The BLOODLINE

NEWSLETTER



Upcoming Events
Creative Ways to Show Support
Fundraisers
Events
Bleeding Disorder Education





Quarter 4

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Board President's Letter (Julie McAnally)

Upcoming Annual Events for 2026

Feb 9 - Advocacy Day April 10-12 - Annual Meeting May 31 - Men's Retreat June 1 - BDH Golf Tournament June 21-26 - Youth Camp July 25 - Family Education Day August 29 - Adult Retreat Sept 19 - BDH Unite Walk

HFA Symposium

Thank You for Your Support

Creative Ways to Fundraise and Show Your Support Educational Bleeding Disorder Articles NBDF

CONTACT INFORMATION



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The Bloodline is a publication of the Bleeding Disorders of the Heartland. The Bleeding Disorders of the Heartland is a voluntary education and advocacy organization which neither recommends nor endorses the products and services noted within this publication and does not make recommendations concerning treatment regimes for individuals. BDH suggests that you consult your physician or local treatment center before pursuing any course of treatment. The Bloodline is published four (4) times a year.

Quarter 4





FROM THE PRESIDENT'S DESK:

Closing out 2025 and the Year Ahead

DEAR MEMBERS OF BLEEDING DISORDERS OF THE HEARTLAND,

As we close out 2025, I am filled with gratitude for all that we have accomplished together. This year has been one of growth—not only for our organization, but also for our board as we've strengthened our vision and expanded our reach. None of this would have been possible without the dedication of our members and the many partners who have stood alongside us, making each success a shared achievement.

I want to extend a heartfelt thank you to our Executive Director, Brooke Loving, whose leadership and commitment have guided us through this year of growth. I am equally grateful to Amber Smith, for her hard work and passion in serving our community. And to our board members, thank you for your collaboration, and efforts in advancing our mission.

Looking ahead to 2026, I am excited to build on this momentum, deepen our impact, and continue supporting individuals and families affected by bleeding disorders. Together, we are shaping a future of hope, resilience, and community.

CONTACT BDH



) <u>(319) 721-1664</u>

Sincerely,
Julie McAnally





HAPPY HOLIDAYS







Maybe it's because I've always had such great support, but engaging with others is the best way for me to stay happy.

-AJ

AJ | ALTUVIIIO patient

AJ is a promotional speaker compensated by Sanofi.

Connect with an ALTUVIIIO® Peer Mentor

ALTUVIIIO Peer Mentors are real patients or caregivers who have had similar experiences to yours.

You'll have the opportunity to:

• Ask questions • Hear firsthand experiences • Learn helpful tips • Get to know others in

the community



Sign up today to meet a Peer!

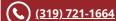


Quarter 4



FOR DETAILED INFORMATION CONTACT BDH

(M) bdh_director@bdheartland.org



UPCOMING EVENTS FOR 2026

<u>Advocacy Day</u>

Feb 9 State Capital, Des Moines, Iowa

Annual Meeting

April 10-12 Dubuque, Iowa

Men's Retreat

May 31 Ankeny, Iowa

BDH Golf Tournament

June 1 Toad Valley Golf Course, Iowa

Youth Camp

June 21-26 Camp tanager, Mt Vernon, Iowa

Family Education Day

July 25 Burlington, Iowa

Adult Retreat

August 29 Iowa City, Iowa

BDH Unite Walk

Sept 19 Clark Park, Hiawatha, Iowa



Scan here for more details on our events and to register!



HFA SYMPOSIUM 2026 IS HEADING TO NEW ORLEANS, LOUISIANA!

APRIL 16-19, 2026
Stay tuned—more details coming soon!







ONGOING FUNDRAISER

Place your order for either pickup or delivery! Enter the fundraising code at checkout. This offer is available at all Panda Express locations across the country. Please share this information with friends and family! Watch Facebook for the monthly code and dates!

