



# Upcoming EVENTS

Men's Retreat
Golf Event
Bleeding Disorders Camp
Family Education Day
Adult Retreat
"Step Right Up" Unite Walk



**SUMMER 2024** 



# The

# BLOODLINE

**NEWSLETTER** 

## Staff

### **EXECUTIVE DIRECTOR**

Brooke Loving bdh director@bdheartland.org



ADMINISTRATIVE g.

## **PROGRAMS ASSISTANT**

Amber Smith 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 Advisors**

Mya Anderson Becca Markl

# Inside This Issue:

**President's Letter** 

**Thomas Savage** 

**Executive Director's Letter** 

**Brooke Loving** 

**Upcoming Events** 

**Annual Meeting Review** 

**HTC Corner** 

Men's Retreat

**Factoring Fairways for Families Golf Event** 

**Bleeding Disorders Summer Camp** 

**Family Education Day** 

**Adult Retreat** 

2024 Step Right Up Walk for a Cause-Unite

# **CONTACT INFORMATION**



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

Tel: (319) 721-1664

Email us at: bdh director@bdheartland.org

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.

# To: Our Bleeding Disorders of the Heartland Family



BDH 103 5th Ave Durant, Iowa 52747

Contact Thomas by email at:

bdh\_president@bdheartland.org

# A Letter from our BDH President

Dear BDH Family,

My name is Thomas Savage and I am excited to be the new Board President for Bleeding Disorders of the Heartland. I wanted to take a moment to introduce myself to those of you who may not know me. I was the first in my family to be diagnosed with a bleeding disorder, Severe Hemophilia A at around 6 months old. I was exposed to Hepatitis C through a blood transfusion I received during birth. I have also gone through the gambit of treatments.

I grew up in this organization and know firsthand how life-changing being a part of this community can be. One of my passions is advocacy. Being able to tell our stories in a way that can bring about change in government as well as make others in our community not feel so alone. With the changing landscape of healthcare as well as our many new treatment options I feel telling our stories and creating that sense of community is more important than ever. I look forward to seeing how we can further grow this organization and continue to create community through advocacy in the upcoming years.

I know right now things can seem very uncertain. Things seem to be changing with legislation, healthcare, and even our medicine at almost a daily rate. But we as an organization will strive to be transparent with you as these changes arise so none of us feel like we have to go through anything alone.

I love telling my stories and hearing other people's stories. If you have any questions, want to help, have a vision for the organization to better help meet your needs, or just need a nonmedical ear to listen to your concerns from someone who lives with a bleeding disorder please reach out to me by email at <a href="mailto:BDH\_President@BDheartland.org">BDH\_President@BDheartland.org</a>.

I look forward to working with you all to make Bleeding Disorders of the Heartland the best it has ever been.

Best Regards, Thomas Savage (They/He) President

**QUARTER 2-UPDATE** 

# EXECUTIVE DIRECTOR BROOKE LOVING



# INDIANAPOLIS, INDIANA April 11-14

I was enthralled by the diverse range of topics discussed at the HFA Symposium. Each day brought new insights and perspectives. From engaging keynote speakers to thought-provoking panel discussions, the symposium was a melting pot of knowledge and ideas. Networking with fellow attendees further enriched my experience, allowing me to forge new connections and friendships. Overall, the symposium was a truly rewarding experience.



# THE SHOWING OF THE FILM

http://www.ontheshouldersfilm.com/ Supported by a contribution from Sanofi, produced by Believe Ltd. This film pays tribute to our past while being hopeful of our future



THE FILM ON THE SHOULDERS OF GIANTS SHOWCASED AT THE SYMPOSIUM WAS TRULY PHENOMENAL.

# NEW ORLEANS, LOUISIANNA

I PARTICIPATED IN A MEMBER ORGANIZATION TRAINING SESSION WITH 25 EXECUTIVE DIRECTORS FROM AROUND THE COUNTRY FROM APRIL 29TH TO MAY 1ST. DURING THE SESSIONS, WE FOCUSED ON BEST PRACTICES AND VARIOUS WORK-RELATED TOPICS. I GAINED VALUABLE INSIGHTS FROM THE OTHER EXECUTIVE DIRECTORS PRESENT.





# Upcoming Exerts





# Men's Retreat

Des Moines, Iowa

**Educational Sessions and** Connection time. Also includes a golf slot at the Factoring Fairways Annual Golf Event on June 10th.

