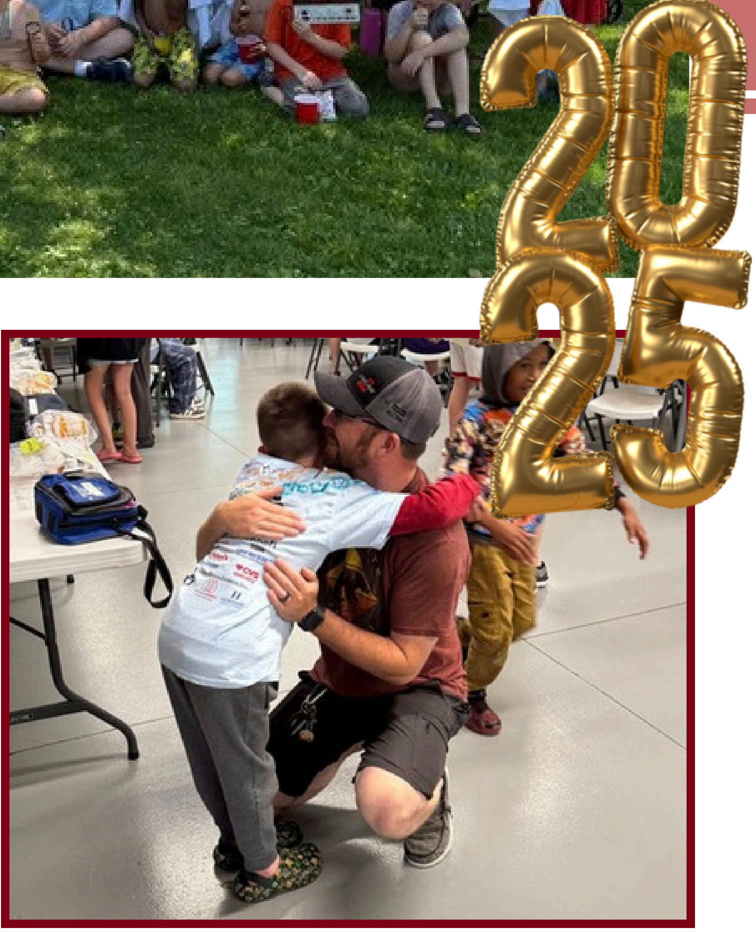
QUARTER 3

The BLOODLINE NEWSLETTER

READ IN THIS 2025 ISSUE



BLEEDINGDISORDERS
OF THE HEARTLAND

PROUD MEMBERS OF THE HEMOPHILIA FEDERATION OF AMERICA
AND THE NATIONAL BLEEDING DISORDERS FOUNDATION

Quarter 3

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BLEEDING DISORDERS
OF THE HEARTLAND

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 3

BLEEDINGDISORDERS
OF THE HEARTLAND

Brooke Loving
EXECUTIVE DIRECTOR

FROM THE DIRECTOR'S DESK:
Reflecting on 2025 and Looking Ahead with Excitement

DEAR MEMBERS OF BLEEDING DISORDERS OF THE HEARTLAND,

Is anyone else wondering where the time has gone? It feels like just yesterday we were ringing in the new year and gearing up for another exciting calendar of programs, events, and community gatherings.

And now here we are—well into the second half of 2025 winding down the year preparing for the holidays!

This year has flown by in the best way possible. It's been filled with meaningful moments, connection, education, and, of course, fun. From The Annual Meeting, Summer Camp to our Men's Retreat, Teen Event's, and our Factoring Fairways for Families Golf Tournament, each event has reminded me why we do what we do—and how lucky I am to be a part of this incredible community.
I've had the joy of watching new families join us for the first time and longtime members deepen their bonds. The energy and support within our community are unmatched, and it's truly inspiring to witness how much we lift one another up through life's challenges and celebrations.

And the year isn't over yet! We still have some fantastic events ahead, including our Family Education Day, Adult Retreat, Step Right Up and Walk for a Cause Unite Walk, Teen Retreat and the FAB women's retreat. I'm especially excited about the memories we'll make together and the opportunities these events give us to learn, connect, and support each other in new ways.

As we look forward to 2026, I'm already getting excited! We're working on some exciting ideas and enhancements to make next year even more impactful and engaging. Whether it's expanding our programming, bringing in new educational voices, or offering more spaces for support and advocacy—our goal is to continue evolving in a way that reflects the needs and dreams of our community members.