Keep an eye on Social Media and Email for Upcoming Panda Fundraiser Dates!





with Dolvett Quince

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

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



Scan for H-Fit.com

Sign up with Novo Nordisk and register at H-Fit.com to get free access to the H-Fit video library.





Thank you to everyone who attended our Stakeholders Meeting!

We had a great discussion about advocacy efforts and worked together to create an exciting plan for the year ahead.

A special thank-you to our sponsors for their generous support and partnership.













NATIONAL PHARMACISTS DAY



The Bleeding Disorders of the Heartland has its exclusive coffee blend crafted by Blue Strawberry, a local business in Cedar Rapids. Purchasing this coffee helps fund our organization.

Get your coffee today!

GROUND AND WHOLE BEAN





GO TO
THE
WEBSITE



CLICK HERE TO ORDER.



BREAKING NEWS //

News From Your Hemophilia Treatment Center

University of Iowa Health Care's (UIHC) relationship with Mission Cancer and Blood Centers across the state marks a significant advancement in expanding access to high-quality care, especially for rural Iowans. This partnership is helping more patients receive essential oncology treatment closer to home, including those who previously could not travel to Iowa City.

However, the only federally funded Hemophilia Treatment Center (HTC) remains at the Iowa City UIHC main campus location. The HTC provides multidisciplinary care using a team of providers, including hematologists, nurses, pharmacists, physical therapists, pediatric dentists, a social worker, research coordinators, and a health record analyst. Together, providers develop individualized treatment plans during comprehensive clinic visits. These visits occur every one to two years, depending on the severity of the patient's condition, and are essential for maintaining continuity of care. These services are not currently available at the Mission Cancer and Blood locations.

Staying current with comprehensive visits ensures patients continue receiving appropriate prescriptions and treatment recommendations to maintain wellness. This clinic appointment also enables our providers to develop and help coordinate safe, effective plans for surgeries or procedures, minimizing the risk of bleeding and promoting healing.

When a patient has missed comprehensive visits for an extended period, or has not been seen in several years, we unfortunately are unable to create a general treatment plan or procedure plan for surgery. Without these, there could be potential bleeding risks during a procedure, surgery, or trauma.

To mitigate this risk, the HTC requires notification at least two weeks in advance of any scheduled surgery, dental procedure, or other invasive intervention (excluding emergencies). Patients should inform their primary provider of their bleeding disorder and request recommendations from the HTC. If a patient's treatment plan has expired, we recommend rescheduling the procedure until the patient can be seen in our HTC comprehensive clinic.

This summary reflects our commitment to patient safety and the highest standard of care. We appreciate the continued collaboration of our partners across the state in ensuring that every patient receives the comprehensive support they need.

BREAKING NEWS //

New Treatment Announcement

An oral treatment for Hemophilia A has recently been developed and is now being tested in a clinical trial at the University of Iowa. If you have a FVIII level ≤15% and are currently treating on-demand, you may be eligible for the trial. Ask your HTC nurse or see the Iowa Healthcare Clinical Research and Trials Website for more information:



Overview

The Voyager2 study is the first-ever clinical trial to test an oral treatment for patients with hemophilia A. The new medicine, called Inno8, is a pill taken once a day in the morning before eating. The study is looking at how safe the new medicine is, how well people tolerate it, and how it works in the body.

What's involved?

- A screening visit to see if you qualify
- A 10-day treatment period: take the pill daily and come in for 7 clinic visits
- A 35-day follow-up period: 6 clinic visits

You might qualify for the study if:

- 1. You are a male aged 18-64
- 2. You have hemophilia A with FVIII activity of 15% or less
- 3. You are not currently on prophylaxis

You might not be able to participate in the study if:

- 1. Your BMI is 30 or higher
- 2. You take medicine for high blood pressure or high cholesterol
- 3. You smoke more than 5 cigarettes a day

Compensation is provided for study visits. Travel costs—including hotels, meals, and mileage—will also be reimbursed.





