

THE

DECEMBER 2024

# BLOODLINE

NEWSLETTER

## 2024

REVIEW QUARTER  
3 & 4 EVENTS AND  
OTHER HIGHLIGHTS  
FROM THIS YEAR

## A HOLIDAY NOTE FROM OUR BDH PRESIDENT



**BLEEDINGDISORDERS  
OF THE HEARTLAND**

*WHAT NOT TO MISS*  
**A GLIMPSE  
OF EVENTS  
HAPPENING  
IN 2025**

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



*Happy Holidays*

FROM BLEEDING DISORDERS OF THE  
HEARTLAND BOARD AND STAFF

**QUARTER 4**  
**Winter**  
RECAP

**Step Right Up Walk for a Cause**  
**Sponsor Dinners**  
**FAB Women's Retreat**  
**Adult Retreat**

**BLEEDINGDISORDERS**  
OF THE HEARTLAND

*Coming Soon* 

- Advocacy Day
- Annual Meeting & Much More!

## BDH Staff

### EXECUTIVE DIRECTOR

Brooke Loving

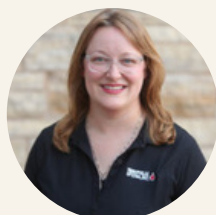
[bdh\\_director@bdheartland.org](mailto:bdh_director@bdheartland.org)



### ADMINISTRATIVE & PROGRAMS ASSISTANT

Amber Smith

[bdh\\_staff@bdheartland.org](mailto:bdh_staff@bdheartland.org)



### Executive Committee

#### **PRESIDENT**

Thomas Savage

#### **VICE PRESIDENT**

Julie McAnally

#### **TREASURER**

Connor Corcoran

#### **SECRETARY**

Meg Gillins

### Board of Directors

(MEMBERS AT LARGE)

Nate Stirgus

Asa Kelley

Dayna Leichty

Nicholas Reuter

### Board of Advisors

Mya Anderson

Becca Markl

## INSIDE THIS ISSUE:

**A Letter from our BDH President**

**Board of Directors Search**

**Event Dates for 2025**

- **Advocacy Day**
- **Annual Meeting**
- **Golf Tournament**
- **Bleeding Disorders Camp**
- **Family Education Day**
- **Retreats**

**Bleeding Disorder Educational Materials**

**HTC Corner**

**Variety Club Grant Announcement**

**Recap of 3rd Quarter Events**

- **Step Right Up Walk for a Cause**
- **FAB Women's Retreat**
- **Fall Dinners & Luncheons**
- **Rural Working Group**
- **CLS & More!**



**BLEEDINGDISORDERS  
OF THE HEARTLAND**

Bleeding Disorders of the Heartland  
103 5th Ave  
Durant, Iowa 52747

Tel: (319) 721-1664

Email us at: [bdh\\_director@bdheartland.org](mailto:bdh_director@bdheartland.org)



*From the Desk of*  
*Board President Thomas Savage*

**Season's Greetings from Bleeding Disorders of the Heartland!**

Dear Community Members, Friends and Family-

As the holiday season unfolds, I want to extend our warmest wishes to you and your loved ones. Whether you're celebrating Christmas, Hanukkah, Kwanzaa, Yule, or simply cherishing the joy of togetherness, may this season bring you peace, happiness, and good health.

This time of year, reminds me of how grateful we are to have such a supportive and inspiring community. Your strength, kindness, resilience and willingness to be there for each other continue to amaze me!

As we look ahead to 2025, I am excited about the opportunities to reconnect, learn, and grow together. Thank you for being an essential part of our community, and we can't wait to see what the future holds. From myself and the rest of the board and staff at Bleeding Disorders of the Heartland, Happy Holidays and best wishes for a wonderful new year.

*Thomas Savage*





# STILL CHRISTMAS SHOPPING?

Do you want to make your shopping even more meaningful this year? When you purchase gift cards through this special fundraising platform, a portion of the proceeds will come back to BDH!

It's an amazing way to give back while still crossing off your gift list. There is no extra cost to you, it's just one simple way to support what we do. This will be available all year long.

How it works:

1. Visit this link: <https://www.raiseright.com/enroll/3XJTFTQBRLZZ>
2. Shop for gift cards to your favorite stores.
3. A portion of the proceeds benefits our organization—helping us continue our mission

Get your shopping done, give back, and spread some holiday cheer!



# 2025 BDH Events

Visit [www.bdheartland.org](http://www.bdheartland.org) for the latest updates and registration information.

**FEBRUARY  
4-5TH**

**Advocacy Day at the Iowa State Capital  
Des Moines, Iowa**

**MARCH  
14-16TH**

**Annual Meeting  
Des Moines, Iowa**

**JUNE  
2ND**

**Golf Tournament  
Toad Valley Golf Course**

**JUNE  
15-20TH**

**Bleeding Disorders Camp  
Camp Tanager, Mt Vernon, IA**

**JULY  
26TH**

**Family Education Day  
Lost Island, Waterloo, Iowa**

**AUGUST  
16-17TH**

**Adult Retreat, TBD**

**SEPTEMBER  
27TH**

**BDH Step Right Up & Unite Walk  
Clark Park, Hiawatha, IA**



Scan the QR code for more info or  
to register for specific events on our  
website!



# Bleeding Disorders of the Heartland Industry Dinners

Upcoming

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February

4

Sanofi

Advocacy Dinner  
Urbandale, Iowa

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March

25

Genentech

Educational Dinner  
Iowa City, Iowa

---

July

12

CSL Behring

Mens Educational Dinner  
Des Moines, Iowa

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These are the dinners scheduled so far. More will be added and will be updated on the website as they are scheduled for 2025. Register on the website to attend.