Thank you for being part of this journey with us. Whether you've attended one event or many, volunteered your time, shared your story, or simply followed along, YOU are what makes Bleeding Disorders of the Heartland so special.

Here's to the rest of 2025 and an even brighter 2026. I can't wait to see what we'll accomplish together.

Blessings,

.

Brooke Loving

CONTACT BDH

✉ bdh_director@bdheartland.org

☎ (319) 721-1664

BLEEDINGDISORDERS
OF THE HEARTLAND

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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

> 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.

Sign up today to meet a Peer!

sanofi

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BLEEDINGDISORDERS
OF THE HEARTLAND

FOR DETAILED INFORMATION

CONTACT BDH

✉ bdh_director@bdheartland.org

☎ (319) 721-1664

UPCOMING EVENTS FOR 2025

Adult Retreat

AUGUST 16-17th

Educational time for adults to connect. Cedar Rapids, Iowa

UNITE Walk

SEPTEMBER 27th

Step Right Up and Walk for a Cause! Fundraising event! Hiawatha, Iowa

Next Chapter: Teen Retreat

OCTOBER 3-5th

Educational Event for Teens 13-20 yrs of age.
Iowa City, Iowa

FAB - Women’s Regional Event

OCTOBER 10-12th

Ladies consider joining us in Kansas City, Kansas

SCAN ME

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

Quarter 3

UPCOMING INDUSTRY DINNERS

THESE DINNERS ARE FREE FOR MEMBERS TO ATTEND.
IT'S A GREAT WAY TO LEARN AND CONNECT WITH OTHER FAMILIES.

Sanofi Education Lunch

AUGUST 16th	Educational time for adults to connect. Cedar Rapids, Iowa

Sanofi Education Lunch

SEPTEMBER 27th	Cedar Rapids, Iowa

Novo Nordisk Lunch

OCTOBER 5th	Iowa City, Iowa

BCDI Education Dinner

OCTOBER 20th	Moline, Illinois

Super Biologics

NOVEMBER 1st	Des Moines, Iowa

Novo Nordisk Lunch

NOVEMBER 2nd	Des Moines, Iowa

SCAN ME

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

HFA

Hemophilia Federation of America™

HFA SYMPOSIUM 2026 IS HEADING TO NEW ORLEANS, LOUISIANA!

SYMPOSIUM 2026

APRIL 16-19, 2026

Stay tuned—more details coming soon!

PANDA EXPRESS
CHINESE KITCHEN

28%
OF SALES IS DONATED BACK TO BDH

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!

H-Fit

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.

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

Scan for H-Fit.com

Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.

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AUGUST

NATIONAL IMMUNIZATION AWARENESS MONTH

RAISING AWARENESS OF THE VALUE OF VACCINES AND IMMUNIZATION

BLEEDINGDISORDERS
OF THE HEARTLAND

COFFEE

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.

A FOND FAREWELL

Or At Least a “See You Later”

Karla Watkinson has retired from her role as the hemophilia/bleeding disorder coordinator at the HTC. Karla has been a staple in the bleeding disorders community for over 40 years. She has made a meaningful and lasting impact on the community and those lucky enough to work with her. Her dedication to, passion for, and extensive knowledge of bleeding disorders have helped countless people all over the state of Iowa and beyond. Karla has shown compassion, kindness, and empathy to all those she treats across all communities. Namesake Karlas and Karls are running around the Midwest because of the positive impact she has made. She will leave behind a legacy of life-span care and will be sorely missed not only by the Hem/Onc team, but by the hundreds of patients and their families whose lives she improved through her exemplary care.

See you later, Karla!

DEAR FRIENDS AND FAMILY

From the bottom of my heart, I thank you for allowing me to be a part of your lives for the past 35 years. It has been so rewarding. My journey however began 40 years ago, in 1985, when I was a young nurse caring for children with bleeding disorders on the inpatient unit, 3JCW, a school-age/adolescent unit. Unbeknownst to me at the time, I began to dedicate my nursing career caring for those in the bleeding disorder community.

