



GATEWAY CONNECTION

Winter 2021

CALENDAR OF UPCOMING EVENTS

February

- 8 Understanding Accumulator
Adjuster Programs (virtual)

March

- 1-5 NHF's Washington Days (virtual)
10 MO Advocacy training (virtual)
11 MO Advocacy Day (virtual)

April

- 16 Young Adult Hike
Lake Ozark, MO
16-18 Adult Retreat-Lodge of 4 Seasons
Lake Ozark, MO

July

- 9-11 Family Education Weekend
Doubletree Chesterfield Hotel
11 Unite Walk & 5K
Doubletree Chesterfield Hotel

**Stay up to date by following
us on social media!**



@gateway
hemophilia
association



@Gateway
Hemo



@gateway
hemophilia



Midwest
Hemophilia
Association

Missouri Advocacy Day

Due to the ongoing COVID-19 pandemic, Missouri Advocacy Day will be entirely virtual this year. This will include virtual training and virtual meetings with legislators.

While our virtual Advocacy Day is limited to residents of the State of Missouri, all community members are invited to join us for our virtual Advocacy Training.

Advocacy Training

Wednesday, March 10th
7:00 pm

Advocacy Day

Thursday, March 11th
Meeting times TBD

Deadline to register for Advocacy Day is February 25th

"Understanding Accumulator Adjustor Programs"

Community members are invited to attend this virtual training event, as we will be discussing accumulator adjustors with our legislators at Missouri Advocacy Day.

Monday, February 8th
7:00 pm

Registration is open for all 3 events at
gatewayhemophilia.org/events

WWW.GATEWAYHEMOPHILIA.ORG

Gateway Connection
is published quarterly by

Gateway Hemophilia Association

**4976 Eichelberger St.
St. Louis, MO 63109
314-482-5973
gatewayhemophilia.org**

**Email us at
info@gatewayhemophilia.org**

BOARD OF DIRECTORS

President

Mike Miller

Vice President

Lori Moore

Treasurer

Ben Moramarco

Secretary

Stephanie Bauman

Maria Hanse

Jeana Huntoon

Kristina Klein

Kari Moellenhoff

Anne Parrott

Nikole Schroeder

Lizzie White

EXECUTIVE DIRECTOR

Bridget Tyrey

COMMUNICATIONS AND PROGRAMS MANAGER

Jennifer McNamee

A Message from the Executive Director, Bridget Tyrey

“No matter how hard the past is, you can always begin again.”

- Jack Kornfield

This past year has challenged all of us to rethink how we live, work, and connect with others. GHA's staff, board of directors, and volunteers had to rethink how to continue to best fulfill our mission in uncertain and trying times.

We process change in different ways; from feelings of gratitude over a break from the hurried life we had, to fear of contracting the virus, to anxiety over financial worries, and to the weariness of caring for loved ones, as well as living with a rare bleeding disorder. Whatever your perspective and need may be, please know GHA is here for you.

Please stay connected, there are many benefits of connecting with others. Connecting can increase your quality of health, strengthen your immune system, and lower anxiety and depression. I urge you to reach out if there is anything GHA can help you with. When we are happier and healthier, we are better able to care for our community and those in it. Over 100 individual volunteers supported GHA's efforts last year with over 1,000 documented volunteer hours. We also saw care in our donors and corporate partners who continue to donate to GHA because the need for services and education does not stop during a pandemic.

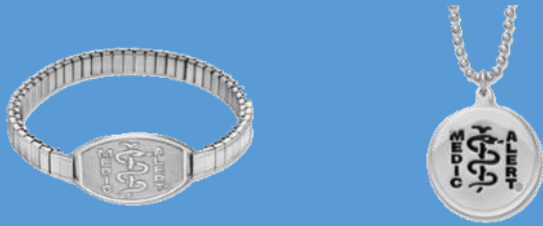
We are committed to serving those with a bleeding disorder and are thankful to have the support from so many. Last year we were able to offer 40 educational programs, of those 25 were virtual, and totaled 65 days of events and programs. We continue to offer advocacy, education and support to families affected by bleeding disorders. Check GHA's website for upcoming programs.

GHA will continue to serve individuals and families with rare bleeding disorders regardless of race, religion, gender, or financial ability to pay. GHA's college scholarship applications are available online, as is our emergency assistance form, and medic alert application. We will continue to offer a variety of relevant resources and education to you via Zoom and hope that we will be able to “see” you virtually! Please reach out to us if you would like assistance accessing or learning that technology.

Here is to a bright New Year, to the things that are yet to come, and to the memories that we hold. We might be apart today, but you are always in our hearts. May you have a prosperous New Year!