FREE MEALS WITH GREAT COMPANY AND VALUABLE INFORMATION

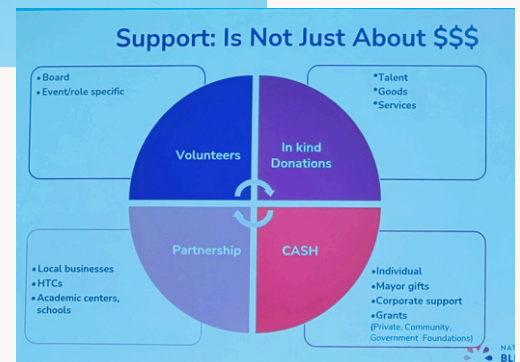
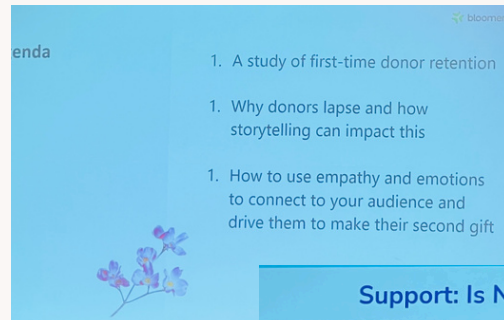
[www.bdheartland.org](http://www.bdheartland.org)

# NATIONAL CONFERENCES

## BROOKE LOVING

### NBDF CHAPTER LEADERSHIP

I attended the Chapter Leadership Seminar in San Antonio, where I was joined by Executive Directors and leadership from chapters across the country to exchange ideas and learn best practices. Throughout the seminar, I gained invaluable knowledge from peers, discovering innovative strategies to strengthen chapters and enhance their impact.



The training sessions were extensive, and among my favorites were those focused on storytelling and creating a meaningful impact.



The energy in the room was palpable, with each person bringing their unique experiences and perspectives to the table. It was inspiring to see such dedication and passion, as everyone worked collaboratively to drive positive change and strengthen their communities. The camaraderie and support among the leaders created an environment ripe for innovation, where ideas flourished and solutions to challenges were crafted with creativity and determination.

I had a great time at this year's Chapter Leadership Summit. There were a lot of meaningful connections made, and I am excited to bring the ideas I learned back to BDH.

-Thomas Savage, BDH President

I also took on an active role at the conference by presenting at a session. Sharing my own insights, experiences, and contributing to the collective wisdom of the group.



This opportunity empowered me to grow as a leader, expand my network, and bring fresh ideas back to my own chapter, furthering its success and influence in the community.



# NATIONAL CONFERENCES

## BROOKE LOVING

### PACT TRAINING IN NEW JERSEY



We had executive directors, chapter leaders and advocacy leaders at the PACT Training. The information learned at this training will be very helpful for our upcoming Advocacy Day in February at the State Capitol Building in Des Moines, Iowa.

I attended PACT training in New Jersey, where I gained valuable insights into advocacy efforts for 2025 from leaders across the nation. I was surrounded by passionate individuals committed to making a difference, I am learning how to use my voice to create change and support impactful initiatives. Through discussions, workshops, and presentations, I am developing the skills to advocate for causes close to my heart, preparing to play an important role in shaping the future. This experience is not only empowering me with knowledge but also connecting me to a nationwide network of advocates dedicated to driving positive change for the bleeding disorders community. -Brooke

### BDH Secretary and affected member Meg attended the Pact Training with me.



It was great to be surrounded by people from all over the country to learn alongside them. Although the politics and insurance information was a heavy subject. It was presented in a way that we could understand and discuss. -Meg



# HTC CORNER

After a presentation at the ATHN National Summit by Iowa Hemophilia and Thrombosis Center data manager Alison Currie, our HTC providers and other team members have been receiving accolades and questions about the different services offered here. At our HTC, we are driven by our mission to provide comprehensive, patient-centered care for individuals with hemophilia and related bleeding disorders. In alignment with UI Healthcare's We Care values, our HTC strives to enhance the quality of life for patients through advanced medical care, research, education, and community support. As such, we offer a variety of services not offered elsewhere in the state, as well as unique services not offered any where else in the nation.

In this issue, social worker Ellie Van Holland talks about our program for transitioning patients from pediatric to adult care within our healthcare system. In following issues, we will introduce other services, subspecialties, and members of our team.



*Alison Currie*



*Ellie Van Holland*



PART OF THE  
TEAM &  
VOLUNTEERS AT  
AMISH OUTREACH

# HTC

## TRANSITIONING TO ADULT HEALTHCARE: WHAT YOU NEED TO KNOW

At the University of Iowa, we are committed to helping patients prepare for the transition from pediatrics to adult healthcare. For some patients and families, this transition is no big deal, and for others, transitioning to adult healthcare seems intimidating and overwhelming. Below are some answers you may have to questions about this process at the University of Iowa.

### 01 WHAT DOES IT MEAN TO TRANSITION TO ADULT HEALTHCARE?

When you transition to adult healthcare, the responsibility for taking care of your health falls primarily on you (instead of parents/caregivers). You will need to have some basic skills and knowledge to navigate the healthcare system and keep yourself healthy.

At the University of Iowa, when you transition to adult care, most care team members remain the same including nurse coordinators, social workers, physical therapists and pharmacists. However, you will now see a different doctor who specializes in adult care and your clinic visits will be in a different clinic location.

### 02 WHO IS INVOLVED IN MY TRANSITION PROCESS?

Caregivers, your care team, and you as the patient all work together to make this transition possible. Caregivers will help by involving you in making decisions, teaching you about your medical history, and giving you opportunities to practice new skills. Your care team will offer information and resources to help you make decisions about your health and help you set goals that build independence. You are responsible for practicing skills, learning about your health, and asking for help when you need it.

### 03 WHEN DOES THE TRANSITION HAPPEN?

Typically, most patients transition to adult healthcare before the age of 22. When patients turn 12, we introduce the idea of transition and start discussing it regularly during your comprehensive clinic visits.

### 04 WHERE ARE ADULT CLINICS LOCATED?

Adult clinics are held in the Main Campus hospital in the Clinical Cancer Center, lower level of the Pomerantz Family Pavilion. Don't hesitate to call the clinic if you need help with directions.

### 05 WHY IS PREPARING FOR TRANSITION IMPORTANT?

Preparing for transition is important because it is a change from how you were previously taking care of your health. You need time to practice and learn new information and skills so you can successfully take care of your health on your own.

