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THE ARTERY

SPRING/SUMMER 2025

THIS ISSUE

HFMICH.ORG ● SERVING THE BLEEDING DISORDERS COMMUNITY

DEAR FRIENDS,

Each year brings new opportunities, and of course, also includes new challenges. This Spring 2025 issue of the Artery focuses on advocacy, and we certainly have several areas where advocacy efforts are at the forefront of our work. Advocacy truly serves as a cornerstone of HFM's mission to improve the quality of life for our Michigan bleeding disorders community.

Your willingness to reach out and share experiences as a loved one, or as someone living with a bleeding disorder — the difficulties as well as the triumphs — makes a significant impact with HFM's educational work in advocacy. Providing your life experiences, your stories, to legislators, fellow community members, organizational leaders, friends, families, and others is needed now more than ever to maintain the structure of care and education that is currently available. If advocating sounds too daunting, we have folks who are happy to assist you in this effort step by step.

So much of what we do is rooted in advocacy — from meeting with members of Michigan's legislative offices, connecting with federal representatives, as well as speaking up for yourself and your family with healthcare providers, schools, friends and family, even at times in the workplace.

> "NEVER DOUBT THAT A SMALL GROUP OF THOUGHTFUL, COMMITTED CITIZENS CAN CHANGE THE WORLD. INDEED, IT IS THE ONLY THING THAT EVER HAS." - MARGARET MEAD

Hopefully you've received email notifications or social media information from HFM, and/or the National Bleeding Disorders Foundation, Hemophilia Federation of America, and/or other bleeding disorder organizations specific to the closure of the Centers for Disease Control Division of Blood Disorders and Public Health Genomics (CDC BDPHG). These notifications outline the importance of the CDC BDPHG to our community. For more information on issues like these, sign up for HFM's advocacy action alerts by scanning the QR code below and please consider the information and requests.

Engagement and education provided by our community is what 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, online Ruby Connection and Dinner Talks. We are here to come together, share experiences, and join one another in support, empathy, and kindness.

Heartfelt appreciation,

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

SIGN UP FOR ADVOCACY ACTION ALERTS

Top photo: Susan Lerch and Eliza VanZweden representing the Michigan bleeding disorders community at Washington Days in March.

Center photo: Michigan advocates brought their passion, personal stories, and commitment to Washington Days. Pictured left to right: Becky Steele, Tara Stockham, Kathy Gerus, and Susan Lerch

IN THIS ISSUE

THANK YOU TO OUR CONTRIBUTING AUTHORS

Front Cover: Michigan bleeding disorders advocates convened at the Capitol for the Hemophilia Foundation of Michigan's Lansing Days legislative advocacy event, March 18-19, 2025. © Brian Sevald Photography

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PAID CONSUMER OUTREACH INCLUDED IN THIS NEWSLETTER

WE ARE SO PLEASED THAT OUR HFM MEMBERSHIP INCLUDES BOTH LIFETIME MEMBERS AND ANNUAL MEMBERS WHOSE GIFTS HELP SUPPORT HFM'S WORK EVERY DAY. EACH OF THESE INDIVIDUALS HAS MADE A SPECIAL COMMITMENT TO THE MICHIGAN BLEEDING DISORDERS COMMUNITY. WE ARE VERY APPRECIATIVE OF OUR NEW AND RETURNING 2024 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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- Voting for the HFM Board
- Member reception at SpringFest
- Special recognition in print, online, and more!

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

hfm MEMBER

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THANK YOU TO OUR INDIVIDUAL FINANCIAL DONORS. THIS LIST REPRESENTS CONTRIBUTIONS RECORDED FROM JANUARY 1, 2024, THROUGH DECEMBER 31, 2024, 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 2024 CALENDAR YEAR. PLEASE CONSIDER MAKING A DONATION TO HFM IN 2025. YOUR SUPPORT TRULY MAKES A DIFFERENCE.

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

GIVING TUESDAY

A SPECIAL THANK YOU TO EVERYONE THAT DONATED TO HFM DURING OUR GIVING TUESDAY DRIVE. WE KNOW THAT THERE ARE COUNTLESS OPTIONS TO GIVE, ESPECIALLY DURING THE HOLIDAY SEASON. WE APPRECIATE YOUR SUPPORT MORE THAN YOU KNOW! TOGETHER, WE CAN CREATE POSITIVE CHANGE FOR MICHIGAN'S BLEEDING DISORDERS COMMUNITY!

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

We're focused on him so he can focus on the things that matter most.

Find out about our support for the rare bleeding disorder community.

Explore more at hemabio.com

HEMA Biologics®

Tara Dryer

Regional Account Manager
Serves IN, KY and MI

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

Tara.Dryer@hemabio.com
248.376.8483

HEMA Biologics®

PAID CONSUMER OUTREACH

TEEN RETREAT WAS BACK AT CAMP HENRY FOR 2025!

HFM's Associate Camp Directors, Travis Miller and Gelli Kelley, along with HFM medical support and camp alumni, joined 14 teens for a weekend of fun, laughter, and growth. Through activities like archery tag, low ropes courses, and "Engineering for Success" we fostered skills in teambuilding, leadership, and creative problem solving! Teens had the opportunity to create flipchart presentations to persuade their peers about topics they are passionate about! We wrapped up our weekend together with a movie night before having to say goodbye 'til next time.