The patients I remember most from my early years, on the inpatient unit, are those who required hospitalization frequently and were very ill. The very first one I took care of was a pre-teen who had something called Acquired Immune Deficiency Syndrome (AIDS) and pneumocystis carinni pneumonia. At the time, everyone was very nervous and really didn't know anything about this new disease, or if it was contagious. I remember telling him, I am not going to take care of you any differently than I would anyone else, and I didn't.

Another boy was in the same situation, however just starting school. His community was outraged and refusing to let him go to school, despite the education the hemophilia staff later provided.

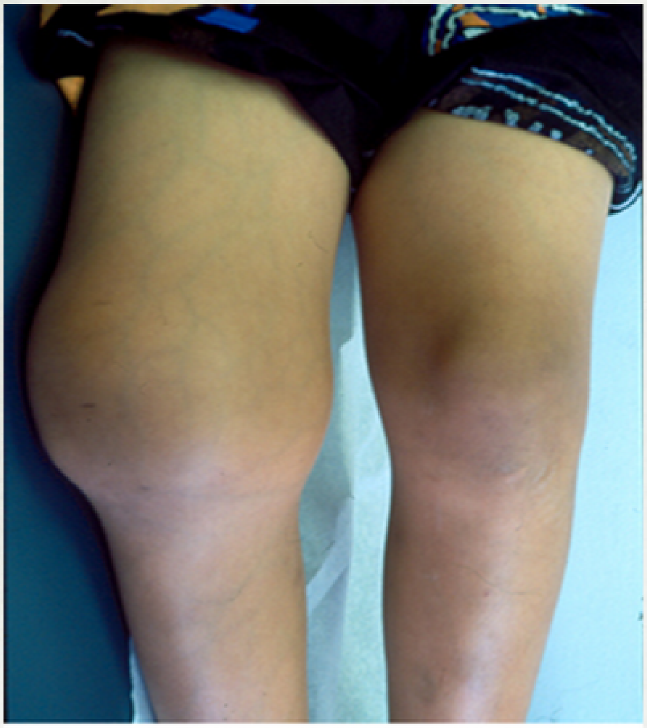
The family dealt with many difficult situations in their community. Due to this, most families, even those not infected, were keeping their bleeding disorder a secret and instructed their child and families members not to talk about it to avoid being ostracized. A few others I remember was a boy with hemophilia who had a ruptured appendix and very ill; another was a dare devil and decided to jump off the roof of his garage; needless to say, he was hurt badly and in the hospital for quite some time.

I interviewed for the hemophilia/bleeding disorder coordinator and was pleasantly surprised when I got the job! Oh my, did I have a lot to learn from our team in a short time; 6 weeks later I was on my own at summer camp. Thankfully, our doctor and director, was there with me telling me to watch the kids guard their joints, limp, but always continuing to participate because they didn't want to stop having fun and some of them were avoiding being treated.

Treatment products at the time were plasma-derived, were a large volume to infuse, and time consuming. It was not uncommon for me to see knees that looked like the picture below during the early years.

Thankfully, as I am sure you'll see in pictures about camp, that is not what we see today!

Over the years with you, we have shared difficult times, tears, and anger about what you and others have lived through. So many lost their lives. However, there has also been joy, such as getting to know each of you, your families and being there for you during the good and difficult times. I feel so blessed to have been a part of this community. Everyone of you holds a special place in my heart and I will remember you always. Thank you so much.



knee bleed

Love,

Karla

Thank you!

New Paper Features Narrative History of Hemophilia Screening in Women

Source: National Bleeding Disorders Website

Historically, women and girls affected by hemophilia have experienced protracted delays in securing an accurate diagnosis and care that takes bleeding disorders into full account. A newly published paper takes a 200+ year view of this history and provides a better understanding of just how this underserved population has slowly but surely garnered greater visibility and awareness – if not equitable care – over the decades.

The paper, “The History of Women and Hemophilia: A Narrative Review of Evolving Beliefs and Testing Practices,” appears in The Journal of Thrombosis and Haemostasis. The authors conducted a broad and narrative literature review focused on women and hemophilia from 1800 to 2023, including but not limited to case reports, larger studies, and review articles. Papers about the history of hemophilia were also included in their search. Their findings helped to identify and characterize nine distinct time periods of hemophilia history. These time periods represented fundamental shifts in beliefs and/or testing practices spurred on by scientific breakthroughs in genetics, screening methods, and other technologies.