Government Relations Update - October 2025

Source: National Bleeding Disorders Website | Nov 12 2025

Government Shutdown (Updated)

On November 10th, 8 Senate Democrats joined Republicans to re-open the government. Although Senators were promised a vote on Advanced Premium Tax Credits before their expiration on December 31st, we do not have any information yet on the timeline nor content of that vote. NBDF's top priority is to extend the Advanced Premium Tax Credits, and will be advocating alongside our chapters and partners to demand Congress take action before their expiration. Please reach out to your Member of Congress through our <u>legislative action center</u>.

ACA Tax Credits

Although the ACA Marketplace tax credits do not officially expire until December 31, 2025, open enrollment is about to start (November 1), and many Americans have already received notices showing a steep increase in premiums for 2026. While some think that it's too late for Congress to act now that open enrollment has begun, if Congress extends the tax credits, then the Administration and insurers will work together to implement the new law and lower premiums.

NBDF continues to advocate to make these tax credits permanent. Much of this advocacy work is done through NBDF's participation in the Partnership to Protect Coverage (PPC). In mid-October, NBDF joined a PPC <u>statement</u> stating the urgency for Congress to act on this issue. We also urge the bleeding disorders community to act. Use NBDF's <u>action alert</u> on this issue and tell contact your members of Congress to act now on the tax credits. It's not too late.

WHAT'S NEXT? YOU DECIDE.

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

SCAN THE QR CODE TO SEE HOW WHAT'S NEXT, TOGETHER.



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GENENTECH IN HEMOPHILIA

Genentech

Empowering you to treat and manage your bleeding disorder

- Dedicated pharmacy transition support
- · Timely medication delivery with an overnight shipping option
- In-home nursing support program for patient infusion education
- Assistance with prior authorizations, copay management and more

See how we can help. PARAGONHEALTHCARE.COM/HEMO





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Becca Robbins District Sales Manager brobbins@paragonhealthcare.com 479.685.2532



THE BLOOD EXPERTS

SERVING THE QUAD CITIES & ILLINOIS

WE TREAT THE WHOLE PERSON, NOT JUST THEIR SYMPTOMS.

DISORDERS WE TREAT:

- · Hemophilia A & B
- ITP
- Von Willebrand Disease
- Clotting Factors
- · Factor Deficiencies
- Platelet Function Disorder

Arthur

HSHS St. Mary's Hospital Building 525 N. Vine St. Arthur, IL 61911

SIU Center for Family Medicine 300 W Oak St. Carbondale, IL 62901

Champaign OSF Medical Group – Primary Care 1405 W Park St., Suite 306 Urbana, IL 61820

Crossing Healthcare 320 E. Central Ave. Decatur, IL 62521

Macomb

Medical Arts Building 527 E. Grant St. Macomb, IL 61455

Pediatric Specialty Clinic 515 Valley View Drive Moline, IL 61265

Ottawa

Fox River Cancer Center 1200 Starfire Dr. Ottawa, IL 61350

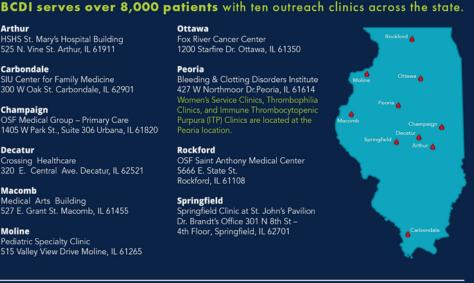
Bleeding & Clotting Disorders Institute 427 W Northmoor Dr.Peoria, IL 61614 Clinics, and Immune Thrombocytopenic Purpura (ITP) Clinics are located at the

Rockford

OSF Saint Anthony Medical Center 5666 E. State St. Rockford, IL 61108

Springfield

Springfield Clinic at St. John's Pavilion Dr. Brandt's Office 301 N 8th St -4th Floor, Springfield, IL 62701











Are you looking for a small way to make a difference?