### 06 HOW WILL I KNOW WHEN I'M READY TO TRANSITION?

One of the ways we assess when you're ready to transition to adult healthcare is by using a transition readiness assessment. At the University of Iowa, we have an assessment that covers a wide range of important topics like healthy habits, how to schedule appointments, keep medical records, assess and manage risks, maintain insurance, manage medications, and develop an emergency plan. Throughout your teenage years we will discuss these topics with you. At times you may be asked to complete an assessment so we can track your progress and help you set goals. As you reach these goals, you will know you're making progress and ready to successfully make the transition.

And remember...just because you transition to adult health care doesn't mean you're all alone! Our staff is always happy to answer any questions you have, and your personal support system can be a great place to go for help as well.

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

2025

# ADVOCACY DAY

## JOIN US AT THE CAPITOL

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

**February 4th Dinner/Training 6-9pm in Urbandale, Iowa**  
**February 5th 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 Lawmakers

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.



Contact Us  
319--721-1664



Visit Our Website  
[www.bdheartland.org](http://www.bdheartland.org)



Our Location  
103 5th Ave,  
Durant, Iowa 52747



# BDH ANNUAL

MARCH 14-16  
DES MOINES, IA

# MEETING



Register online today!  
<https://bdheartland.org/events>

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

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

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 2024 Bleeding Disorders of the Heartland Bleeding Disorders Camp.

“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 underprivileged, at-risk, critically ill, or living with special needs. Grant funding is provided to programs and initiatives that directly impact the well-being of children in our community.

For more information on Variety grants and programs please visit [varietyiowa.com](http://varietyiowa.com).

### **Contact:**

Brooke Loving

Bleeding Disorders of the Heartland

319-721-1664

[bdh\\_director@bdheartland.org](mailto:bdh_director@bdheartland.org)





# Panda Express ongoing Fundraiser



**28%**  
OF SALES  
ARE  
DONATED  
BACK  
TO BDH!

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!



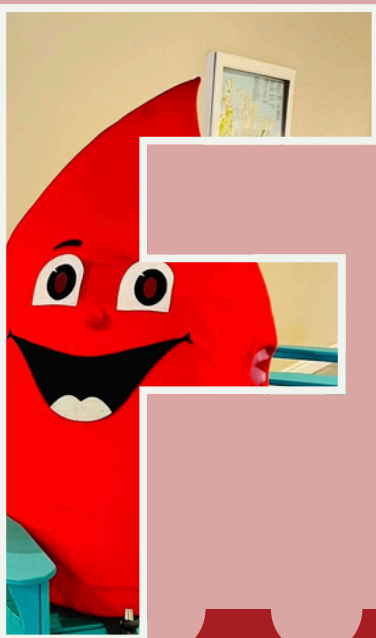
We had a FABulous 2024 FAB. We enjoyed great company, tasty food, and FABulous educational sessions! We Can't wait for this event in 2025!

Thank you  
**octapharma**  
for the opportunity for this FABulous event!



FAB Women's Retreat





## Medicare and Bleeding Disorders: What you Need to Know

**What is Medicare?** Medicare is a federal health insurance program for individuals aged 65 years and older and certain younger people who qualify due to disability (learn more on this below).

Medicare is typically referred to by its different parts – Part A, Part B, Part C, and Part D.

- **Part A is for hospital insurance** and helps cover things like inpatient hospital stays, home health care, and care in skilled nursing facilities.
- **Part B is for medical insurance** and helps cover things like doctors' services, outpatient care, preventive services and clotting factor and other bleeding disorders therapies.
- **Part C, also known as Medicare Advantage**, is an alternative to Traditional Medicare run by private health insurers.
- **Part D covers prescription drugs**, like medications you might take for other conditions besides your bleeding disorder. \*See below for changes coming to Part D in 2025!

[Learn more.](#)

### Types of Coverage

Traditional Medicare (or Original Medicare)	Medicare Advantage (Part C)
Includes Medicare Part A and Part B.	An alternative to Traditional Medicare. MA plans are run by private health insurers that follow certain rules and are then paid by Medicare to provide services.
Part D, prescription drug coverage, is optional coverage and must be added separately.	MA plans are often cheaper than Traditional Medicare, but services and in-network providers are more limited, and you may face additional barriers like prior authorization or step therapy.
You can use any doctor or hospital that takes Medicare, anywhere in the U.S.	You cannot purchase Medigap (supplement insurance) under Medicare Advantage.
You can purchase Medicare supplement insurance (Medigap) to help cover out-of-pocket costs, such as copayments, coinsurance, and deductibles	

Learn more about the [differences between Traditional Medicare and Medicare Advantage.](#)

### Enrollment Basics

An individual becomes eligible for Medicare at age 65 (\*see below for more information on qualifying for Medicare due to disability). If you do not have employer-sponsored insurance, you should enroll in Medicare at age 65 to avoid [late enrollment penalties](#). If at age 65 you still have group coverage through your job or your spouse's job, you can wait to enroll in Part B. Medicare Open Enrollment is October 15 – December 7 every year! [Learn more.](#)

### What will Medicare cost me?

Medicare is not free. Your costs may include premiums, a deductible, coinsurance and copayments. Out-of-pocket costs under Medicare will vary depending if you are covered under Traditional Medicare vs. Medicare Advantage, or based on the providers you see, and the services you receive. Some costs, such as Part B and Part D premiums, may depend on how much income you make each year. For Part B, you usually pay 20% of the cost for each Medicare-covered service after you've paid your deductible. Because there is no out-of-pocket maximum under Traditional Medicare, some form of supplemental coverage (Medigap, an employer plan, or Medicaid) is essential to help cover out-of-pocket costs, such as copayment, coinsurance and deductibles. Learn more about Medigap below. [Read more about what Medicare costs.](#)

## Medicare Supplement Insurance or Medigap

Medicare supplement insurance or Medigap is extra insurance you can buy from a private health insurance company to help cover out-of-pocket costs (copays, coinsurance, deductibles) under Traditional Medicare. You cannot buy Medigap if you have a Medicare Advantage plan. The Medigap Open Enrollment Period starts the first month you have Medicare Part B (and you are 65 or older) and lasts for 6 months. It is important to enroll in Medigap during this time! After this time period, Medigap plans are able to charge more for things like pre-existing conditions. [Learn more about Medigap.](#)