The period encompassed in the review begins in the early 19th century with early descriptions of the possible role of women in disease transmission, then takes the reader through the 20th and into the 21st century – these latter decades saw great leaps in carrier detection techniques and enhanced awareness of the considerable challenges facing affected women and girls. That said, while strides have been made, many women continue to experience significant diagnostic delays, untreated bleeding symptoms, and barriers to appropriate care.

The authors suggest that systemic sexism in bleeding disorders management could be a root cause of these challenges. This factor could explain, at least in part, the persistent and widely held belief that aside from a woman’s carrier status, hemophilia only affects men in a substantive way. It could also explain why some healthcare providers tend to dismiss female-specific symptoms as only heavy menstrual bleeding, without consideration for underlying causes.

“Clear progress has been achieved yet recent publications document many ongoing issues such as delayed diagnosis, untreated symptoms, and barriers to care,” concluded the authors. “We owe these patients continued focus, targeted research with patient partnership, reparative knowledge translation efforts focused on unlearning discriminatory principles and learning equity/social justice focused health care principles, concerted consideration of the female patient’s lived experiences from consideration of her childbearing capacity, and monitoring of progress until the knowledge learned is fully translated into practice with real-world outcomes in screening, diagnosis, treatment, and prevention of bleeding.”

This is a fascinating article, recommended for anyone interested in this important if less understood period of hemophilia history. It could also be a useful resource for advocacy and outreach efforts as it encompasses key context to help explain how far we have come and how much farther we still need to go to ensure that these women receive equitable care.

Read the full open access article here to learn more.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MEN'S RETREAT

THANK YOU !

DES MOINES, IOWA

JUNE 1ST

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BLEEDINGDISORDERS
OF THE HEARTLAND

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

Contact Amber at bdh_staffbdheartland.org
or (319)721-3477 to start this process!

SWINGING WITH PURPOSE

2025 FACTORING FAIRWAYS FOR FAMILIES GOLF EVENT TEES UP SUPPORT FOR BLEEDING DISORDERS COMMUNITY

The sun was shining, the greens were flawless, and the spirit of giving was in full swing at the 2025 Factoring Fairways for Families Golf Event, hosted at Toad Valley Golf Course on June 2nd. This annual fundraiser brought together community members, industry partners, and passionate supporters for a memorable day of golf, all in support of families affected with bleeding disorders.

The event was more than just a tournament, it was a celebration of connection, compassion, and community impact. “It’s not just about golf; it’s about building a stronger community around the families we serve. The money raised today helps us provide access to resources, host educational events, and send kids to camp. These are things that truly make a difference in the lives of families living with a bleeding disorder.” Said Brooke Loving, Executive Director of BDH. Teams from across the region came ready to play, network, and help raise crucial funds that directly support education, advocacy, and family support services for those living with bleeding disorders. “We are so grateful to everyone who showed up, whether you played, volunteered, sponsored, or simply cheered us on,” said golf committee chairperson Connor Corcoran “It’s this kind of support that keeps our mission moving forward.”

Plans are already in the works for the 2026 event, with hopes of an even bigger turnout. Until then, Bleeding Disorders of the Heartland remains focused on its mission: to educate, connect and support those affected with bleeding disorders.

Thank you to our Event Sponsors!

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Madison County Abstract Co.
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BCDI Bleeding & Clotting Disorders Institute
ASAP A Specialty Advocate Pharmacy “Where we Always Say A Prayer for you!”
Bleeding Disorders of the Heartland
sanofi
Holmes Murphy

SWINGING WITH PURPOSE

2025 FACTORING FAIRWAYS FOR FAMILIES GOLF EVENT TEES UP SUPPORT FOR BLEEDING DISORDERS COMMUNITY

Thank you to our sponsors for allowing our 'Top Secret Agents' to enjoy a week full of adventure and mystery at the 2025 Bleeding Disorders Summer Camp!

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Polish & Power Zoom

SEPTEMBER 8, 2025
MONDAY @ 6:00 PM

~PROFESSIONAL SKILLS~
WORKPLACE ETIQUETTE, COMMMUNICATION, AND NETWORKING

~RESUME WRITING 101~
CRAFTING A STRONG AND PROFESSIONAL RESUME

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READY FOR THE FUTURE?