GHA Board of Directors meetings are open to the public and held the 2nd Tuesday of every odd numbered month at 6:00pm at 4976 Eichelberger Street, St. Louis, MO 63109. Changes to these dates may be necessary due to scheduling conflicts and will be announced at www.gatewayhemophilia.org/about-us/board-of-directors as soon as they are available.

Do You Have Your Medical Alert ID?



A Medical Alert ID is essential for people with bleeding disorders. Wearing a Medical ID ensures emergency responders and hospital staff have up-to-date medical information the moment they need it to make informed decisions about treatment and care.

Did you know that GHA assists with MedicAlert memberships and IDs for patients with hemophilia and vWD? Visit <http://www.gatewayhemophilia.org/resources/medical-information/> for more information or to apply for assistance with a Medic Alert ID due to financial hardship.

COVID-19 Support

If you and/or your family are struggling, GHA is here for you.

Visit gatewayhemophilia.org/covid-19 for a list of resources

or

contact us at
info@gatewayhemophilia.org
314-482-5973

Volunteer of the Year

Do you know an amazing GHA volunteer? We are accepting nominations for 2020 Volunteer of the Year!

Submit your nomination to
info@gatewayhemophilia.org
by June 30, 2021



Unite
for Bleeding Disorders

July 11, 2021

**DoubleTree
Chesterfield Hotel**

Join us for GHA's Unite for Bleeding Disorders Walk by signing up your team at gatewayhemophilia.org today!

Then kick off your fundraising by helping us collect gently used items (below). Any money raised will be divided amongst participating teams!

Contact GHA to set up delivery to the GHA office before April 1st.

FUNDrive®
savers | value village®

What we accept

All items must be in good, clean, and sellable condition.



CLOTHING Men's, women's and children's



SHOES Men's, women's and children's



TEXTILES Towels, sheets, blankets, pillows, curtains, tablecloths



ACCESSORIES Hats, mittens, scarves, ties, socks, purses, wallets, backpacks, bags

We cannot accept:

Mattresses, baby gear, appliances, large furniture, auto parts, building materials, cleaning products, tires, flammable materials

We're Listening



At Pfizer Hemophilia, we have always been deeply committed to listening to what you have to say. Our programs and resources are all designed in response to the needs of the hemophilia community.

We are grateful for having the chance to partner with you.

—Your Pfizer Hemophilia Team

Fall Membership Meeting

On October 24th, GHA members donned their masks and gathered for an outdoor membership meeting at Stuckmeyer's Farm in Fenton. The morning included an update from GHA, pumpkin painting, raffles, lunch and a hayride. Though it was a chilly day, all were happy for the opportunity to gather safely and visit with friends.

Thank you Sponsors

ARJ Infusion Services, CSL Behring, CVS Specialty, Genentech, InfuCareRx, Medexus Pharma, Octapharma, Paragon Healthcare

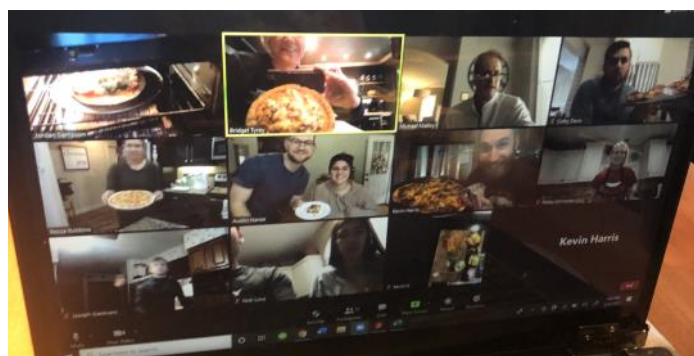


Ugly Sweater Holiday Cookie Extravaganza

On December 6th, GHA teamed up with the New England Hemophilia Association (NEHA) for an Ugly Sweater Holiday Cookie Baking Extravaganza. Led by Chef Edgar Martinez, participants learned to bake a cookie unique to each chapter's region. GHA selected gooey butter cookies, and NEHA selected whoopie pies cookies as their signature treats. The virtual event was filled with holiday music, baking mishaps, and lots of laughter and smiles. Ahead of the event, participants were sent two recipes, a supply list, a gift card to purchase ingredients, and two commemorative aprons. Our thanks to Octapharma for sponsoring this fun holiday event, and to Chef Edgar for his expert instruction.

Young Adult Virtual Events

On December 19th, GHA Young Adults got together on Zoom for a little holiday fun and a chance to check in with one another. One topic discussed was GHA's Adult Retreat scheduled for April 16-18 at The Lodge of 4 Seasons in Lake Ozark, MO. Young Adults age 19-25 with a bleeding disorder and a plus one are invited to come to the Lake a day early (April 15th) and participate in a morning hike on April 16th.