## Qualifying for Medicare due to Disability

Sometimes individuals living with bleeding disorders qualify for Medicare due to disability, meaning their bleeding disorder makes it difficult to perform daily tasks or to maintain a job. To access Medicare because of disability, an individual must first meet certain criteria outlined by the Social Security Administration (SSA). If you qualify, there is then a five-month waiting period prior to accessing Social Security Disability Insurance (SSDI), monthly payments, and then a subsequent 24-month waiting period to then access Medicare. [Learn more.](#)

\*It is important to note that accessing supplemental insurance, or Medigap, can be harder when you qualify for Medicare due to disability. [Availability of Medigap plans will vary by state and your age.](#)

## What is Medicare Part D?

- Part D is optional coverage for prescription drugs and must be added separately under Traditional Medicare.
- Under Medicare Advantage, all plans (except private fee-for-service plans) must offer an option that includes the Part D drug benefit, but not all MA plans cover prescription drugs.
- If you are choosing a Part D plan, it is very important to review plan formularies to make sure that the specific drugs you take are covered. Plans will vary in which drugs they cover and how much they charge you for out-of-pocket costs. Check out these [tips for choosing Medicare prescription drug coverage.](#)

## What's New in 2025?

There are a number of changes coming to Medicare Part D – also known as the Medicare Prescription Drug Plan – for 2025. And while treatments for bleeding disorders are covered under Medicare Part B, often individuals are using Part D drugs to address other chronic illnesses, including treatments for HIV/AIDS. Here's what you need to know!

**CAP ON OUT-OF-POCKET COSTS:** Out-of-pocket costs under Part D will be capped: people will not pay more than \$2,000 in out-of-pocket costs for Medicare Part D covered drugs in 2025.

**MEDICARE PRESCRIPTION PAYMENT PLAN:** Beginning in 2025, people will have the option to join the Medicare Prescription Payment Plan (MPPP) which will allow them to pay out-of-pocket drug costs under Part D in monthly installments over the course of the plan year, rather than at the pharmacy when they are incurred.

- Any individual enrolled in a Medicare Part D plan is eligible to enroll.
- Individuals must opt-into the MPPP and can choose to opt-out at any time.
- The first opportunity to enroll will be during the Medicare Open Enrollment Period (October 15 – December 7, 2024) but individuals can opt-in **anytime** throughout the plan year.
- Find information on the MPPP on Part D websites and in annual Medicare mailings.
- The MPPP is not right for everyone – it makes the most sense for individuals with high out-of-pocket costs early in the plan year. Use this [tool](#) to figure out if the MPPP is right for you.

Check out the CMS [website](#) and [factsheet](#) to learn more about this new program. The [factsheet is also available in Spanish.](#)

# Company- 'Alhemo' receives positive opinion from EMA for approval as first prophylactic treatment for hemophilia A/B

*First prophylactic treatment for hemophilia A/B*



**EUROPA PRESS**  
OCT 31, 2024

MADRID 31 Oct. (EUROPA PRESS) - Novo Nordisk has announced that concizumab, registered as 'Alhemo', has received a positive opinion from the Committee for Medicinal Products for Human Use (CHMP) of the European Medicines Agency (EMA), recommending its approval as the first daily subcutaneous prophylactic treatment (continuous treatment to prevent bleeding) for people aged 12 years or older with haemophilia A or B with inhibitors. Hemophilia is a rare and serious bleeding disorder affecting about 1 in 10,000 people.

It is caused by a deficiency or dysfunction of the proteins essential for blood clotting, namely factor VIII (hemophilia A, HA) and factor IX (hemophilia B, HB), which leads to a reduction in thrombin generation.

Hemophilia is usually treated by replacing the missing clotting factor through intravenous infusions, also known as replacement therapy.

However, sometimes the body can produce inhibitors as an immune response to the clotting factors in the therapy, rendering the replacement therapy ineffective and limiting treatment options. Currently, it is estimated that up to 30% of people with severe hemophilia A develop inhibitors, and 5-10% of those with severe hemophilia B also develop inhibitors.

This monoclonal antibody works by inhibiting the tissue factor pathway (TFPI) and, if approved by the European Commission, will be the first daily subcutaneous prophylactic treatment for people with haemophilia A or B with inhibitors<sup>5</sup>. This medicine is designed to block a protein called TFPI, which is a natural blood anticoagulant. By blocking TFPI, it ensures thrombin production and prevents bleeding, even when other coagulation factors are missing or deficient. This is particularly important, as it means that this anti-TFPI monoclonal antibody allows thrombin generation even in the presence of inhibitors<sup>6</sup>.

"The CHMP positive opinion for Alhemo is an important milestone for patients. If approved, it would be an important addition to our growing portfolio of hemophilia treatments, offering the potential for daily prophylaxis to prevent bleeding in people with hemophilia who have developed the complication of inhibitors," said Stephanie Seremetis, Global Medical Director for Hemophilia at Novo Nordisk.

“ if approved by the European Commission, will be the first daily subcutaneous prophylactic treatment for people with haemophilia A or B with inhibitors<sup>5</sup>. ”



# Bleeding Disorders of the Heartland is now accepting Scholarship Applications

**Deadline to apply is February 1, 2025**

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 2025 Annual Meeting -March 15th in Des Moines, Iowa.

**APPLY NOW**



**Our Contact**  
(319) -721-1664



**Our Website**  
[www.bdheartland.org](http://www.bdheartland.org)

# 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.

**GROUND  
AND  
WHOLE  
BEAN**

Get your coffee today!

**\$12  
80Z**



**\$18  
120Z**





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## Open Enrollment for Plan Year 2025 Health Insurance

Open enrollment is the annual period when people can enroll in a new health plan or renew their existing health plan if it still serves their needs. Open enrollment dates vary, depending on whether people get their coverage from their employer, from the Affordable Care Act (ACA) Marketplace, or from another source – but for many people, open enrollment takes place annually in the fall. (Enrollment in [Medicaid](#) is available 365 days per year, based on need, income, and other state-defined eligibility criteria.)