THANK YOU TO OUR SPONSORS

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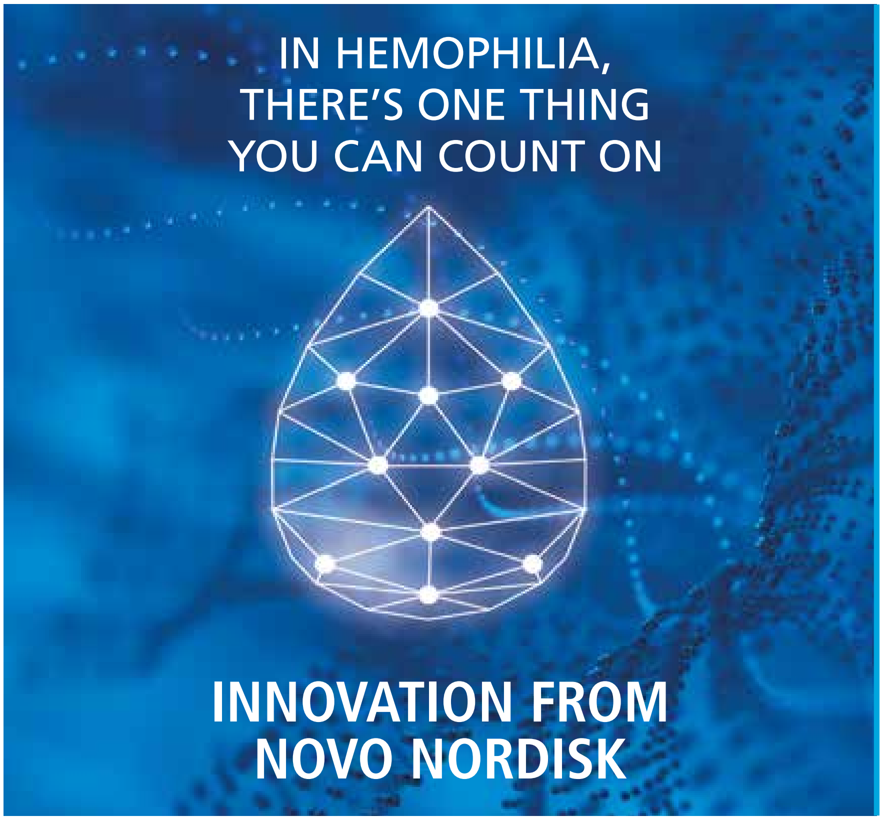

We strive to help improve the lives of people with hemophilia

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

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

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

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

changing hemophilia™

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234

MEMBERS OF THE BLEEDING DISORDERS COMMUNITY ATTENDED ONE OF HFM'S 7 IN-PERSON, SUMMER CAMPING PROGRAMS

43

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

48

PEOPLE MADE 55 VISITS TO MICHIGAN LAWMAKERS DURING HFM'S LANSING DAYS, A TOTAL OF 58 LEGISLATIVE VISITS WERE MADE THROUGHOUT 2024

IN 2024

33

WOMEN FROM THE MICHIGAN BLEEDING DISORDERS COMMUNITY RECEIVED EDUCATION, SUPPORT, AND CONNECTION AT THE WOMEN'S RETREAT

60

MEN WITH BLEEDING DISORDERS PARTICIPATED IN THE MEN'S ACTIVITY GROUP

160

WOMEN FROM ACROSS THE UNITED STATES TRAVELED TO MICHIGAN OR PARTICIPATED VIRTUALLY FOR THE NATIONAL CONFERENCE FOR WOMEN WITH HEMOPHILIA AND RARE FACTOR DEFICIENCIES

345

COMMUNITY MEMBERS JOINED HFM IN ANN ARBOR, MICHIGAN FOR OUR ANNUAL PATIENT AND FAMILY EDUCATION CONFERENCE—SPRINGFEST!

9

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

275

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

WHILE WE DON'T HAVE THE SPACE NECESSARY TO LIST ALL OF HFM'S 2024 PROGRAMS – OR ALL THE SMILES THAT WERE CAPTURED AS WE GATHERED TOGETHER – HERE ARE SOME OF OUR HIGHLIGHTS THAT YOU MADE HAPPEN!

862

INDIVIDUALS WITH BLEEDING DISORDERS RECEIVED A COMPLIMENTARY MEDICAL ID TAG VIA HFM'S MEDICAL ID PROGRAM

204

MEMBERS OF THE BLEEDING DISORDERS COMMUNITY ATTENDED 13 VIRTUAL EDUCATION DINNER TALKS

END-OF-YEAR COMMUNITY GATHERING

HFM's End-of-Year Gathering was held on December 7, 2024, and was a heartwarming celebration. The gathering welcomed 162 attendees including children, adults, HFM staff, and volunteers alike, to celebratorily round out 2024.

As part of the holiday celebration, every family had the chance to visit Santa Claus, also known as our very own Santa Antonio. Young attendees browsed through an array of gifts, including Legos, Squishmallows, wellness essentials, and gift cards and selected one gift to call their own. A sincere thank you to Cascade Hemophilia Consortium for generously donating many of the gifts. Guests were also treated to a delicious spread, including pizza, salad, mostaccioli, soda, and a variety of desserts that delighted all ages.

In addition to the festive meal, visiting with Santa Antonio, and the gift selection, the gathering was greatly enhanced through a collaboration with the students at Troy High School's LEAD organization. The LEAD students worked with vigor and enthusiasm, providing fun and entertainment that brought joy to all who participated. This partnership enabled attendees to enjoy a range of holiday-themed games, crafts, and family-oriented activities. Families not only built the foundation of their gingerbread houses, but also the foundation of their perpetual connection to their bleeding disorders community.

As families came together to celebrate the spirit of the season, this final gathering of 2024 generated everlasting memories, spread holiday cheer, and served as a reminder of Michigan's bleeding disorders community's unity. It was an event filled with joy and gratitude reflecting the fellowship of our bleeding disorders community.

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“WHAT IS AN ACCUMULATOR ADJUSTMENT PROGRAM?”

For individuals living with rare and chronic conditions, like hemophilia, cancer, and arthritis, the high cost of drugs has a direct impact on patient access. These patients often rely on copay assistance from manufacturers and nonprofit organizations, which save thousands of dollars in deductible and other out-of-pocket costs so that they can afford their lifesaving medication.

However, there are insurance policies impacting copay assistance for patients. Under these policies, generally called “accumulator adjustment programs,” copay assistance from manufacturers will no longer be applied toward patients’ deductibles or out-of-pocket expenses. Patients will still be able to use the copay card, but when the funds run out (typically a few months into the year) they will be responsible for their full deductible and maximum out-of-pocket costs. This shifts the burden on chronic and rare disease patients, who already face high out-of-pocket costs to treat their rare or chronic conditions. As a result, these patients now may be required to pay thousands of dollars out-of-pocket for their medication all at once.

Pharmacy Benefit Managers (PBMs) and/or insurance companies argue that patients who have no “skin in the game” may choose more expensive drugs without considering cost (because the patient wouldn’t be the one paying the price) regardless of any other considerations. PBMs and/or Insurers say that accumulator adjuster programs incentivize patients to choose lower cost drug options. However, for many patients with rare and chronic disorders, lower cost alternatives are often not available. When implemented, the insurance plan and/or PBM accepts the full amount of the manufacturer copay assistance in addition to the deductible paid by the patient. The insurer ends up collecting more money while leaving patients struggling to access their prescription medication.

For several years the bleeding disorders community has been a leading force in advocating that any amount paid by the patient or on behalf of the patient is required to be applied to the patient’s co-pay for a prescription drug. HFM has been working closely with other patient advocacy organizations and stakeholders to advocate on a state and federal level to ensure that patient assistance is counted towards a patient’s copays and to inform lawmakers of the consequences of these changes. This issue has been and remains HFM’s top priority, and because of the work of the bleeding disorders community, we have been able to educate lawmakers about the importance of this issue.