The young adults also discussed their desire to get together more often, so a virtual Pizza Cooking Class was held on January 10th. Thank you Kitchen Kevin for sharing your pizza making skills. Thank you Medexus Pharma and Paragon Healthcare for your sponsorship.

If you would like more information about the Adult Retreat or the Young Adult Hike, please contact Bridget at bridgettyrey@gatewayhemophilia.org. If you are a young adult with a bleeding disorder and would like to be added to our Young Adult email list, please contact Jen at jmcnamee@gatewayhemophilia.org

GHA's Academic Scholarship

GHA is proud to award academic scholarships annually to GHA members with a bleeding disorder who are pursuing their post high school education.

To apply for GHA's Academic Scholarship, and for more information about this and other scholarships available to members of the bleeding disorders community, visit

gatewayhemophilia.org/our-programs/scholarship-program/

Application deadline: March 31st



Thank you Volunteers!

James Addie
Sandy Addie
Connor Ancel
Josh Ancel
Nikolas Ancel
Nora Ancel
Zayne Ancel
Mathew Angelly
Adam Arbin
Dominic Arbin
Judy Bagato
Jake Bauman
Stephanie Bauman
Bill Berger
Dr. Morey Blinder
Anne Bollinger
John Carleton
Pam Carleton
Tina Charpentier
Todd Daube
Kevin Ellebrecht
Daytona Flax
Danielle Flores
Gabi Flores
Tony Flores
Joe Gassiraro

Mary Griser
Jim Guasto
Pat Gute
Austin Hanse
Maria Hanse
Kevin Harris
Sandy Hennessy
Laura Herman
Kirstie Hilty
Jeana Huntoon
Dan Johannes
Lydia Johnson
Michael Johnson
Kristina Klein
Mia Korte
Paige Korte
Steve Kreher
Andrea Lewis
Sharon Lewis
Susan Lewis
Kathy Logan
Jessica Lovercamp
Craig MacDonald
Carly Magee
Kristin Marema
Trenton Marema

Chris McGovern
Joan McGovern
Ayden Meadows
Charity Meadows
Elijah Meadows
Evan Meadows
Kate Miller
Mike Miller
Kari Moellenhoff
Lori Moore
Randy Moore
Ben Moramarco
Sue Pardeshi
Anne Parrott
Maggie Poronto
Brian Power
Vickie Power
Kim Prewitt
Dr. John Puetz
Brian Rodgers
Kimberly Rosenfelt
Emily Samspon
Jordan Sampson
Sheri Sampson
Robyn Schmit
Abby Schneider

Chris Schneider
Rieley Schneider
Holly Schollmeyer
Nikole Schroeder
Dan Shelton
Kristin Shelton
Makenzie Sledd
Blake Snarey
Elizabeth Snarey
Evan Snarey
James Snarey
Mareena Snarey
Nathan Snarey
Carrie Stigers
Dirk Stringer
Trudy Stringer
John Thorson
Ann Tisone
Tony Vetter
Patrick Welch
Lizzie White
Diane Woepke
Tiffany Woffard
Cody York
Joe Zwier

2020

Over the course of



1 Year



103 Volunteers
generously gave



over 1,000 Hours
to support GHA



saving GHA over
\$27,000

Holiday Trivia Night Fundraiser

GHA's Annual Trivia Night Fundraiser was held on November 14th at The Pavilion at Lemay. Due to the ongoing COVID-19 pandemic, the event was kept smaller than previous years. A number of precautions were also taken to ensure the safety of all involved. Attendees had their temperatures taken at the door, wore masks, and maintained social distancing throughout the event. Despite Trivia looking a bit different, the crowd enjoyed a fun night of holiday-themed trivia, games, silent auction, and numerous costume changes by Emcee Trudy Stringer! Thank you to our donors, sponsors, and volunteers for supporting this event.

Congratulations Winners!

Unique this year was a 3-way tie for 1st place! With a score of 69 points a piece, a "Guess Your Final Score Without Going Over" game at the start of trivia broke the tie.

1st Place Table #7 - ARJ (right)

2nd Place Table #10 - FEFA

3rd Place Table #11 - Tracey Edler



Thank You Sponsors!