June 2024



# Factoring Fairways Annual Golf Event

Toad Valley Golf Course

One of our biggest fundraisers of the year! You can find registration information on the website. www.bdheartland.org

June



# Bleeding Disorders Summer Camp Camp Tanager, Mount Vernon, Iowa

Deadline to register is May 20th. All information can be found by scanning QR code or the website. www.bdheartland.org

June 2024



# Family Education Day

Fun City, Burlington, Iowa

Scan the QR Code above to go to the Website! All events are listed, get yourself or family registered today!

July 2024



# ANNUAL MEETING

Thank you to our

**MAKING MAGIC MEMORIES** 





PREMIERE SPONSORS

Genentech



sanofi

A Member of the Roche Group







**CSL Behring** 



Biotherapies for Life<sup>™</sup>



NATIONAL BLEEDING DISORDERS FOUNDATION

















promptcare<sup>™</sup>











































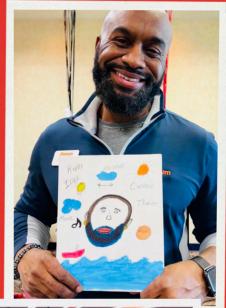




























Thank you for taking the time to join us in "Making Magical Memories" with your bleeding disorders family!

Sincerely,
Bleeding Disorders of the Heartland Board & Staff



# HTC CORNER



# **HTC Important Phone Information:**

Important Phone Number Information to know about UI Health Care and the Hemophilia/Bleeding Disorder Team: Please save the following phone number in your contacts so you do not miss calls from the University of Iowa Hospitals and Clinics or UI Health Care: 319-338-2111

This one number is used for all outgoing calls to patients! When you see this number, it will be related your health care. Save it as "UI Health Care".

If you block this number, you will not get appointment reminders, scheduling updates, pharmacy requests, or other important information.

This number is not a number that you can call back, so please always have the hemophilia/bleeding disorder team and main hospital numbers as well.

# Other Important Phone Numbers:

Hemophilia/Bleeding Disorder Team: 319-356-4277 (Monday-Friday, 8-5)

319-356-1616 (After hours, weekends, holidays, 24 hours/day-ask to speak with the hematologist on call)

319-356-2229 (Pediatric Scheduling)

319-356-4200 (Adult Clinical Cancer Center Scheduling)

319-356-4965 (Hemophilia Specialty Pharmacy team)

# **HTC CORNER**





Do you have Spring or Summer Allergies? Do you get Nosebleeds?

By Karla Watkinson, RN

Do you have allergies that begin in the spring or summer? If so, you are not alone. Approximately 20% of people of all ages have allergic rhinitis, otherwise known as "hay fever". The risk of developing allergic rhinitis is higher in people with asthma or eczema, or a family history of asthma or rhinitis. Allergic rhinitis can begin at any age, however most people first develop symptoms in childhood or as a young adult. The symptoms are often worse in childhood and at age 30-40 but can vary throughout life. Symptoms of allergic rhinitis are caused by a nasal reaction to small airborne particles called allergens, or substances, which cause an allergic reaction. Most commonly these substances, or allergens, are pollens from trees, grasses and weeds, as well as spores from mold and fungi. This reaction causes congestion which is fluid build up in the nasal tissue, then cause itching, sneezing, and runny nose. Other symptoms can include itchy watery eyes, feeling of grittiness in the eyes, sore throat, popping of the ears, itching in the throat or ears, mouth breathing, and fatigue. Over several hours, these substances cause an inflammatory response in the cells lining the nasal tissue and can cause persistent symptoms. The nose is a vascular structure with blood vessels very close to the surface; these qualities enable the nose to filter, humidify, and warm inhaled air, but also predispose it to bleeding. When the nasal membranes become irritated due to allergies, the lining becomes inflamed, and then the blood vessels are more prone to injury which then causes bleeding. A diagnosis of allergic rhinitis is based on a physical exam and symptoms experienced. Further medical testing can confirm the diagnosis and identify the allergens causing it. It is often possible to identify the culprits by noting the time of year when symptoms begin, are there factors or triggers that cause symptoms, and can you identify potential allergens in the home, work, or school environment. Sometimes skin tests are needed for people whose symptoms are not well-controlled by medication to identify the organisms causing symptoms.

# **HTC CORNER**

T: 319-356-4277 Monday-Friday, 8am-5pm

Treatment of allergic rhinitis includes reducing exposure to the allergens or triggers in combination with medication such as Cetirizine (Zyrtec), Loratadine (Claritin), Diphenhydramine (Benadryl), as well as others. Some medication can cause drowsiness.