### Some key points to note for the Fall 2024 Open Enrollment Period (OEP) in the ACA Marketplace

- **When is open enrollment?** The OEP for 2025 health insurance runs from at least November 1, 2024, to January 15, 2025, in almost every state; however, people must generally enroll by December 15 for coverage that begins January 1, 2025.
  - Idaho is the only state with an OEP that begins and ends earlier (Idaho's OEP is currently scheduled for October 15 through December 15, though [those dates may change](#)).
  - A few states (CA, DC, MA, NJ, NY, RI) have extended their OEPs beyond January 15.
  - Individuals and families with incomes [below 150% of the Federal Poverty Level](#) (less than \$22,590 for an individual, or \$38,730 for a family of 3) can enroll at any time through a special enrollment period in most states.
- **What should I think about when shopping for a plan?** Check if your health care providers and medications are covered. Weigh the trade-off between monthly premiums and the costs you will have to pay from your own pocket when you receive care – don't decide based on premiums alone!
  - **Start your search at [www.healthcare.gov](http://www.healthcare.gov).** The ACA Marketplaces carry *only* ACA-compliant health plans, with comprehensive benefits – so Marketplace shoppers are assured they won't end up in "junk" plans. If anyone in the shopper's household qualifies for Medicaid or CHIP coverage, the Marketplace will facilitate enrollment in those programs.
- **How much will my plan cost, and how can I get help affording it?**
  - Enhanced premium subsidies (temporarily raised in 2021) are still available. **About 80% of people can expect to find a plan with premiums of \$10/month or less.** Premium subsidies are available only for plans purchased through the Marketplace.
  - Most Marketplaces offer four categories of plans – Bronze, Silver, Gold and Platinum. **Generally, plans with lower monthly premiums will require enrollees to pay higher out-of-pocket costs for care and will include narrower networks of providers.** Subsidies that make deductibles and copays more affordable for certain income-eligible individuals ("cost-sharing reductions") are only available in connection with qualified Silver plans.
  - Plans and plan costs change every year. Consumers should check if their old plan is still the best fit for them rather than automatically renewing.
- **Will I be able to use copay assistance to afford my medications?** To date, 21 states have passed laws prohibiting state-regulated plans from implementing copay accumulator adjusters. In addition, under the terms of a 2023 court ruling, health plans [may not apply copay accumulator adjusters](#) to brand name drugs that lack a medically appropriate generic alternative. Unfortunately, a [recent survey](#) shows that many plans continue to include copay accumulator adjusters even when prohibited by law. Insurance shoppers should carefully read their plans for the presence of copay accumulator language and, if an accumulator is present,



should follow up with their health plan, hemophilia treatment center, patient organization, or state insurance commissioner. They can find draft talking points for conversations with their health plans [here](#).

- **New eligibility category.** This fall, for the first time, DACA recipients will be eligible for coverage and premium subsidies through the Marketplace.

### Some state-specific highlights:

- **Programs for people without legal immigration status.** [Colorado](#) and [Washington](#) have special programs for certain low-income individuals who don't currently qualify for federal premium tax credits to apply for subsidized coverage regardless of immigration status – but these programs have limited enrollment caps and tend to reach capacity within days if not hours of opening.
- **Basic Health Programs.** BHPs are a form of affordable coverage for people whose income is just above the Medicaid eligibility level, and for legal immigrants who aren't eligible for Medicaid because of the 5-year waiting program. Starting in July 2024, Oregon started operating a BHP — [OHP Bridge](#) — joining New York and Minnesota ([MinnesotaCare](#)) as just the third state in the country to offer a BHP. Coverage under the OHP Bridge program is available to adults under age 65 whose household income is between 138% and 200% of the FPL. Coverage under New York's BHP (the [Essential Plan](#)) is now available to enrollees with incomes up to 250% of the FPL.
- **Additional state subsidies.** The following states offer additional state subsidies that “stack” on top of the federal subsidies:
  - Additional state-provided **premium subsidies** are available for certain population or income groups:
    - [CT](#) (adults with incomes up to 175% of FPL)
    - [MD](#) (young adults up to age 37)
    - [MA](#) (enrollees with incomes up to 500% FPL)
    - [NJ](#) (enrollees with incomes up to 600% FPL)
    - [NM](#) (enrollees with incomes up to 400% FPL)
    - [NY](#) (enrollees with incomes up to 250% FPL now eligible for NY Essential Plan)
    - [VT](#) (enrollees with incomes up to 300% FPL)
    - [WA](#) (enrollees with incomes up to 250% FPL)
  - Additional state-provided **cost-sharing subsidies** are available for certain population or income groups:
    - [CA](#) (all Covered California enrollees qualify)
    - [CO](#) (available to enrollees up to 200% FPL)
    - [CT](#) (adults with income up to 175% of FPL)
    - [MA](#) (enrollees with incomes up to 500% FPL)
    - [NM](#) (enrollees with incomes up to 400% FPL)
    - [NY](#) (enrollees with income up to 400% FPL; diabetes/pregnancy/postpartum)
    - [VT](#) (enrollees with incomes up to 300% FPL)

# Bleeding Disorders Conference, 2024

Attending the Bleeding Disorders Conference by NBDF this year was such an honor. I was able to attend both chapter staff track sessions and consumer sessions. My husband, Tony went to the consumer track and Logan was on the kids track. We spent our days learning about the newest information about bleeding disorders treatment, advocacy work and so much more. It was wonderful to connect with other bleeding disorder families from across the country. We left the conference feeling inspired and ready to get to work for our own local chapter! “

- Amber Smith

BDH Programs and Administrative Assistant

Learn, Grow,  
Connect at the  
Bleeding Disorders  
Conference!