Our Raise Right Campaign is the perfect way to do so!





You can purchase digital gift cards and within moments put them on your digital wallets to use instantly!

It only takes a few clicks. Then their company will donate a percentage to us... with no increased cost to you!



SUBWAY



AND MORE!

Click this button to learn more and start making a difference today!

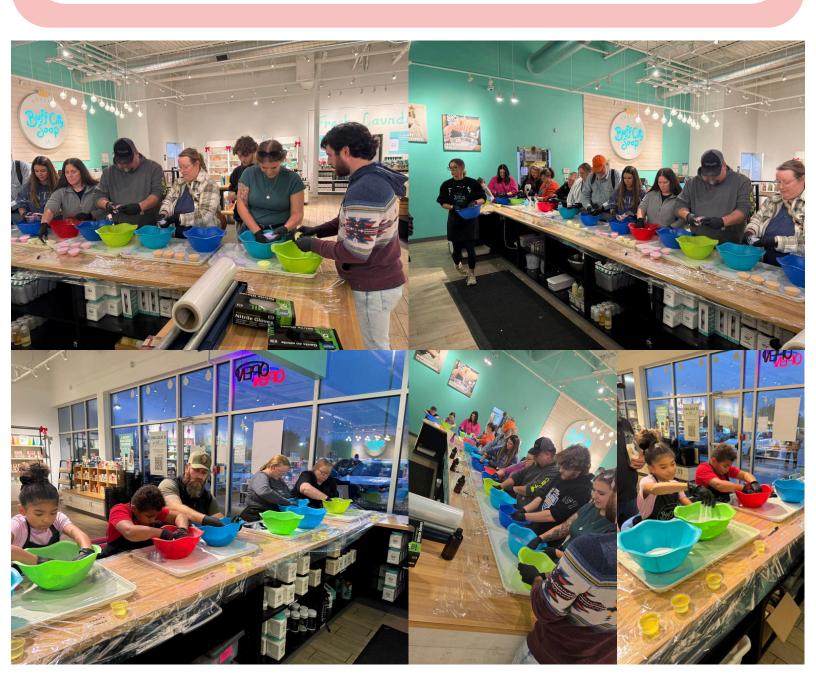


CLICK HERE



Thank you to SUPERIOR for hosting such a wonderful community education night at Buff City Soap!

It was a fantastic evening of creativity, learning, and connection. We loved the opportunity to make something together while strengthening bonds within the bleeding disorders community.





Looking for a Way to Support Bleeding Disorders of the Heartland?

We're currently collecting gift baskets for upcoming events, and we'd welcome your help!

Are you a small business or know someone who owns a small business looking to get your/their name out there?

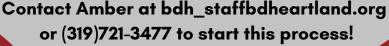
Do you want to support our mission in a fun and meaningful way?

Looking for a simple way to give back to the bleeding disorders community?

This is the perfect opportunity! Donating a basket is a great way to showcase your products or services while making a difference for families affected by bleeding disorders.

Interested or want more info? We'd love to hear from you!

CONTACT









REGISTRATION & INFORMATION
CAN BE FOUND
ON THE WEBSITE ON THE EVENTS TAB

2026

ADVOCACY DAY

Click Here to Register

JOIN US AT THE CAPITOL

Bleeding Disorders of the Heartland invites <u>YOU</u> to be a voice for individuals and families affected with bleeding disorders.

February 9th Dinner/Training 6-9pm in Urbandale, Iowa February 10th at the Capitol Building, Des Moines, Iowa



Make a Difference

Your voice matters!

Help advocate for policies

that directly impact the

bleeding disorders

community.



Connect with

Meet with state and federal representatives to discuss critical issues.



Strengthen Our Community

Stand together with others who understand the challenges faced by those living with bleeding disorders.