It is best to work with your primary care doctor or allergist to obtain a diagnosis and find the best medication for you. Hopefully by controlling the allergies the number of nosebleeds will decrease. Nasal cares are also recommended to help decrease and prevent bleeding. These include keeping the nose moist by using a saline nasal spray or gel several times a day, avoiding digital manipulation or picking the nose, and using a humidifier in the bedroom while sleeping when the air is dry.

In order to stop a nosebleed, follow these guidelines: 1) Stay calm.

- 2) Sit or stand while bending forward slightly; do not lie down or tilt your head back. This may cause you to swallow blood which can lead to vomiting.
- 3) Grip the soft part of both nostrils at the bottom of your nose. Do not grip the bony bridge and do not apply pressure to just one side, even if it is only bleeding from one side.
- 4) Squeeze your nose for at least 10-15 minutes (children and adults), release to see if it is still bleeding. If the nose is still bleeding then squeeze and apply pressure for 10-20 more minutes. This step can be repeated. Be sure to keep your mouth open during this time.
- 5) A cold compress or ice pack can also be applied to the bridge of the nose. This will help the blood vessels to constrict and slow the bleeding down also.
- 6) For bleeding lasting longer than 20-30 minutes: Use medication if prescribed by your hematologist such as factor, DDAVP, Amicar or Tranexamic Acid per your treatment plan. Afrin nasal spray (per package directions) can be sprayed or applied on a cotton ball to constrict the blood vessels also. Consider salt pork.
- 7) Avoid hot food, bending over, and vigorous exercise or activity.
- 8) For bleeding not responding to local measures and treatment, seek medical care.
- 9) Do not forget to inform the Hemophilia team about frequent nosebleeds as we may want to refer you to other services.





Get ready to recharge, reconnect and unwind at the Men's Retreat. It's a one-of-a-kind chance to join a tribe of bros who get it. Take a break from the hustle and bustle of everyday life, and just be yourself.

You'll be in a safe space, where you can share your story and be heard. Whether you're caring for someone with a bleeding disorder or dealing with your own health battles, this retreat will give you a chance to bond with other men who understand what you're going through.

Get ready to make lifelong connections and leave with a renewed sense of energy.

For more details scan the QR code:

Gold Sponson:



\$40
INCLUDES
HOTEL ROOM,
MEALS, ACTIVITIES
& GOLF SPOT FOR
GOLF EVENT
(CLUB RENTAL
AVAILABLE FOR \$10)

REGISTER ON OUR WEBSITE TODAY!

DEADLINE FOR REGISTER IS MAY 22

# **MENS RETREAT**

Sunday June 9, 2024

1:00 PM	Registration
1:30 PM	Break Out Session
2:30 AM	Break Out Session
3:30PM	Break/Snack
4:00 PM	Break Out Session
5:00 PM	Round Table Discussion
6:00 PM	Hotel Check-In
6:30 PM	Dinner at Big Grove Brewery
9:30 PM	Return to Hotel for casual Hangout time





Register at by scanning the QR Code or visit the events page at www.bdheartland.org

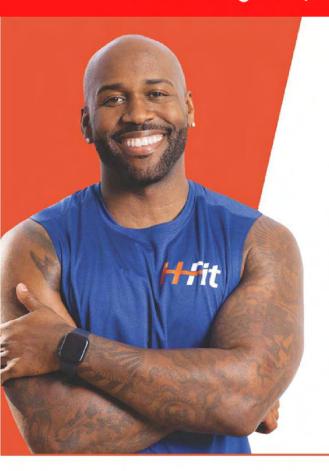


# **CSL Behring**Biotherapies for Life<sup>™</sup>

Proud to serve the bleeding disorders community with the latest technologies, innovative therapies and support.



Mike Appleseth
Manager, Coagulation Products
641-757-0499 / mike.appleseth@cslbehring.com
Serving Iowa, Nebraska, Kansas and Missouri





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.







JUNE 16-21

# BLEEDING DISORDERS

SUMMER CAMP

Registration closes
May 20th apply on the
website at
www.bdheartland.org
Scan the QR Code to
view a video!



"Camp was so much fun! You got to make lots of friends!" - Quincy, Age 10



"I felt normal at camp with kids just like me. I can't wait to come back next year!"
- Katy, Age 16





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

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

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 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 variety jowa.com.

Contact:
Brooke Loving
Bleeding Disorders of the Heartland
319-721-1664
bdh\_director@bdheartland.org











A HIIGE shout out and thank you to Variety, the Children's Charity, for their support of Bleeding Disorders of the Heartland that helps make our summer camp possible to all of our families!