**SAVE THE DATE:**

**BUFF CITY SOAP  
COMMUNITY EVENT**

SPONSORED BY:

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BLEEDINGDISORDERS  
OF THE HEARTLAND

**JANUARY 19, 2025 | 5:30-7:30PM  
CEDAR RAPIDS, IOWA**

***Bleeding Disorders***  
***Virtual Rural  
Needs Action  
Summit***

***Tuesday • November 12th, 2024***

THIS VIRTUAL SUMMIT FEATURED SUBJECT MATTER EXPERTS DISCUSSING A RANGE OF ISSUES RELATED TO BARRIERS TO REACHING, RECEIVING, AND CONTINUING TREATMENT/CARE FOR A BLEEDING DISORDER. THE EXPERTS WELCOMED PARTICIPANT ENGAGEMENT THROUGH QUESTIONS AND COMMENTS USING THE VIRTUAL PLATFORM.

**Follow the links below to view the sessions.**

**2024 Virtual Rural Needs Summit**

**Session One**

**<https://www.youtube.com/watch?v=ydpnevNcls4>**

**Session Two**

**<https://www.youtube.com/watch?v=ZoS5g-Mw-kk> 2024**

**Session Three**

**[https://www.youtube.com/watch?v=OeHLza\\_6Bbc](https://www.youtube.com/watch?v=OeHLza_6Bbc)**

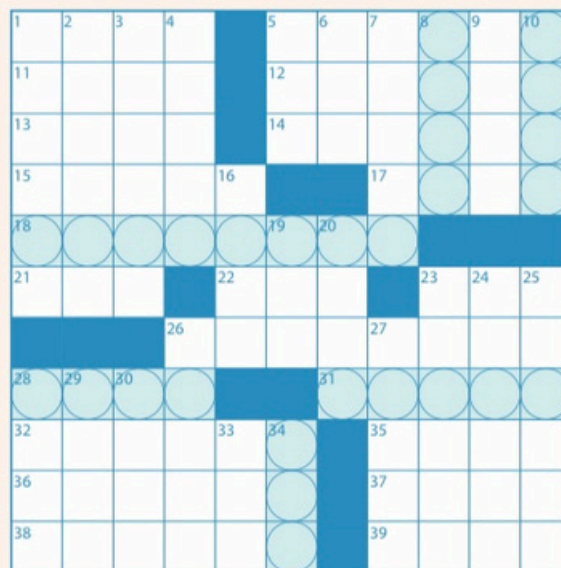


CAN YOU SOLVE

# FOR A DIFFERENT HEMOPHILIA A

TREATMENT?

Test your HEMLIBRA knowledge



## ACROSS

1. Wine barrel
5. Deep fissures
11. Mideast gulf port
12. District
13. Ripped
14. Familiar with
15. Mean
17. Roost
18. The #1 prescribed prophylaxis for people with hemophilia A without factor VIII inhibitors\*

\*According to IQVIA claims data (various insurance plan types) from September 2021–August 2022 (refreshed November 2022), accounting for prophylaxis use in the US.

21. Calendar divs.
22. Regret
23. Banquet hosts (abbr.)
26. International travel necessity
28. Check out the \_\_\_\_\_ treated bleeds data with HEMLIBRA
31. Number of dosing options HEMLIBRA offers

32. Small hole in lace cloth
35. Central Plains tribe
36. Melodic
37. Towering
38. Reduce
39. Spanish cheers

## DOWN

1. Memorable, as an earworm
2. Devotee
3. Medical fluids
4. Prepare to propose, perhaps
5. PC's "brain"
6. Owns
7. Concert venue
8. See Medication Guide or talk to your doctor about potential \_\_\_\_\_ effects
9. Winter hrs. in Denver and El Paso
10. HEMLIBRA is the only prophylactic treatment offered this way under the skin

16. Pre-Euro currency in Italy
19. Subway alternative
20. Relax
23. Human
24. New Orleans cuisine
25. Mentally prepares
26. Collared shirts
27. Instagram post
28. Ardent enthusiasm
29. Brontë heroine Jane
30. Old Portuguese coins
33. Opposite of WNW
34. More than \_\_\_\_\_ thousand patients have been treated with HEMLIBRA worldwide<sup>†</sup>

<sup>†</sup> Number of people with hemophilia A treated as of October 2021.

## SOLUTIONS

Across: 1. cask, 5. chavros, 11. Aden, 12. parish, 13. tore, 14. used to, 15. cruel, 17. nest, 18. HEMLIBRA, 21. yrs, 22. rue, 23. M.Cs, 26. passport, 28. zero, 31. three, 32. eyelid, 35. Croc, 36. aniose, 37. tall, 38. lessen, 39. oles  
Down: 1. cask, 2. advice, 3. summs, 4. kneel, 5. CPU, 6. has, 7. arena, 8. side, 9. MST, 10. shot, 16. lira, 19. bus, 20. nest, 23. mortal, 24. Creole, 25. steels, 26. polos, 27. photo, 28. zeal, 29. Eye, 30. Res, 33. ESE, 34. ten

Discover more at [HEMLIBRA.com/answers](https://www.hemlibra.com/answers)

## 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

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 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 (eg, increase in bleeds).**

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

**What is HEMLIBRA?**

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

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

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

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

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

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

**How should I use HEMLIBRA?**

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

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

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

**What are the possible side effects of HEMLIBRA?**

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

**The most common side effects of HEMLIBRA include:**

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

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

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

**How should I store HEMLIBRA?**

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

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

**General information about the safe and effective use of HEMLIBRA.**

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

**What are the ingredients in HEMLIBRA?**

**Active ingredient:** emicizumab-kxwh

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

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

HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan  
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For more information, go to [www.HEMLIBRA.com](http://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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# STEP RIGHT UP AND WALK FOR A CAUSE 2024





# 2024 Walk Hiawatha, IA



# CSL Behring

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bleeding disorders  
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**Mike Appleseth**

**Manager, Coagulation Products**

**641-757-0499 / [mike.appleseth@cslbehring.com](mailto:mike.appleseth@cslbehring.com)**

**Serving Iowa, Nebraska, Kansas and Missouri**



# 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.**



Scan for H-Fit.com

**Sign up with Novo Nordisk and register at [H-Fit.com](https://www.h-fit.com) to get *free access* to the H-Fit video library.**



**ADVATE**  
[Antihemophilic Factor  
(Recombinant)]

**ADYNOVATE**  
[Antihemophilic Factor  
(Recombinant), PEGylated]

# Your life is your canvas

Whether it's **ADVATE** or **ADYNOVATE**, look to the **TAKEDA** family to be there with you wherever life takes you.