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A huge thank you to





for presenting at our Fall Family Event at Putts and Pins in West <u>Des Moines</u>.

We're so thankful for your support and partnership!





Bleeding Disorders of the Heartland is now accepting Scholarship Applications

Deadline to apply is March 1, 2026

Please see the website for all of the information about scholarship requirements and directions to apply. If selected applicant MUST be able to attend the 2026 Annual Meeting -April 11th in Dubuque, Iowa.

Click Here to Apply



Amber Smith (319) -721-3477



Our Website www.bdheartland.org Our teen event was full of energy, focus, and future goals in motion. These young people came ready to work — building, editing, and polishing their résumés with care and confidence. They really took the time to think through how to present their strengths and experiences.

Thank you to our sponsors!













Help shape the future of the bleeding disorders community by joining an HFA Voice of the Community session! Share what life with a bleeding disorder looks like — what helps you thrive, what challenges you face, and what you want to see change.

Each 60-minute session is facilitated by HFA staff, guiding discussion as we:

- Explore the future together.
- Share ideas and lived experiences.
- Co-create possibilities debuting at Symposium 2026.

Session times appear under each dated sign-up option.

We would like to thank our sponsors for making this fun filled day possible!! We always look forward to the conversations, laughter, and meaningful connection at our Family Education Day every year! Thank you for advocating for the needs of all people with bleeding disorders! We appreciate you!

It was so wonderful to catch up with our BDH families! We can't wait to see you again soon at the next BDH event!!



Thank you to our sponsors!



Biotherapies for Life®















promptcare











Bleeding Disorders of the Heartland receives grant from Variety - the Children's Charity of Iowa

Bleeding Disorders of the Heartland has received a grant from Variety - the Children's Charity of Iowa to fund our 2026 Camp.

Bleeding Disorders of the Heartland is a nonprofit organization serving families throughout the state of Iowa diagnosed with bleeding disorders. The Variety grant will be used to help cover the cost of 2026 Bleeding Disorders of the Heartland Bleeding Disorders Camp and vein locators/simulators.

"The grant received will be utilized to help us further our mission by providing children with the opportunity to attend camp. This is one of the most impactful ways to make a difference in the life of a child who has a bleeding disorder. The impact of this grant doesn't just impact a week at camp... it changes the lives of every child who attends, their families, and their communities for years to come." - Brooke Loving, Executive Director

About Variety - the Children's Charity of Iowa

Variety - the Children's Charity is dedicated to improving the lives of children who are at-risk, underprivileged, critically ill, or living with special needs throughout Iowa. Funding is provided to programs and initiatives that directly impact the well-being of children throughout Iowa. For more information on how you can be a part of Variety's work, please visit variety iowa.com.



Contact:

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Bleeding Disorders of the Heartland
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bdh_director@bdheartland.org





MASAC Approves Recommendations on Non-Factor Hemophilia Therapies, HTC Social Worker Roles