If you have questions or want to get involved with HFM’s advocacy, contact HFM’s Government Relations & Communications Manager, Zach Ryan at **zryan@hfmich.org.** 💧

> AS MICHIGAN BLEEDING DISORDERS ADVOCATE, KEN MARTIN PUTS IT, “PATIENTS BATTLING ILLNESS OR MANAGING A CHRONIC CONDITION DESERVE TO FOCUS ON THEIR HEALTH, NOT BATTLING THEIR INSURERS AND PHARMACY BENEFIT MANAGERS TO GET THE CARE THEY NEED.”

TAMAR
HEMLIBRA PATIENT SINCE 2019

DEVON
HEMLIBRA PATIENT SINCE 2020

MIRANDA
HEMLIBRA CAREGIVER TO TWIN SONS
TRISTAN & TALAN (AGE 11) SINCE 2018

VERONICA
HEMLIBRA CAREGIVER TO SON
IAN (AGE 7) SINCE 2020

HEMLIBRA: TRUSTED BY THE COMMUNITY FOR 7 YEARS AND COUNTING

SOREN
HEMLIBRA PATIENT SINCE 2022

HARVEY
HEMLIBRA PATIENT SINCE 2016

MARIA
HEMLIBRA CAREGIVER TO SON
CARLOS (AGE 16) SINCE 2019

OLIVIA
HEMLIBRA CAREGIVER TO SON
ARLO (AGE 6) SINCE 2018

First approved in 2017.*
Over 8,100 patients in the US treated with HEMLIBRA.†

SCAN TO HEAR STORIES FROM THE COMMUNITY

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

†Number of patients with hemophilia A treated with HEMLIBRA in the US as of March 2024.

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**.

HEMLIBRA®
emicizumab-kxwh
injection for subcutaneous use
150 mg/mL

PAID CONSUMER OUTREACH

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
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HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan

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: 03/2023

HEMLIBRA®
emicizumab-kxwh
injection for subcutaneous use
150 mg/mL

Genentech
A Member of the Roche Group

VWD SYMPOSIUM

TOOLS FOR THRIVING

VWD SYMPOSIUM EMPOWERS COMMUNITY WITH PRACTICAL STRATEGIES

The virtual Von Willebrand Disease (VWD) Symposium, aptly titled "Tools for Thriving," proved to be a powerful and informative event, offering invaluable resources and support for individuals and families affected by VWD. The symposium, held virtually on February 22nd, brought together hematologists, researchers, nurses, physical therapists, and community members for a day of education, connection, and empowerment. We were excited to welcome a high of 42 households logged in and enjoying the Symposium!

Personalized treatment approaches discussed by experts included the latest advancements in treatment and emphasized the importance of therapy tailored to individual needs and lifestyle factors. Recognizing the holistic nature of VWD management, some sessions focused on the importance of healthy lifestyle choices. Experts covered key aspects of health management, including joints, iron levels, gynecological care, and aging.

The symposium closed with a fun and interactive VWD game show!

The "Tools for Thriving" VWD Symposium served as a vital resource for the VWD community. One participant posted in the chat, "I had to turn my video off so that you can't see me running around my house screaming, "YES!!! This is all me. I knew I wasn't going insane!" We are so glad that the education resonated with them, and we are inspired to continue planning such meaningful content.

The 2026 VWD Symposium will take place in person in Kalamazoo on Friday evening, April 17, just before the start of SpringFest 2026. We look forward to seeing you there!

Thank you to our Community Planning Group who offered their perspectives on sessions and topics: Mary and Angela Jaehnig, Emma Baker, and Jennifer Wakefield! ●

THANK YOU TO OUR SPONSORS

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DONOR RECEPTION

On March 13th, we were thrilled to welcome donors into our office for a special evening of appreciation. Guests were treated to delicious appetizers, drinks, and desserts, but the real highlight of the evening was the wonderful conversation and sense of community we shared.

This event was our way of expressing deep gratitude to those who prioritize the Hemophilia Foundation of Michigan with their generous giving. Supporters make a lasting difference in the lives of individuals and families affected by bleeding disorders, and HFM is honored to partner with them in this important work.

A special thank you goes to Inez Hernandez-Walsh, who volunteered his time and talent as our bartender for the evening.

To everyone who attended, thank you for joining us. Your continued support and presence mean the world to us. 💧

LANSING DAYS

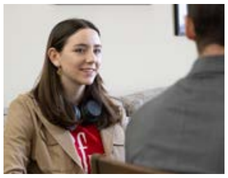
On Tuesday, March 18, and Wednesday, March 19, 2025, forty-four Michigan bleeding disorders advocates joined the Hemophilia Foundation of Michigan (HFM) for our legislative advocacy event, Lansing Days. On Tuesday evening at the Kellogg Hotel and Conference Center HFM staff provided legislative advocacy training, discussed our asks, and held a patient advocate panel conversation that was so helpful in talking through their tips, challenges, and successes in past meetings, and so much more!

We were excited to welcome State Senator Stephanie Chang of Detroit who discussed the importance of being a patient advocate, and the difference it can make by helping legislators understand how issues impact their constituents. Senator Chang graciously answered questions following her remarks, and our advocates were able to gain better insight into how she gathers information from her staff after meeting with constituents and community groups and how she took the first step in running for a seat in the State House.

On Wednesday, our group of bleeding disorders advocates traveled in small groups to the capital to visit forty-five state legislator offices to share 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 other options may not be available.

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. You can read more about this issue in our article, "What is an Accumulator Adjustment Program?".



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 physicians.

We were excited to discuss our support for House Bill 4169, legislation to establish a Rare Disease Advisory Council, which Representative Jason Morgan reintroduced two weeks before Lansing Days. We're very happy that funding was included in last year's appropriations bill and 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 2025 was an incredible success. We are so thankful for the support of our sponsors and the participation and passion of our community advocates.

Together, we are making a difference!

THANK YOU TO OUR SPONSORS

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ALTUVIIIO®
Antihemophilic Factor (Recombinant),
Fc-VWF-XTEN Fusion Protein-ehtl

A FIRST-IN-CLASS, ONCE-WEEKLY INFUSION

FACTOR UP with ALTUVIIIO®

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

High sustained Factor VIII activity levels

Above 40% (near-normal to normal range) for most of the week in adults and for ~3 days in kids.*

48 Hour half-life in adults

ALTUVIIIO offers the longest half-life of any Factor VIII therapy across all age groups.†

0.7 Bleeds per year‡

Mean annual bleed rate observed in 128 people previously treated with prophylaxis therapy.§

In adults and adolescents taking ALTUVIIIO in the XTEND-1 study, 20.1% experienced headache and 16.4% experienced joint pain.