# Don't Delay Register Today



Bleeding Disorders of the Heartland
Summer Camp

is a program for children ages 6-17 affected with a diagnosed bleeding disorder.

Camp Tanager in Mount Vernon, Iowa.





# **SWITCH IT UP** like Joey did!

a real ALTUVIIIO patient

Joey has been compensated for sharing his story.

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



**CONNECT WITH YOUR CORE TODAY** 



# Save the Date August 25, 2024

Bayer will be hosting an educational lunch program.

Watch the website for details.



# Explore Head-to-Head Pharmacokinetic (PK) Study Data

See half-life, clearance, and other PK data from the crossover study comparing Kovaltry® and Advate®.

Visit Kovaltry-us.com to find out more.

© 2023 Bayer. All rights reserved. Bayer, the Bayer Cross, and KOVALTRY are registered trademarks of Bayer. PP-KOV-US-0690-1 03/23

BLEEDING DISORDERS
OF THE HEARTLAND

# 

A great time for our community members, where we spend time together, learn, laugh, and create beautiful memories together.



Fun City Burlington, IA



**Connection Time** 



Education for the entire family

SATURDAY
JULY 27TH



Free Dinner and Educational Program May 23,2024 in Davenport, Iowa.







Join BDH and Bayer for an evening of great company, free food and learning!



# FREE DINNER & FDUCATIONAL PROGRAM



sanofi

Join Sanofi and Bleeding Disorders of the Heartland for a FREE dinner and Educational Program "One Family"

Presented By

# **Jessica Hutchinson**

May 29th, 2024 from 6-8pm

The Edison 475 Northland Ave NE Cedar Rapids, Iowa 52402







# SAVE THE DATE

2024 Gettin' in the Game<sup>SM</sup>
Junior National Championship (JNC)
Applications open on the chapter website.

www.bdheartland.org September 20 – 22, 2024

Henderson, Nevada

It gives us great pleasure to announce CSL Behring will be hosting the Gettin' in the Game Junior National Championship (JNC) in Henderson, NV from September 20 - 22, 2024. It has been 22 years since CSL Behring created the JNC, the first and currently the only, national sports competition for children with bleeding disorders.

Participants will have the opportunity to learn the fundamentals of their respective sport, participate in friendly competition, and have a chance to connect with fellow members of the bleeding disorders community from across the country. Additionally, educational seminars focusing on the importance of physical fitness and other related topics will be available on site.

This event is for children ages 7 through 18, to represent their chapter during this national competition. Each participant will have the opportunity to choose either baseball, basketball, golf or swimming for this year's JNC.

# 

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

WWW.BDHEARTLAND.ORG



Save the Date for the 2024
Adult Retreat!
Details and registration
will be available on the
website soon!