Keep Painting Your Story



Patient Portrayal



Get access to  
**Takeda Patient Support**



  
antihemophilic factor  
(recombinant) PEGylated-aucI



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Scan this QR code to learn  
more about the data at  
**[JiviExtensionStudy.com](https://www.jiviestensionstudy.com)**

**ALTUVIIIIO**<sup>®</sup>  
Antihemophilic Factor (Recombinant),  
Fc-VWF-XTEN Fusion Protein-ehtI



Brian  
Real ALTUVIIIIO<sup>®</sup> patient

# SWITCH IT UP like Brian did!

Brian is a promotional speaker compensated by Sanofi.

Sanofi Community Relations and Education (CoRe) Managers are dedicated professionals who can provide personalized education about ALTUVIIIIO, and point you toward helpful support and resources.



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# Adult Retreat 2024

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Simplifying Complex Care

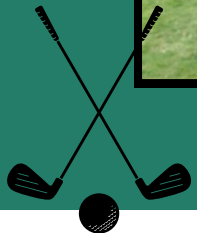
**HEMA**  
Biologics



♥ **CVS specialty™**

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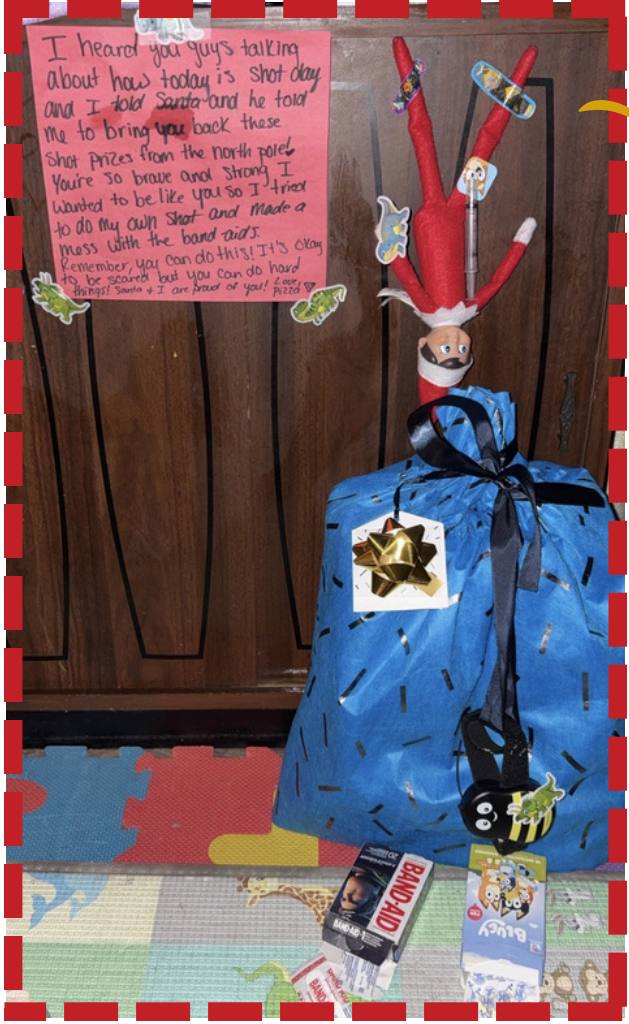




TWO YOUNG ATHLETES ATTENDED THE JUNIOR NATIONAL CHAMPIONSHIPS IN HENDERSON, NEVADA, WHERE THEY CONNECTED AND LEARNED SKILLS WITH THEIR PEERS FROM ACROSS THE COUNTRY. THESE RISING STARS WERE EXCITED TO SHOWCASE THEIR HARD-EARNED SKILLS AND ENJOYED MAKING FRIENDS WITH OTHER AFFECTED KIDS. FOR THESE TWO KIDS, THE CHAMPIONSHIP WAS NOT JUST A COMPETITION, BUT A DREAM IN THE MAKING, IT WAS AN OPPORTUNITY OF A LIFETIME. THANK YOU CSL BEHRING FOR THE OPPORTUNITY TO ATTEND.



ho ho ho!



# holiday CHEER CORNER

Check out what Landyns elf, "Pizza" did for his shot day for Hemlibra!

That's support we love and can get behind!  
Great work, Pizza, and great job, Landyn!



Industry Luncheons & Dinners



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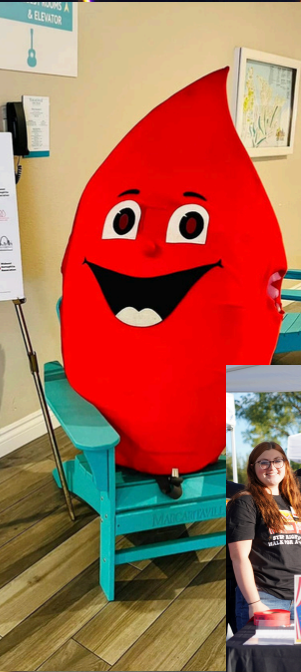
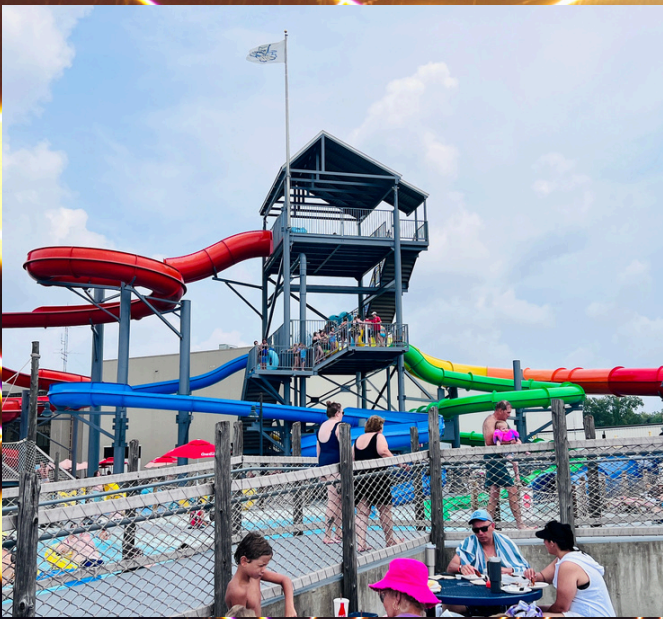


**Optum**

**CarePartners**  
Specialty Infusion

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## CHECK OUT MORE INFO WITH THESE EDUCATIONAL ARTICLES BELOW...