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

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

‡Data based on treated bleeds.

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

INDICATION

ALTUVIIIO® [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 ALTUVIIIO when you have surgery.

IMPORTANT SAFETY INFORMATION

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

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 ALTUVIIIO so that your treatment will work best for you.

Who should not use ALTUVIIIO?

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

What should I tell my healthcare provider before using ALTUVIIIO?

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 ALTUVIIIO?

You can have an allergic reaction to ALTUVIIIO. 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 ALTUVIIIO. This can stop ALTUVIIIO from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

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

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

Please see full Prescribing Information.

Connect with your CoRe today

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

Sign up to connect and learn more today!

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MAT-US-2300853-v3.0-06/2024

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Patient Information **Rx Only**

ALTUVIIIO® (al too'vee oh)

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

Single-dose vial

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

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

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Who should not use ALTUVIIIO?

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

What should I tell my healthcare provider before using ALTUVIIIO?

Talk to your healthcare provider about:

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

How should I use ALTUVIIIO?

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

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

What are the possible side effects of ALTUVIIIO?

You can have an allergic reaction to ALTUVIIIO. 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 ALTUVIIIO. This can stop ALTUVIIIO from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

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

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

What are the ALTUVIIIO dosage strengths?

ALTUVIIIO comes in seven different dosage strengths with 3 mL sterile water for injection (sWFI). The actual number of international units (IU) of Factor VIII activity in the vial will be imprinted on the label and on the box. The seven different strengths are as follows:

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

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

How should I store ALTUVIIIO?

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

After mixing with the diluent:

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

What else should I know about ALTUVIIIO?

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

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

Manufactured by:
Bioverativ Therapeutics Inc.
Waltham, MA 02451
A SANOFI COMPANY
US License Number 2078

Revised: MAY 2024

AHF-PPI-SL-MAY24

COMMUNITY MEMBER SPOTLIGHT

BECKY STEELE

My name is Becky Steele, and I am the mom and aunt to three brave and strong young men with severe Hemophilia B. I am also a public school teacher, a former elected official in my west Michigan community, and a member of the Hemophilia Foundation of Michigan's (HFM) Advocacy Committee.

When my husband and I welcomed our third child into this world and received his hemophilia diagnosis, the journey that we were beginning felt daunting and uncertain. As the daughter of science teachers, I first learned of my carrier status around our kitchen table – stories of a grandfather who had passed away when my mom was very young, and a lesson on Punnett squares that was timed to parallel my eighth-grade science class's unit on heredity and inherited traits. As we embarked on our parenting journey with our sweet little bruiser more than a decade later, I was endlessly thankful for the trailblazing spirit and masterful "Hemo Mom" parenting that my sister had been modeling for years. After meeting the Hemophilia Treatment Center (HTC) team at Helen DeVos Children's Hospital, I became keenly aware of the village that was ready to help us raise our child.

Our son was born during Bleeding Disorders Awareness Month (March), and my efforts to build connections within the hemophilia community following his birth quickly brought stories to my inbox and social media feeds that illuminated some of the darker challenges faced within the hemophilia community, including the HIV/AIDS crisis, insurance obstacles, and inequitable access to treatment options. I fell more in love with our little guy each day, and intertwined with that love was a growing awareness of our privilege and blessings, and of the lives and legacies of those in the community who came before and walked alongside us. And therein lies the passion that drives my advocacy work: an unwavering belief that it is incumbent upon each of us to use our voices to promote positive change in and for our community.

My favorite pieces of advocacy work are Lansing Days and Washington Days, when HFM and the National Bleeding Disorders Foundation (NBDF) facilitate opportunities to connect with our elected officials. The energy of the capitol buildings, and the opportunity to put the stories of our community in front of decision makers who have the power to further legislative initiatives that would make a meaningful difference for those with complex medical diagnoses, is an exciting endeavor that I encourage everyone to take part in.

I also cherish the advocacy work I get to do alongside my newly seven-year-old son. We talk with his teachers about hemophilia at the start of the school year and have found that welcoming them into our village and communicating his needs proactively has lessened our need for a 504 plan. We also celebrate World Hemophilia Day each April with his class, because a special snack to share with friends and a lesson on how we are each unique builds empathy and connection. We love partnering with our HTC team to help aspiring physicians at Michigan State University's College of Human Medicine grow in their knowledge of bleeding disorders, pediatric patients, and empowered knowledgeable parents, and we were excited to see Grand Rapids' Blue Bridge light up red in late March in honor of Bleeding Disorders Awareness Month.

We are strongest when we work together. I hope to see you at advocacy events in the months and years ahead!

FROM THE CAPITOL BUILDING TO THE CLASSROOM, WORK SPACE, AND BEYOND

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

“ADVOCATE FOR YOURSELF”
“BE YOUR OWN BEST ADVOCATE”
“BE AN ADVOCATE FOR MYSELF, AND OTHERS LIKE ME”
“ADVOCACY IS EMPATHY, COMPASSION, AND COMMUNITY AT WORK”

THESE POWERFUL QUOTES CERTAINLY RESONATE WITH THE BLEEDING DISORDERS COMMUNITY. THERE ARE SEVERAL WAYS TO ADVOCATE FOR YOURSELF AND THE COMMUNITY. WHILE LANSING DAYS IS AN EXAMPLE OF ONE OPPORTUNITY TO CONNECT WITH OTHERS IN THE COMMUNITY AND GET FACE-TO-FACE TIME WITH MEMBERS OF THE MICHIGAN LEGISLATURE AND THEIR STAFF, THERE ARE OTHER WAYS THAT WE ADVOCATE ON A MORE DAILY BASIS.

Advocacy can take place in the form of requesting assistance from your hemophilia treatment center (HTC). While this can be uncomfortable, or bring up negative feelings, please be assured that the staff at your HTC approach these requests with compassion and kindness. The staff understands that while no two situations are the same, there are unique challenges that only happen to persons with bleeding disorders. Please reach out to your HTC if you are in need of community resources, financial assistance, or insurance information. You may also need special accommodations for work or school. For example, you or your child may need to use the restroom more frequently throughout the day, have a private space to take medications, or have limits on heavy lifting. You may also need paperwork to excuse you from work or school to attend comprehensive visits. Your HTC can help.