Next Chapter: A Weekend Retreat

For teens and young adults ages 13-20

OCTOBER 3RD-5TH, 2025
IOWA CITY, IA

*This program aims to empower teens
with the knowledge and confidence they need to
transition into adulthood,
advocate for themselves, and
prepare for future career opportunities.*

LEARN MORE

Government Relations Update

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

In June, the U.S. Senate began its own work on the “mega-bill” that seeks to use savings from federal health programs to advance the President’s tax, border, and defense policy priorities. The earlier, House-passed version of the legislation made deep cuts to the Medicaid program and destabilizing changes to Marketplace coverage. Senate committees in June took some of these policies even further. As we go to press, it is unclear whether the Senate will be able to pass a bill by its self-imposed deadline (before July 4th). What is clear is that any legislation along the lines of either the House or the Senate bill would cause widespread coverage losses among the American public generally and within the bleeding disorders community.

<u>Medicaid cuts in the budget reconciliation bills</u>

- The House and Senate bills would require all states, by December 31, 2026, to implement work reporting requirements for their Medicaid expansion population (non-disabled adults ages 19-64) – but the Senate bill goes even further than the House version by applying the work reporting requirements to parents of children above the age of 14.

- The Senate bill, like its House counterpart, would apply mandatory cost-sharing requirements to the Medicaid expansion population. Beginning in October 2028, states would be required to impose cost-sharing of up to $35 per item or service, capped at 5% of the individual’s income. Providers could at their option reduce or waive cost-sharing on a case-by-case basis.

- Both bills would require more frequent eligibility checks on Medicaid enrollees, requiring renewals every six months rather than annually, and the Senate bill would repeal (rather than delay, as per the House bill) certain Biden-era rules designed to streamline and facilitate enrollment.

The Senate legislation also goes further than the House bill in targeting Medicaid expansion states with devastating cuts to the mechanisms (i.e., state provider taxes) that states use to fund their share of Medicaid program costs. (Whereas the House bill prohibited all states from establishing new provider taxes, or increasing the rates of existing taxes, the Senate bill reduces provider tax rates in expansion states only.) This provision has caused widespread concern among Senate moderate Republicans.

LEARN MORE

Government Relations Update

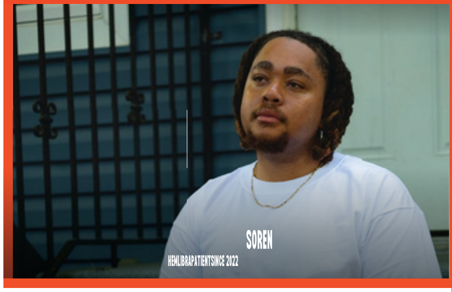
Source: National Bleeding Disorders Website/Released July 6, 2025

Affordable Care Act (ACA) Marketplace cuts in the budget reconciliation bills

The Senate bill, like the House version, contains numerous policies that would make ACA insurance more expensive and less accessible: fewer and shorter enrollment periods, less eligibility for advance premium tax credits (APTCs), more stringent eligibility verification requirements, and almost no pathway to coverage for many groups of lawfully present immigrants.

As on the House side, a notable feature of the Senate bill is something it does NOT do. The bill does NOT extend the enhanced APTCs for ACA insurance, which have been in place since 2022 and are set to expire at the end of 2025. If the enhanced APTCs are not extended, premiums for 2026 ACA health insurance are expected to increase by over 75% on average. Lower-income and older enrollees, as well as people living in non-Medicaid-expansion states, would face the highest premium increases, and nationwide up to 5 million people are projected to lose coverage.

HEMLIBRA: TRUSTED BY THE COMMUNITY FOR 7 YEARS AND COUNTING



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

SCAN TO HEAR STORIES FROM THE COMMUNITY

---

* 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

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 legs
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fastheart 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 moreinformation aboutsideeffects.

What is HEMLIBRA?

HEMLIBRA is a prescriptionmedicine used for routineprophylaxis 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
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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

BLEEDING DISORDERS
OF THE HEARTLAND

WHY WE NEED YOU...

At Bleeding Disorders of the Heartland, every program, camp, retreat, and educational event we provide is made possible because of people like you. Your support directly impacts families across our region—helping them feel connected, educated, and supported as they navigate life with a bleeding disorder.

If you've ever been touched by the work we do, or believe in building strong, supported communities—now is the perfect time to give.