**August 12-13** 

Visit the webite www.bdheartland.org





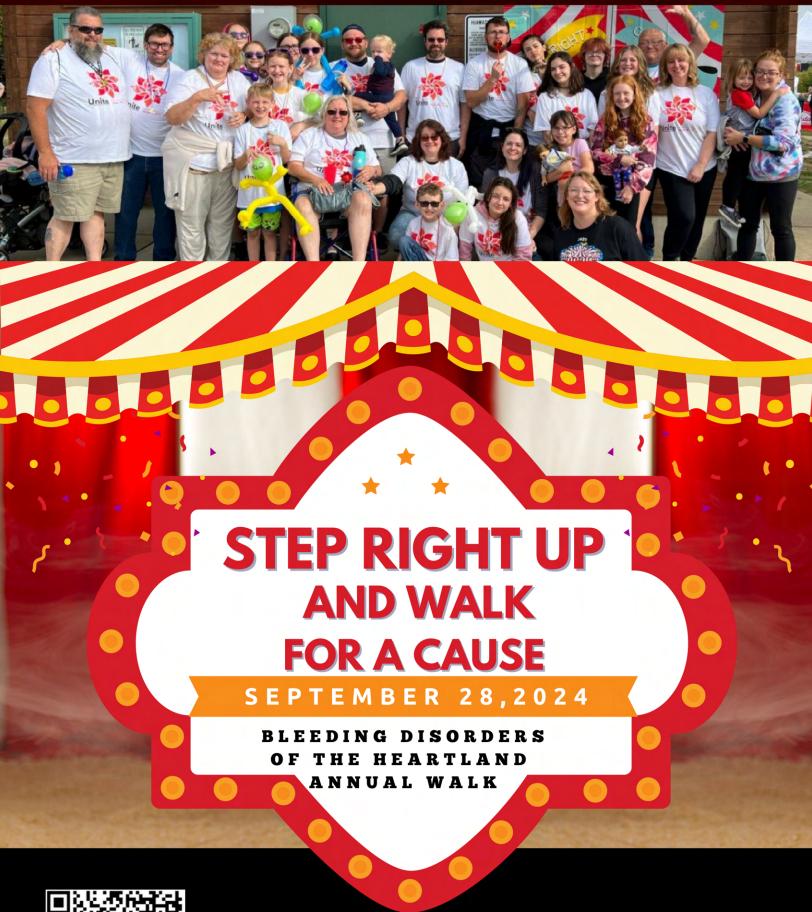


Cathy Jo Crosby was an avid supporter of the bleeding disorders community. Since her passing on February 14, 2024 her family and friends have donated over \$5000 in her memory to Bleeding Disorders of the Heartland. We are honored that she left us in her legacy plan.

We would like to say
thank you to all who have donated
and share our sincerest condolences
for your loss.

Your donations will change the lives of families with bleeding disorders forever.

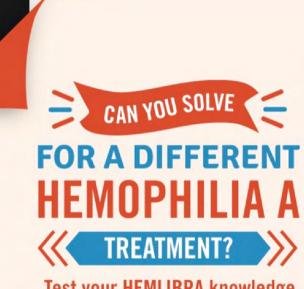
Are you interested in learning how to add Bleeding Disorders of the Heartland to your legacy plan? Contact us today at bdh\_director@bdheartland.org and we





Bleeding Disorders of the Heartland Tel: (319) 721-1664

Email us at: bdh\_director@bdheartland.org



# Test your HEMLIBRA knowledge

1	2	3	4		5	6	7	8	9	30
11	+	+			12	+			1	
13	+	+			14	+			4	
15		+		16			17		1	
18		Y			19	20	Y			
21				22				23	24	25
			26			+	27		+	
28	29	30				31	Y	Y	Y	Y
32		$\uparrow$		33	34		35	1	1	
36		+					37		+	
38						1	39			

### **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 \_ 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

- 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> Number of people with hemophilia A treated as of October 2021.

### **SOLUTIONS**

Across: 1. cask, 5. chaers, 11. Aden, 12. parish, 13. tone, 14. used to, 15. cruel, 17. nest, 13. tone, 14. used to, 15. cruel, 17. nest, 18. defended to the constant of the

# Discover more at (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
- 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
- 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

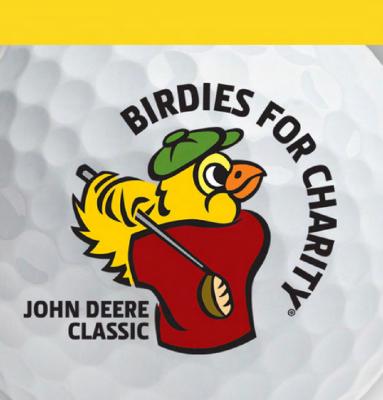
HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan ©2021 Genentech, Inc. All rights reserved. For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.

This Medication Guide has been approved by the U.S. Food and Drug Administration Revised: 03/2023



HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan. The HEMLIBRA logo is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan. The Genentech logo is a registered trademark of Genentech, Inc. All other trademarks are the property of their respective owners. @2023 Genentech USA, Inc. All rights reserved. M-US-00011998(v3.0) 08/23





# WE ARE REGISTERED!

Donate online at BirdiesforCharity.com/donate

# Visit the above website to donate today! Our birdie number is #2419

Birdies For Charity will donate a bonus on top of your donation!

Bleeding Disorders of the Heartland will receive 100% of your donation, plus a bonus of up to 5% on top of that!

You will also have the chance to win a 2 year lease on a 2024 Lexus NX!





# 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 enhance the lives of those affected by bleeding disorders.

# We need You!

BLEEDING DISORDERS OF THE HEARTLAND

BLEEDING DISORDERS OF THE HEARTLAND is expanding our board of directors.

Do you know someone with legal expertise, tax knowledge, CPA certification, or board experience? We are actively searching for qualified individuals to join our board of directors and help us grow.

Scan the QR Code to donate or contact BDH



Are you able to assist us in Diversifying Funding?
We're seeking your assistance! Do you have funds available for donation or know of companies or organizations that are interested in supporting a good cause or looking for a tax write-off? We're looking to diversify our funding sources.

Additionally, have you formed a walk team yet? It's never too early to begin raising funds to help our organization advance its mission to educate, connect, and support those affected with bleeding disorders.

Visit www.bdheartland.org