If you have any questions or any concerns, please reach out to your HTC for more information. Please note that this coordination of care often involves disclosing a limited amount of personal health information with school or work staff. Your HTC social workers or nurses can review this in advance to ensure that only the necessary amount of information is shared. In certain situations, you may find it helpful for direct education. Many HTC staff will meet with school officials or at the workplace if you are interested in more direct and personal support and education.

In a community as diverse as ours, we know that everyone has different needs. Please contact your HTC with any questions, concerns, and opportunities to join with you! You’re not alone. 💧

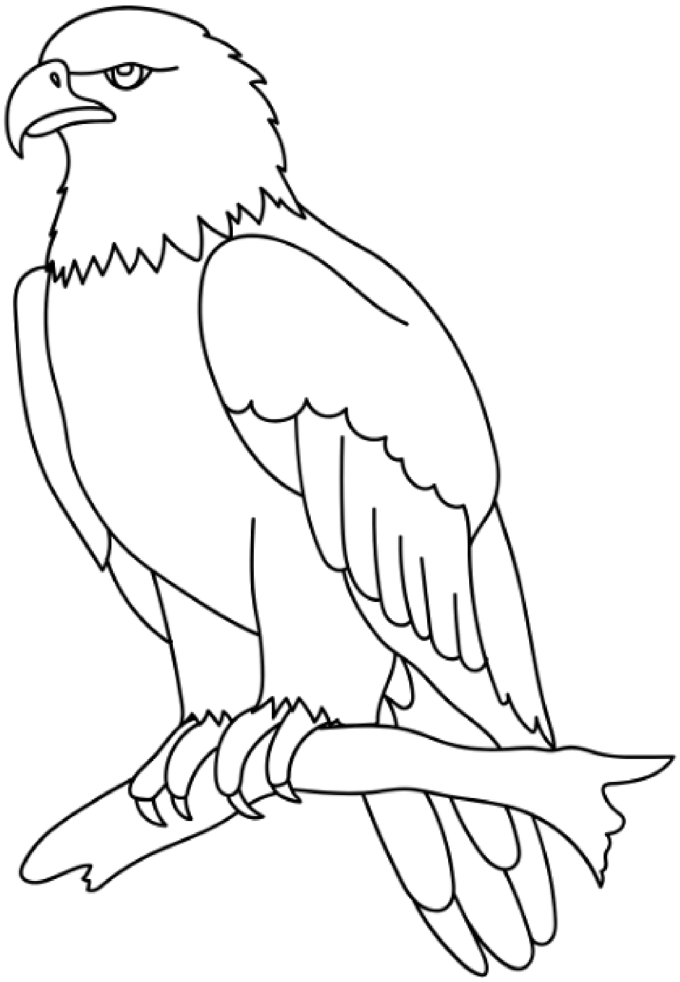
Eligibility for assistance is based on different circumstances, and you are highly encouraged to contact your local hemophilia treatment center if are in need. Resources are unfortunately limited, and assistance is not always guaranteed. If you are experiencing a medical or mental health emergency, please dial 911 or go to your nearest emergency room.

TINY CLOT CHRONICLES

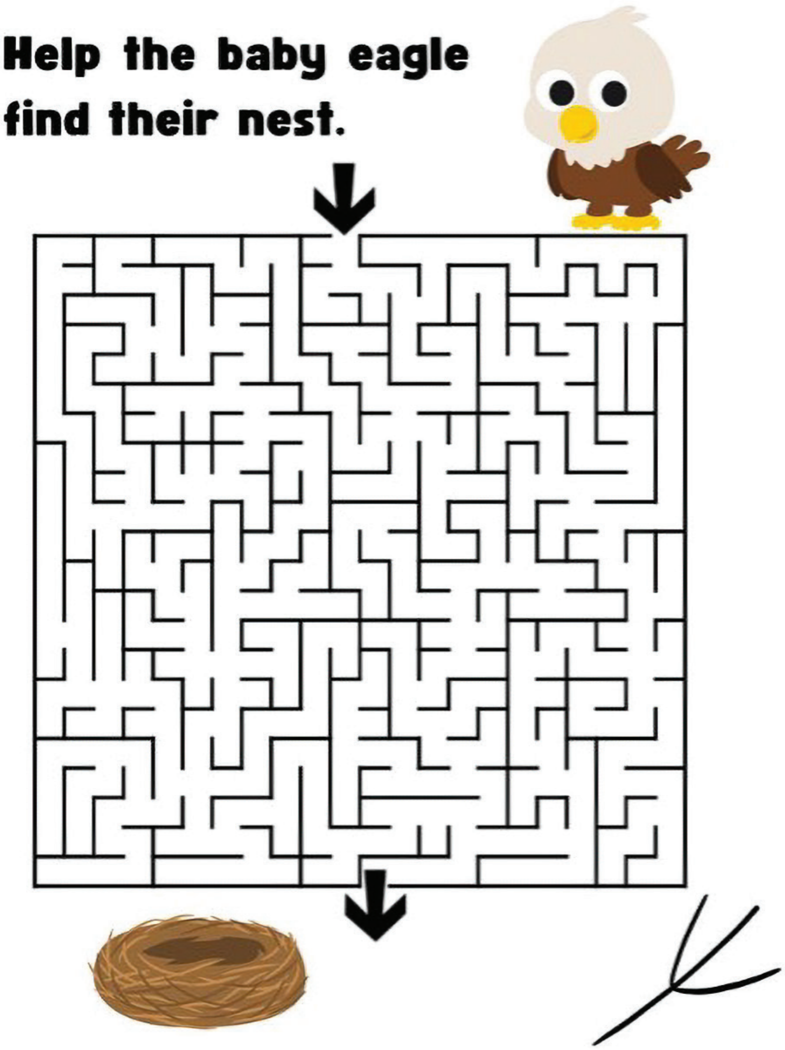
Welcome to the Tiny Clot Chronicles! Enjoy coloring the Bold Eagle, completing the maze, and challenging a friend in a game of tic-tac-toe. We've also included some inspiring quotes from our 2025 Teen Retreat participants and Associate Camp Directors about why you should come to Camp Bold Eagle!

COLOR IN THIS BOLD EAGLE

colored pencils and crayons work best



MAZE



LET'S HEAR FROM THE ASSOCIATE CAMP DIRECTORS!

ANGELLICA "GELLI" KELLEY

Camp Bold Eagle means the world to me. I have been coming to camp since 2012. The magic of camp is something that has changed me forever. I have made lifelong friends and so many great memories. The growth I have experienced at camp has shaped me into the person I am today. It is an amazing experience to be surrounded by others who have a bleeding disorder like you. Take an Eagle Step and join us at camp!