Source: National Bleeding Disorders Website/Released July 6, 2025

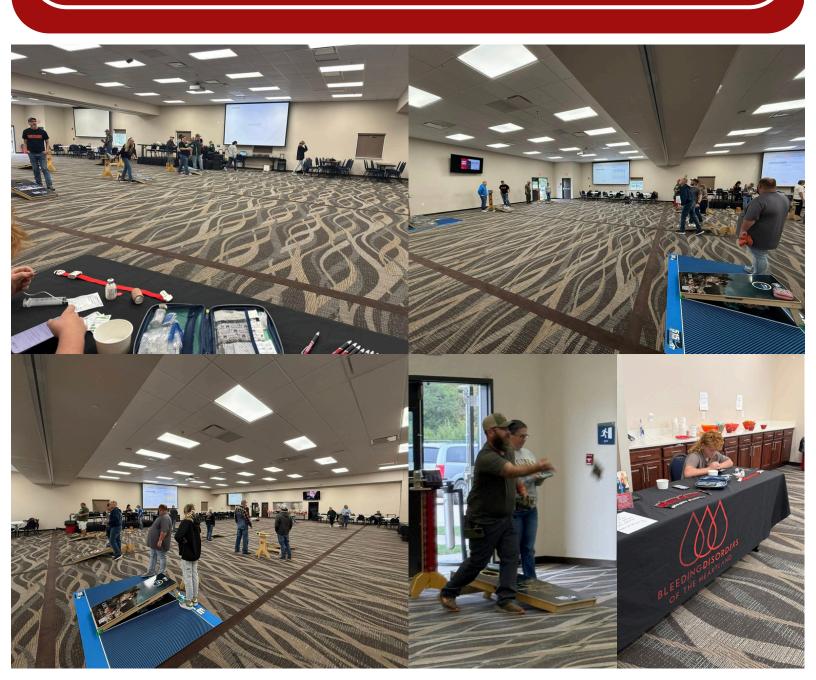
Three new documents have been issued by NBDF's Medical and Scientific Advisory Council (MASAC), which creates recommendations and advisories on current treatment, research matters, and other general health concerns for the inheritable bleeding disorders community.

- 1) Off-Label Use of Emicizumab in Acquired Hemophilia A
- 2) Use of Anti-Tissue Factor Pathway Inhibitors in Hemophilia
- 3) The Role of HTC Social Workers

Thank you, 515 Cornhole, and community members Skylar, Shelby and family for putting on such a wonderful fundraising event!

Your hard work and dedication made it a huge success, and we're so grateful that the proceeds are supporting Bleeding Disorders of the Heartland.

Your generosity and community spirit truly make a difference!



Choosing health insurance can feel overwhelming —but for someone living with a bleeding disorder, it's more than just paperwork. It's about access, stability, and care that can't wait.



This open enrollment season, check out the Personal Health Insurance Toolkit from the National Bleeding Disorders Foundation to help you make informed choices.

INSURANCE TOOLKIT

Utilize resources to help you choose the best option for your health insurance today!







HEMLIBRA: TRUSTED By the community for 7 years and counting













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

* 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.



SCAN TO HEAR STORIES FROM THE COMMUNITY

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.



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 vesselsthat 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 1.555.
 - swelling in arms or legs pain or redness in your

 - arms or legs shortness of breath
 - chest pain or tightness
 - fastheart rate
- cough up blood - feel faint
- headachenumbness in your face
- eye pain or swellingtrouble 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®)

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"

more White matthe atossible side effects of HEMLIBRA? " for

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 tohelp your blood clot.

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

- are pregnantor plan to become pregnant. Itisnot known if HEMLIBRAmay harm your unborn baby. Females whoare 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.
 HEMLIBRAIS givenasan injection underyour skin
- (subcutaneous injection) byyouor acaregiver.

- 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 thevial to thesyringe, HEMLIBRA should be used right away.
 Throw away (dispose of) any unused HEMLIBRA leftinthe 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 thanthose 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

U.S. LICENSE NO. 1046

HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan ©2023 Genentech, Inc. All rights reserved.

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



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MISSION UPDATE:

After an intense day of sessions, our agents regrouped at Spare Time for a covert dinner & connection op. Under cover of laughter and dinner, we debriefed, bonded, and built memories.

Strategic conversations? Precision bowling? Questionable.

Escape room? We cracked the code and escaped just in time!

Another successful chapter in the Operation: Adult Retreat 2025 dossier. Shoutout to every agent who showed up with heart, humor, and hunger.



Thank you to our sponsors!



























NBDF's 2025 Research Roundtable: Advancing Bleeding Disorders Research for Women and Girls

The meeting convened researchers, industry leaders, nonprofit organizations, and lived experience experts to discuss ways to enhance the inclusion of women and girls with bleeding disorders in research.