Watch our story and see the impact your gift makes:

Click Here!

Together, we're stronger.
Together, we're changing lives.

The NFRC Features Mental Health Resources for Bleeding Disorders Community

The Resource Round Up is a monthly communication designed to connect the bleeding disorders community with timely, practical, and readily accessible resources.

Source: National Bleeding Disorders Website/May 29, 2025

Because May was Mental Health Awareness Month, the Neil Frick Resource Center (NFRC) is dedicating its most recent Resource Round Up (formerly HANDI Highlights) to supporting mental well-being. This edition approaches this vital topic from a variety of perspectives, with information delivered through multiple formats, including videos, articles, referral resources, and podcasts.

If you are new to the Resource Round Up, it is a monthly communication designed to connect the bleeding disorders community with timely, practical, and readily accessible resources. Previous topics include rare and ultrarare bleeding disorders, joint health, back-to-school issues, pain management, financing secondary education, and more. Access previous editions of the RR.

Visit the NFRC homepage for contact and background information, to access publications and additional resources, and to find answers to frequently asked questions.

Click this button to access this NBDF Article.

LEARN MORE

Click this button to access the most recent Resource Round Up.

LEARN MORE

Click this button to access the NFRC homepage and previous sessions of RR.

LEARN MORE

WHAT AN ADVENTURE!

Regional Men's Event

JULY 11-13, 2025 | JESTER PARK

This year's Regional Men's Event was facilitated by Healthy Trails to Living and brought together men from across Iowa and Nebraska for a powerful weekend of connection, education, and outdoor adventure. Set in the great outdoors, attendees enjoyed cooking over an open fire, kayaking, and a competitive (and hilarious!) game of mini golf.

In between activities, meaningful conversations and educational sessions focused on wellness and life with a bleeding disorder helped deepen bonds and build lasting support. It was a refreshing and impactful reminder that the men in our community are not alone and that their voices matter. The attendees are already making plans with us for the 2026 retreat.

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Access New Healthcare Provider Education on Bone & Mental Health in Women with Bleeding Disorders

This activity explores illustrative case studies, presentations, and thoughtful discussions about the critical need for regular screening for anxiety/depression and bone health in women with inherited bleeding disorders.

Source: National Bleeding Disorders Website/July 15, 2025

BNBDF is delighted to share our latest Collaborative Learning Exchange (CLE), "Assessing the Wellbeing of Women with Bleeding Disorders: Focus on Bone and Mental Health." Recorded live and virtually on June 25th, the activity featured illustrative case studies, presentations, and thoughtful discussions about the critical need for regular screening for anxiety/depression and bone health in women with inherited bleeding disorders.

The dynamic faculty included Meera Chitlur, MD, from the Children's Hospital of Michigan, Divyaaswathi Citla-Sridhar, MD, from the Arkansas Center for Bleeding Disorders at the Arkansas Children's Hospital, and Nathan Connell, MD, MPH, FACP from the Brigham and Women's Faulkner Hospital.

The video is a must watch for U.S. hematologists/physicians, physician assistants, DOs, and nurse practitioners who are seeking timely and readily accessible education on critical topics affecting underserved populations. This free webinar can be found on the NBDF website. Please note that videos from earlier CLE activities focused on women, girls, and people with the propensity to menstruate can also be accessed on this page.

Click here to view the free webinar on NBDF's website.

LEARN MORE

ESCAPE THE ORDINARY. UNLOCK THE EXTRAORDINARY.

AUGUST 16-17, 2025

2025 ADULT RETREAT

BDH is excited to see all who will be attending our 2025 Adult Retreat! There is still time Register today! See you there!

Unite
for Bleeding Disorders

2025 STEP RIGHT UP AND WALK FOR A CAUSE

SCAN TO REGISTER OR CLICK HERE.

SATURDAY, SEPTEMBER 27
8 TO 11 AM

FAY M MEMORIAL CLARK PARK
HIAWATHA, IA

CONTACT US FOR MORE INFORMATION OR SUPPORT:

AMBER SMITH
BDH_STAFF@BDHEARTLAND.ORG
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Start Friday, 5 PM

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CLICK HERE TO REGISTER! →

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Durant, Iowa 52747
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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 ____

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BDH is a nonprofit 501 © 3 organization that exists to enhance the lives of those affected with bleeding disorders.