TRAVIS MILLER

I started going to camp when I was 14. I was nervous at first because I had never gone to a summer camp before! Once I got to know a few people, I was much more comfortable. Little did I know I was going to go to camp for the next 7 years straight! I met so many new people who I am still friends with to this day. As a kid from a small town where no one else had a bleeding disorder, coming to camp and seeing all that others and myself were capable of was empowering! I hope this year you decide to come to camp too.

TEEN RETREAT QUOTES

WE ASKED OUR TEENS AT THE SPRING TEEN RETREAT WHY YOU SHOULD GO TO CAMP!

You should go to camp because...

- You make lifetime friends.
- You make friends that will always be there for you.
- It is FUN!
- It is a very special place.

10
YEARS
TRUSTED

ALPROLIX®
[Coagulation Factor IX
(Recombinant), Fc Fusion Protein]

CELEBRATING
10 YEARS OF ALPROLIX®
SUPPORTED BY SANOFI'S COMMITMENT TO OUR COMMUNITY

As it has for the past decade, our community continues to motivate and inspire us. That's why we look forward to a future filled with possibility, backed by the community support that unites and raises us all.

CONNECT WITH A CoRe

Sanofi Community Relations and Education (CoRe) Managers provide information about ALPROLIX, treatment options, and more.

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THANK YOU TO SANOFI FOR THEIR LEADERSHIP AND SUPPORT OF HFM'S 2024 NATIONAL CONFERENCE FOR WOMEN WITH HEMOPHILIA AND RARE FACTOR DEFICIENCIES

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CSHCS:
CHILDREN'S SPECIAL HEALTH CARE SERVICES

WHAT IS IT?

Children's Special Health Care Services (CSHCS) is a program within the Michigan Department of Health and Human Services, administered under Title V of the Federal Social Security Act. It was created to find, diagnose, and treat children and some adults in Michigan with chronic health care needs. CSHCS is committed to removing barriers to appropriate health care and may be able to help with paying specialty medical bills, covering insurance co-pays and deductibles for private insurance, helping families to keep private insurance, and addressing transportation needs for medical care. As of October 1, 2023, CSHCS expanded eligibility for the program to age 26 for individuals with a qualifying medical condition. However, the age limitation is waived for patients with certain blood disorders (hemophilia and other bleeding disorders), sickle cell disease, and cystic fibrosis. 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.

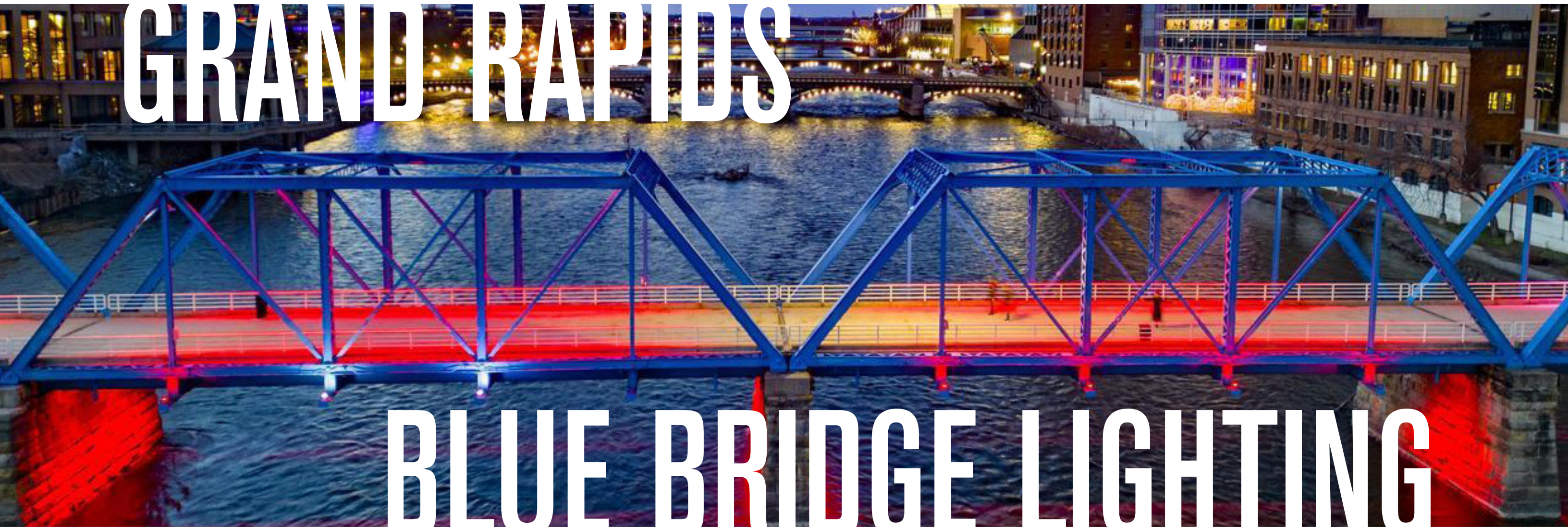
Visit www.michigan.gov/cshcs or call the CSHCS Family Phone line at 800.359.3722 for more information.

WHY DOES HFM ADVOCATE FOR CSHCS EVERY YEAR AT LANSING DAYS?

CSHCS's funding can change yearly. The program is funded through a combination of federal (Medicaid and Title V) funds, as well as state general funds. While Title V funds are capped, state general funding levels may vary based on the state budgetary needs. Additionally, language providing adult coverage must be maintained in the annual appropriations bill each year to ensure access for our adult population. In 2005, the Granholm Administration proposed eliminating coverage for cystic fibrosis and hemophilia adults in the Title V population. The bleeding disorders community organized an effective campaign against the proposal and successfully saved adult coverage.

CSHCS provides valuable assistance to our bleeding disorders community. We invite you to join us at HFM's annual advocacy day, Lansing Days, to talk to elected officials about the value of the program to ensure it is not faced with such a threat again.

GRAND RAPIDS BLUE BRIDGE LIGHTING



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From March 25-30 the iconic Blue Bridge in downtown Grand Rapids turned red in honor of Bleeding Disorders Awareness Month, and we were ready to celebrate!

On the first night of the lighting, our community was invited to the Eberhard Center at Grand Valley State University. This venue provided a spectacular view of the bridge.

The evening started with a visit to our sponsors, followed by a delicious pasta buffet. We sat together in a conference room to eat, have some fun, and to let it get darker outside for the glowing bridge “big reveal.”