Source: National Bleeding Disorders Website | November 21, 2025

BNBDF's inaugural Research Roundtable was held in Washington, D.C. on October 15-16, 2025. The meeting brought together lived experience experts (LEEs), researchers, healthcare providers, and industry leaders in a pre-competitive, product-agnostic setting to address barriers faced by women, girls, and people with the potential to menstruate in bleeding disorders research. Although the FDA could not attend due to the government shutdown, NBDF engaged with them on key agenda topics beforehand and plans to resume the dialog with them further once the government reopens.

Focus on Women, Girls, and Menstruating Individuals in Clinical Trials

The 2025 Research Roundtable focused on the participation of women, girls, people with the potential to menstruate in clinical trials for conditions such as hemophilia, von Willebrand disease (VWD) and Glanzmann thrombasthenia.

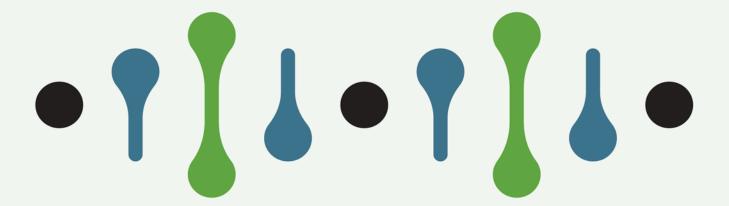
The goals of the conference included identifying barriers to participation in research, developing strategies to overcome these barriers, identifying best practices, and defining actionable steps and measurable outcomes to improve clinical trial design and participation. Historically, women and girls and menstruating individuals have been excluded from medical research overall, and that includes research into bleeding disorders. This gap in understanding has led to these same people being underdiagnosed and undertreated. In some cases, it can impede their access to safe and effective treatment plan, because the indications for medication are based on malefocused studies.



Suspension for intravenous infusion 1×10¹³ vg/mL

Scan QR code to learn more or visit www.BEQVEZ.com





Connect with your PAL by signing up at **TogetherforRare.com.***

*Pfizer PALs are not measured or awarded based on sales performance nor will they ask you to switch products.





Step Right Up and **Walk For A Cause!**



















Thank you to eveyone who came out to support us during our 2025 Unite Walk!

Thank you to everyone who helped make this event such a success.

We could not continue the important work we do without the help of our Team Captains!







AND A SPECIAL THANK YOU TO **OUR UNITE WALK SPONSORS!**

PRESENTING PARTNERS





NATIONAL COMMUNITY PARTNER

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VIRTUAL PARTNER



ADDITIONAL SPONSORS















***These trophies are given to those who qualify as of midnight the night before the

walk starts. Every year we have fun new one!

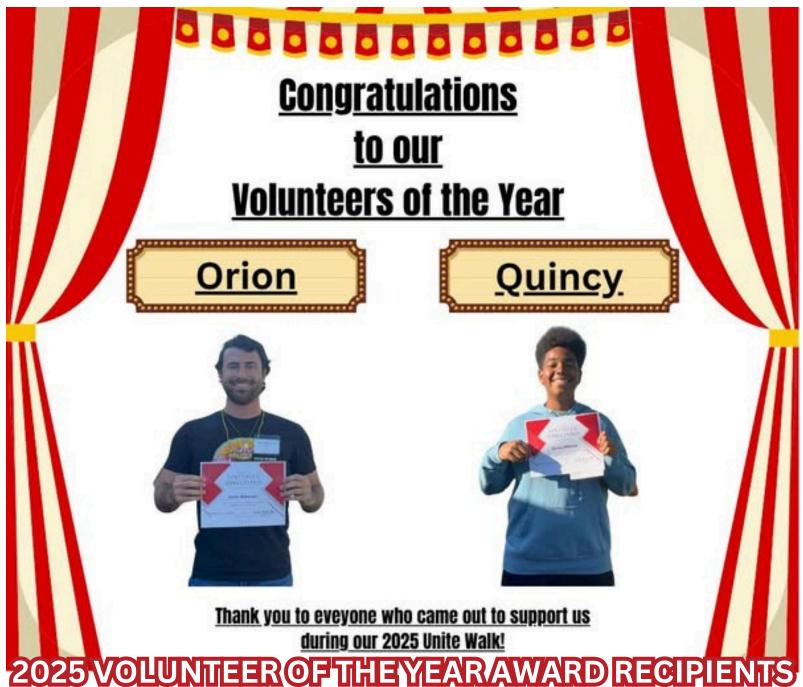
Largest Team: Team Jason - they had the largest number of walkers registered for the event!

