, and shared commitment to the community.



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NAVIGATING OUR TRAVEL ANXIETY

STEVE EDWARDS, LMSW, SOCIAL WORKER, MICHIGAN STATE UNIVERSITY CENTER FOR BLEEDING AND CLOTTING DISORDERS.

Whether it is by car or plane, commercials show us one side of travel. We see smiling parents looking at their well-behaved children in the back seat, friendly airline staff serving snacks to relaxed passengers, and perfect sunny skies. The reality of travel can be very different: construction traffic, flight delays, bad weather, and even worse moods. Despite the unknown, there are several practical strategies that can help reduce anxiety related to travel. An article from Kaiser Permanente Health and Wellness suggests making a list of items to pack, including clothing and other personal comfort items. This may include a neck pillow or a favorite blanket. Make sure to have tablets and phones charged, and bring non-electronic activities including books or travel games. On the trip itself, have healthy snacks available. Some healthy snacks included dried fruits and granola bars. It is suggested that alcohol and caffeine are avoided.

If you are experiencing anxiety, trying breathing exercises. One exercise is the 4-4-4 technique: Breathe in for 4 counts, hold your breath for 4, and then breathe out for 4. You also use an imagery exercise and imagine a place, either your destination or a place that you have made up, that is relaxing. Fully imagine the details, including the sights and sounds. There are several mindful apps and recordings that help provide clear step-by-step instructions.

Many people also find that therapy can help address anxiety and other negative distressing symptoms. Studies show that as many as 40% of people have a fear of flying, or aviophobia. There are programs that specifically address fear of flying. If these are not available in your area, your local HTC social worker can help you get connected with a therapist who specializes in reducing and managing anxiety symptoms, and there are several approaches including mindfulness, exposure therapy, cognitive behavioral therapy, and meditation that can help. Many people find that using a combination of approaches is the best way to reduce overwhelming symptoms. With some planning and preparation, the open road can be more welcoming, and the skies can be friendly.

Adapted from "Aviation incidents amplify fear of flying, but therapy helps people reclaim the skies" by Charlotte Huff, Monitory on Psychology, Vol. 56, No.6. Also adapted from "Travel anxiety tips: How to manage fear of traveling" by Kaiser Permanente Health and Wellness. This article is not a substitute for mental health treatment. Please contact your HTC social worker for resources. If you are experiencing a mental health emergency, please dial 911 or go to your nearest emergency room. 📍

COMMUNITY NEEDS ASSESSMENT COMING IN 2026!

HFM wants to hear from you to better understand the current and emerging needs of individuals and families in Michigan's bleeding disorders community. Your feedback will help guide future programs, education, and support services to better serve our community.

FACTOR UP with ALTUVIIIIO™

Higher-for-longer Factor VIII levels in the near-normal to normal range (**over 40%**) for most of the week

ALTUVIIIIO™
Antihemophilic Factor (Recombinant),
Fc-VWF-XTEN Fusion Protein-ehtl



HIGHER FACTOR LEVELS FOR LONGER

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

48

HOUR HALF-LIFE IN ADULTS

In a Phase 3 study,[†] ALTUVIIIIO offered adults the longest half-life of any Factor VIII therapy.

0.7

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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INDICATION

ALTUVIIIIO™ [antihemophilic factor (recombinant), Fc-VWF-XTEN fusion protein-ehtl] 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.

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, 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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BOARD MEMBER UPDATES

Membership organizations, like HFM, prioritize their constituents by providing them a formal pathway for participation in key decision-making. Each year, our members gather at SpringFest—our annual conference, to review the progress of the organization and when necessary: to vote on issues. Membership is a way for you to have a voice as many formal decisions are made. Some HFM members may feel compelled to give back to the Foundation by serving on the Board of Directors. By doing so, they continue to improve the Foundation and all the benefits it provides. Below are three of HFM's newest directors. At our 2026 SpringFest, Board officers Jason Rogers, Jim Mohnach, and David Hart were also re-elected. We're proud to highlight why each of these leaders chooses to serve. ♦

WHY THEY SERVE



**Becky Steele,
M.Ed., Middle
School Math
Teacher, Jenison
Public Schools**

"I feel called and am unwaveringly

committed to using my voice to promote positive change in and for my community. Advocating for those with bleeding disorders is work that fuels my spirit. I hold a firm belief that we are a stronger community, locally and globally, if we understand each other's stories and support one another from a place of compassion and empathy. Lending my voice and time to the HFM Board of Directors, and staying actively involved with the HFM Advocacy Committee, is an honor and a privilege."



**Eliza VanZweden,
M.S., Formulation
Scientist, Zoetis**

"I am inspired to serve on HFM's board because I want to give back to the Michigan

bleeding disorders community and be a strong voice for individuals with ultra-rare bleeding disorders. The programs and events HFM offers like Camp, Ruby Connection, and Lansing Days are truly life-changing for so many people, including myself. I am honored to help support and strengthen the impact of this community."



**Kathleen Donohoe,
Captain, USCG (Ret.),
Former Associate
Director of Human
Resources, Strategy,
Planning and Policy,
University of Michigan**

"I am deeply committed to serving the bleeding disorders community via participation on the HFM Board. I consider it a privilege to work with such incredibly innovative and resilient leaders."

"I am committed to continuing to support HFM's mission and ensuring strong, sustainable leadership for the future. My long-standing connection motivates me to help expand impact and resources for the community."

– **Jim Mohnach**

"My reason to serve is personal. My son has hemophilia, and I deeply appreciate what HFM has done for my family. Serving on the board allows me to give back to an organization that has made a meaningful difference in our lives."

– **Jason Rogers**

"I care deeply about the bleeding disorders community and the work HFM does to support individuals and families across the state. I'm motivated by the opportunity to give back through thoughtful governance, advocacy, and service, and to use my professional background to help strengthen the organization's impact."

– **David Hart**



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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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UPCOMING 2026 EVENTS

June 7-11

Eagle Quest  
Manistee River Trail

June 13

Community Event:
Potter Park Zoo 
Lansing

June 18

**Blood Buds: Virtual
Escape Room**  

June 23-26

**Eagles Nest
Family Camp** 

Camp Bold Eagle 

Pioneer Trails, Holton, MI

June 28-July 4

Teen Camp (ages 14-17)

July 12-16

Session 1 (ages 6-9)

July 18-24

Session 2 (ages 10-13)

August 2-8

Eagle Outpost 

(ages 14-15)

Various Michigan state parks

August 13

Advocacy Webinar 

August 8-15

Eagle Expedition

(ages 18+)  

Northern California

August 20

Blood Buds: Virtual

Jackbox Game Night  

August 28

Community Night:

Longway Planetarium 

Flint

September 11-13

Old Beagle 

(open to adults and
their families)

Pioneer Trails, Holton, MI

FOR MORE INFORMATION AND
OTHER UPCOMING HFM EVENTS,
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 Virtual

 In-person

 18 and older

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