HFM’s Executive Director, Susan Lerch, welcomed everyone, while Government Relations Manager, Zach Ryan, highlighted the importance of advocacy and how it can be practiced both personally and legislatively. Allan Kucab, Sanofi’s Community Relations and Education Manager, then led engaging crafts and activities in celebration of World Hemophilia Day.

Finally, we all stepped back out into the viewing area for dessert and coffee. The bridge began to glow slowly and those who were able to stay until it was fully dark were met with a beautiful sight.

To raise awareness, signs with QR codes were displayed on the bridge throughout the five days of lighting. These linked to an HFM webpage explaining bleeding disorders. We hope those who came across them discovered something new about our community!

Thank you to each of our sponsors for making this event possible!

THANK YOU TO OUR SPONSORS

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List: 208015
Alhemo®
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150 mg/1.5 mL (100 mg/mL)
For Subcutaneous Use Only
Single-patient-use prefilled pen
Rx only
0
mg

ADVOCACY INVOLVEMENT
WHAT DOES IT LOOK LIKE?

ZACH RYAN, GOVERNMENT RELATIONS AND COMMUNICATIONS MANAGER, HEMOPHILIA FOUNDATION OF MICHIGAN

All people hold the power to affect change on a personal, local, and global scale when they commit to get involved. My passion for this work stems from my lived experience of growing up with a severely mentally and physically disabled sister, which illustrated the positive impact focused legislation can have on individuals and vulnerable populations. However, this type of legislation and policy does not just spring up out of thin air. It takes people getting involved and sharing their stories with their elected officials and helping them to understand the need for specific legislation and policies.

I know firsthand how difficult it can be to find your voice and speak up on issues that are important to you, especially issues as deeply personal as your own health care, but I also know how gratifying it can be when you do step up and get involved. As the Government Relations & Communications Manager at the Hemophilia Foundation of Michigan (HFM), I have the privilege to support those affected by bleeding disorders find their voice and create positive change for the betterment of themselves and all affected by bleeding disorders.

The National Bleeding Disorders Foundation's Washington Days and HFM's Lansing Days are two examples of opportunities for individuals to take action by sharing their story and expressing their concerns with those making decisions. There are also ways to get involved directly in your community by meeting with your representatives at in-district meetings and coffee hours. Together we work to represent the bleeding disorders community and protect our future.

I am here to support you — to find your voice, to share your story, to get involved, and to make a difference for yourself and all those in our community.

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2024 GREAT LAKES REGIONAL MEETING

The 2024 Great Lakes Regional Meeting was a resounding success, attracting 147 attendees, in-person and virtually on November 6, 7, and 8th in Ann Arbor, MI. Attendees included a diverse range of disciplines who provide care for the bleeding disorders community in the Great Lakes Region (Michigan, Indiana, Ohio). The Regional Meeting provided an invaluable opportunity to learn, connect, and collaborate to enhance best care practices for patients with bleeding disorders. Various specialties were represented including social workers, nurses, data managers, physical therapists, hematologists, physician assistants, nurse practitioners, administrators, advocacy specialists, genetic counselors, and a patient panel. All in attendance were united by their commitment to advancing care for the bleeding disorders community

One of the meeting's defining features was the comprehensive offering of discipline-specific continuing education sessions. To ensure accessibility for professionals across the region, these educational opportunities were provided at no cost to attendees and were designed by discipline representatives across the region. Sessions showcased relevant topics of recent healthcare advances, emerging research, patient wellbeing, and interdisciplinary teamwork collaboration. The offered education ensured that attendees left the meeting with a wealth of knowledge and tools to enhance their professional practice.

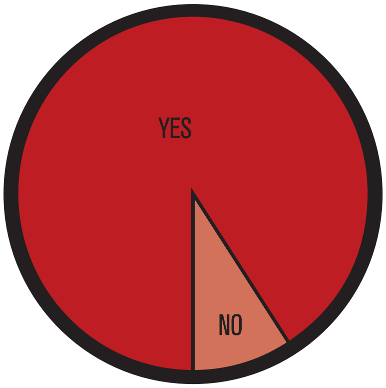
The meeting also included a variety of fun and unique offerings designed to encourage interaction and relaxation. One of the highlights was the spirited Euchre tournament; attendees enjoyed a friendly competition and connected over a mutual love of the game. Another memorable offering was a sound healing session, which provided a calming and restorative experience for attendees seeking relaxation amidst the busy conference schedule.

The meeting fostered camaraderie as attendees had the opportunity to engage with colleagues from various disciplines, HTCs, and states. This curated environment of shared learning and relaxed networking augmented connections across the bleeding disorders community, helping to bridge gaps between disciplines, and ensure patients receive the highest quality of care.

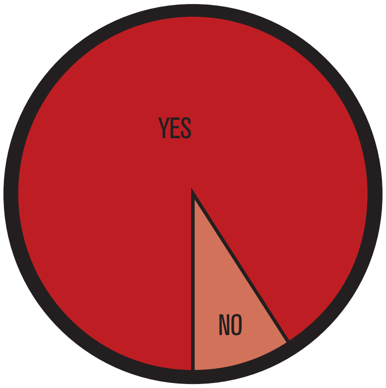
The 2024 Great Lakes Regional Meeting was an advantageous gathering that combined valuable education, networking opportunities, and fun. Attendees left with both an enhanced knowledge and a renewed sense of community, making it a truly remarkable experience for those involved.

93% OF ATTENDEES RATED THE OVERALL EXPERIENCE OF THE 2024 GREAT LAKES REGIONAL MEETING AS EXCELLENT OR GOOD

91% OF ATTENDEES INTEND TO IMPLEMENT LEARNED METHODS AS A RESULT OF THE REGIONAL MEETING



91% REPORTED THE BELIEF THAT THE EDUCATION RETAINED DURING THE REGIONAL MEETING WILL RESULT IN INCREASED PATIENT WELL-BEING



2025 WASHINGTON DAYS

REPRESENTATIVE TOM BARRETT WITH COMMUNITY MEMBERS BEN AND JASON ROGERS

Capitol Hill was filled with a wave of passionate advocates as more than 400 volunteers from across the country gathered in Washington, DC for this year's National Bleeding Disorders Foundation Washington Days. Phil Gattone, NBDF's President & CEO, stated that this year brought 160 new advocates which resulted in over 254 visits to legislative offices on the Hill. We also heard from Congressman Darin LaHood from Peoria, IL, who talked about the impact the bleeding disorders community has had on his work in Congress and expressed appreciation for the volunteer advocates meeting with their congressional offices.