Small But Mighty: *The A Team* - they had the smallest number of registered walkers but a large donation amount!

Highest Raising Rookie Team: *Archer Owen* - They are a brand-new team who raised the most of all new teams!

Early Bird Team: F8 Dominate - they were the first team to get started this year!

Thank you to everyone who helped make this event such a success. We could not continue the important work we do without the help of our Team Captains!



We were honored to recognize our 2025 Volunteer of the Year Award recipients at our September walk! Thank you for making a difference all year long!

Orion has spent countless hours volunteering his IT skills to help our organization. He has a small business where he helps people solve difficult IT related issues and he volunteered his skills to help us as well. He then quickly joined our board to continue to help us further our mission in many more ways!

Quincy is a fabulous young man who always shows up with a smile and willingness to help in any way possible. He has helped handing out papers, carry items and makes sure to say hello to everyone so everyone feels welcome during the events. He even stepped in, last minute, to do our Unite Walk Pinwheel Ceremony this year!

If you are interested in volunteering, reach out to Brooke or Amber to learn more.



1st, 2nd & 3rd Place Adults



1st, 2nd & 3rd Place <u>Kids</u>



Thank you to eveyone who came out to support us

MEDALWINNERS FOR OUR 2025 UNITEWALK

We were so impressed how quickly these guys finished our 2025 Unite Walk!

Congratulations to our 1st, 2nd and 3rd place winners for this year!

Keep an eye on our social media pages every Wednesday for "Walk Wednesday's" where you will get to see a recap of our 2025 walk as well as details for our up-and-coming 2026 walk!

Visit our website to learn more about how we will use your donations to continue to improve lives of those in the bleeding disorders community!



"FAB" Our Ladies Regional Conference was a FABulous event, we are already planning 2026!

A huge thank you to octapharma for sponsoring this incredible opportunity for the women in our community to come together, learn, and connect.

This event is a powerful collaboration between four Midwest chapters, and we are so grateful for all the amazing women represented here. If you didn't get a chance to register this year, go ahead and pencil it in for next October — we'd love for you to join us! It's a FABulous time!







2026 FEMALES AND BLEEDING DISORDERS CONFERENCE









EDUCATION | PERSONAL GROWTH | NETWORKING

SAVE THE DATE!

OCTOBER 9-11, 2026

Kansas City, KS <u>Registration will open in 2026!</u>



Bleeding Disorders of the Heartland 103 5th Ave Durant, Iowa 52747 Tel: (319) 721-1664

Fax: 615-900-1487 Email us at: bdh director@bdheartland.org



The Bleeding Disorders of the Heartland (BDH) asks for your contributions to support the programs and activities of BDH that focus on advocacy, awareness, education and mentorship of families and new families. You can make a financial contribution by going online to our website at www.bdheartland.org or by mailing your check to our office. Does your workplace offer an employee matching gift program? We have numerous fundraising events throughout the year that you can attend and financially support as well. Help us share the word about the mission of BDH.

Thank you for making a difference!

This contribution is made in memory or honor of			
Name:			
Address:			
City:	State:	Zip Code:	

BDH is a nonprofit 501 © 3 organization that exists to educate, connect, and support those affected with bleeding disorders.