### ➔ History of Bleeding Disorders



Here you'll find information on the first documented inherited bleeding disorders dating back to the 2nd century and how things have changed since then!

<https://www.hemophiliafed.org/history-of-bleeding-disorders/>



### ➔ HFA Resources



On this page you'll have access to clinical trials, insurance, employee and financial assistance and further support for all things bleeding disorder related.

<https://www.hemophiliafed.org/resources/>

### ➔ Advocacy Do's and Don'ts



Are you looking to educate family or friends about our bleeding disorders or this amazing community of people?

Here you'll find an awesome list of do's and don'ts to make sure your voice is heard. Do you want to see policy changes or want to contribute to making changes within the industry? Find out how with tips and tricks and then let your voice be heard!

<https://www.bleeding.org/advocacy/how-you-can-take-action/advocacy-dos-and-donts>



## MANAGING BLEEDS: TYPES, SYMPTOMS AND MORE



Prevention is best, but sometimes that's not possible. It's great to have reference points to look at for help when needed, because when a bleed happens, you'll need to act fast.

On this page you'll discover numerous types of bleeds along with information on how or when to best treat the bleed.

### Types of Bleeds:

- Head
- Eye
- Nose
- Mouth
- Throat
- Gastro
- Urinary
- Soft tissue
- Joint
- Muscle
- Deep Cuts



Discover types, symptoms and more at the QR Code here!





# **We are looking for individuals to serve on our Board of Directors**

**Do you know anyone who  
might be interested in serving  
on the board of directors for  
Bleeding Disorders of the Heartland?**

## **Board Member Information**

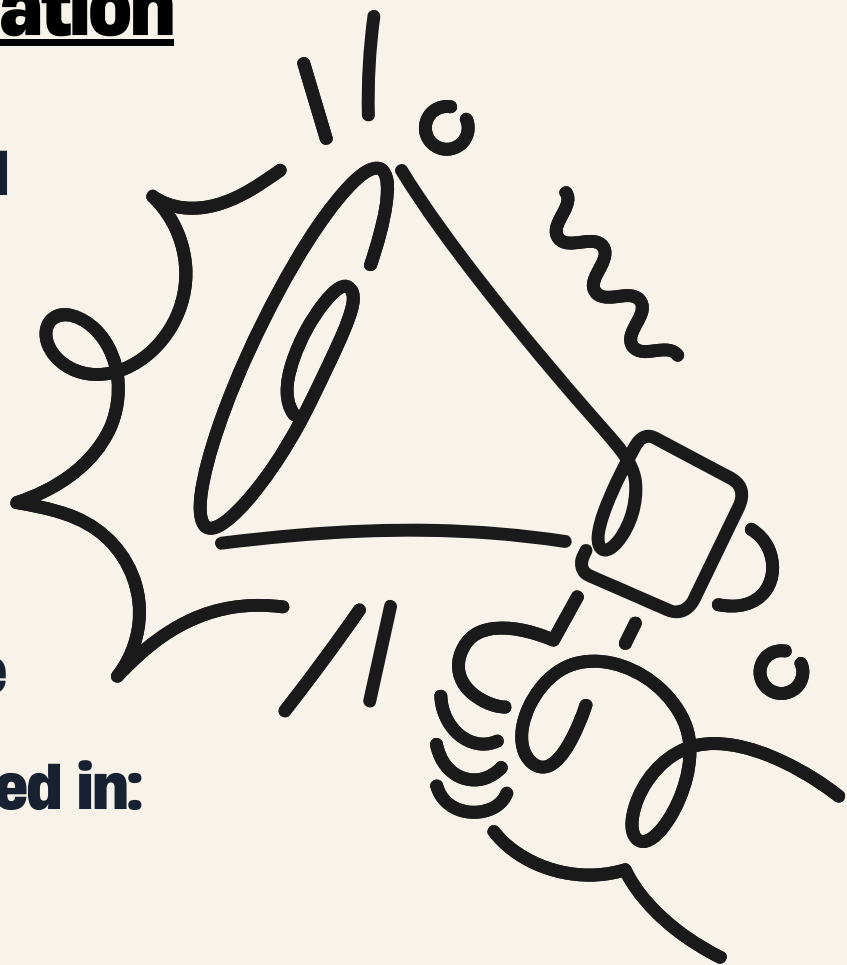
**This is a volunteer position.  
If selected, you must attend  
onboarding session,  
organization events,  
quarterly meetings &  
2 board trainings a year.**

### **Specifically Seeking:**

- **Lawyers**
- **Bankers**
- **Nonprofit Experience**

### **Individuals who are skilled in:**

- **Fundraising**
- **Insurance**
- **Mental Health**
- **Child/Youth Programming**



**Please reach out to Brooke at  
[bdh\\_director@bdheartland.org](mailto:bdh_director@bdheartland.org)  
for a board application or more information.**

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](http://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!*

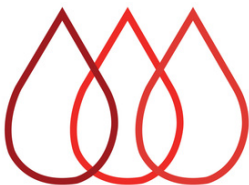
This contribution is made in memory or honor of \_\_\_\_\_

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip Code: \_\_\_\_\_

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



**BLEEDINGDISORDERS**  
OF THE HEARTLAND

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Durant, Iowa 52747

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Email us at: [bdh\\_director@bdheartland.org](mailto:bdh_director@bdheartland.org)