Eleven of us from Michigan had the opportunity to meet with legislative aides from Michigan's two senate offices and several of our representatives' offices to advocate on behalf of the bleeding disorders community.

The discussion focused on patient protections against copay accumulator adjusters and maximizers and asking lawmakers to support S. 864, the HELP Copays Act, which had just been introduced in the Senate the day before our arrival on Capitol Hill. Our advocates also shared that federal bleeding disorders programs at The Health Resources and Services Administration (HRSA), The Centers for Disease Control and Prevention (CDC), and The National Institutes of Health (NIH) provide critical funding to Hemophilia Treatment Centers (HTCs) and help support research, care, and public health monitoring for bleeding disorders. Additionally, we discussed the concerns we have regarding cuts to healthcare programs such as Medicaid, which over 2.5 million Michiganders rely on to get access to high quality health care.

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

But the advocacy didn't stop there as HFM's Lansing Days were only two short weeks away on March 18 and 19.

SINCE NBDF'S INITIAL WASHINGTON DAYS VISITS IN MARCH, THERE HAVE BEEN SIGNIFICANT CHANGES ACROSS FEDERAL HEALTH AGENCIES. TO STAY INFORMED ABOUT UPDATES THAT MAY IMPACT THE BLEEDING DISORDERS COMMUNITY AND BROADER HEALTH ISSUES, PLEASE SIGN UP FOR HFM ADVOCACY ALERTS BY SCANNING THE QR CODE.

CAMP HOLIDAY PARTY

This past December, folks from the camp community gathered at the Camp Holiday Party to celebrate the season together with some classic holiday traditions. A white elephant gift exchange brought plenty of laughs as everyone traded wacky and fun presents! The hot cocoa bar was stocked with all the toppings — marshmallows, whipped cream, caramel, and more. A lively game of “get-to-know-you” bingo had campers reminiscing about their experiences, with a custom camp ornament as the grand prize. And, of course, throughout the night, community members reconnected, shared favorite camp memories, and filled the room with holiday cheer! We were so lucky to be able to spend time with camp friends old and new this year and can’t wait until we get to do it again.

THE IMPORTANCE OF COALITIONS AND PARTNERSHIPS IN PATIENT-FOCUSED ADVOCACY EFFORTS

MICHIGAN ALL COPAYS COUNT COALITION

As a statewide organization, the Hemophilia Foundation of Michigan (HFM) understands that the path to improving patient care, advancing policy change, and increasing access to essential treatments is not one that can be walked alone. Advocacy in the healthcare space requires collective action, collaboration, and the strength of many voices coming together. That is why coalitions and partnerships are at the heart of our advocacy efforts. They allow us to maximize our impact, pool resources, and ensure that the needs of patients are heard loud and clear at the highest levels of decision-making.

One of the most significant benefits of coalitions is amplifying the power of our advocacy. When we join forces with other organizations, we increase our ability to impact policymakers, healthcare providers, and the public. HFM is proud to be a member of the Michigan All Copays Count (MACC) Coalition, which has brought together over 40 organizations to tackle the challenge of accumulator adjustment programs. A coalition of patient groups, such as the MACC coalition, is a louder, more influential voice in the work for policy change.

We can advocate not only on behalf of the Michigan bleeding disorders community, but on behalf of the over 40 organizations that are a part of the MACC coalition, which strengthens our advocacy efforts. Together, we can reach more decision-makers, engage more media outlets, and mobilize more patients and caregivers to act.

Working in partnership not only provides access to more resources, it also brings together a wide range of skills that we might not have on our own. By tapping into the strengths of our partners, we can build more effective campaigns, strengthen our outreach, and ensure that our advocacy efforts are as impactful as possible. HFM's partnerships with national organizations like the National Bleeding Disorders Foundation (NBDF) and the Hemophilia Federation of America (HFA) are great examples of this. Working with NBDF and HFA gives us the opportunity to bring the voices of the Michigan bleeding disorders community to Washington, DC and allows us to work with other states around the country through the State-Based Advocacy Coalition.

Finally, coalitions and partnerships foster innovation and creative solutions to complex problems. By working with other patient-focused organizations, HFM hears success stories from others and discovers new ways to tackle the issues that matter most to our patients. HFM's work with coalitions such as MACC and our partners at the national level, gives us the opportunity to learn of issues that may be on the horizon, and collectively make plans to tackle them.

By coming together with other organizations that share our vision, we can amplify our voices, access more resources, and develop innovative strategies to improve healthcare for all patients. HFM is proud to be part of the collective work that these coalitions and partnerships do to combine efforts and improve outcomes for Michiganders. 💧

CAMP REGISTRATION IS OPEN!

Eagle Quest: (ages 18+): June 4-8

Eagles Nest Family Camp: June 25-28
Open to the immediate families of children with bleeding disorders ages 5-9 who are new to the Camp Bold Eagle experience.

For more details and to register,
visit www.hfmich.org/camp

Camp Bold Eagle:
- **Teen Camp:** (ages 13-17): June 29-July 5
- **Session 1:** (ages 6-9): July 13-17
- **Session 2:** (ages 10-12): July 19-25

Eagle Outpost: (ages 14-15): August 3-9

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

Old Beagle: (open to adults and their families): September 12-14

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UPCOMING 2025 EVENTS

June 4-8
Eagle Quest 👤 (18+)
Pictured Rocks National Lakeshore

June 19
Blood Buds: Virtual Escape Room 💻 (18+)

June 21
Community Event: Detroit's Outdoor Adventure Center 👤
Detroit, MI

June 25-28
Eagles Nest Family Camp 👤
Pioneer Trails, Holton, MI

Camp Bold Eagle 👤
Pioneer Trails, Holton, MI
June 29-July 5
Teen Camp (ages 13-17)
July 13-17
Session 1 (ages 6-9)
July 19-25
Session 2 (ages 10-12)

August 1-2
UP Retreat 👤
Marquette, MI

August 3-9
Eagle Outpost 👤
(ages 14-15)
Various Michigan state parks

August 9-16
Eagle Expedition (ages 16+) 👤
Northern California

August 14
Advocacy Webinar: Disclosing Your Diagnosis 💻

August 15
Community Night: Revel and Roll West 👤
Kalamazoo, MI

August 21
Blood Buds: Virtual Jackbox Game Night 💻 (18+)

September 12-14
Old Beagle (open to adults and their families) 👤
Pioneer Trails, Holton, MI

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

💻 Virtual
👤 In-person
(18+) 18 and older

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