Platinum Sponsors

BioMarin, CVS Specialty

Event Sponsors

CSL Behring, Octapharma, Paragon Healthcare

Snack Sponsors

ARJ Infusion Services, Will & Rachel Pratt,
Washington University HTC

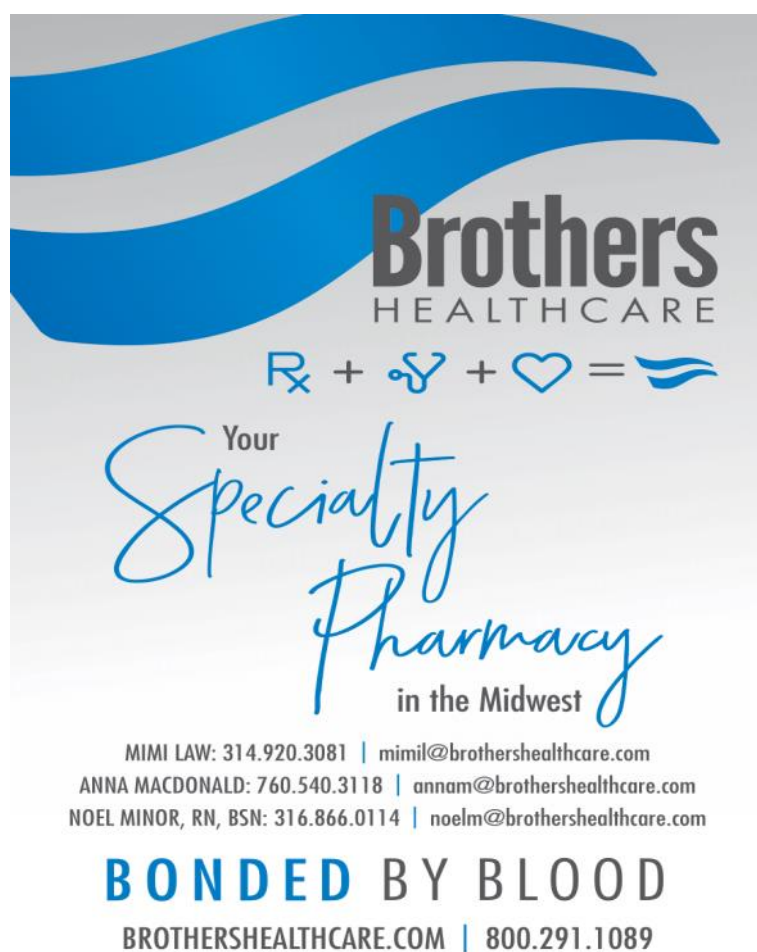
Thank you Volunteers!

Committee

Trivia Chair - Trudy Stringer
Auction Chair - Joan McGovern

Event Volunteers

James Addie, Sandy Addie, Mia Korte, Paige Korte,
Christopher McGovern, Joan McGovern, Kate Miller,
Mike Miller, Emily Sampson, Jordan Sampson, Dirk
Stringer, Trudy Stringer, Lizzie White, Cody York



Brothers
HEALTHCARE

Rx + ∞ + ♥ = ∞

Your
Specialty
Pharmacy
in the Midwest

MIMI LAW: 314.920.3081 | mimil@brothershealthcare.com
ANNA MACDONALD: 760.540.3118 | annam@brothershealthcare.com
NOEL MINOR, RN, BSN: 316.866.0114 | noelm@brothershealthcare.com

BONDED BY BLOOD
BROTHERSHEALTHCARE.COM | 800.291.1089

**BE INFORMED.
FEEL EMPOWERED.**

**ADVANCE YOUR
KNOWLEDGE OF
GENE THERAPY.**

Explore the science of gene therapy
research at **HemophiliaForward.com**.

**HEMOPHILIA
FORWARD.**

Spark
THERAPEUTICS

© 2020 Spark Therapeutics, Inc. N-HEM-US-420091



Ending the Cycle of Financial Struggle

New program provides a way for community members who often struggle financially to take steps to get ahead, stay ahead

By Allison Harrison, MSW,
Certified Financial Social Worker, HFA Staff Writer

As a member of the Helping Hands team, I speak every day to members of the bleeding disorders community who are stuck in a cycle of financial insecurity. Hemophilia Federation of America's Helping Hands team, staffed by social workers, connects with community members in need, delivers financial assistance and educates applicants about support that may strengthen their ability to succeed while living with a bleeding disorder.

While members of the bleeding disorders community are some of the most resilient and resourceful individuals, they also face a set of formidable challenges, such as high expenses due to medical appointments, procedures, medications, transportation to appointments, and items that are not covered by insurance like wheelchairs and protective gear. Many have faced "surprise billing" issues when, in an emergency, they received care not covered by their insurance provider.

EMPLOYMENT

Some community members face challenges with income and financial stability. Because of physical needs or caregiving duties, people in the community may have a hard time finding work flexible enough to accommodate their physical needs. A bleeding disorder may also make it difficult for caregivers and patients to complete higher education that could open doors to higher wages.

We have seen many community members who are under-employed (hours or pay are too low to meet financial needs), find it hard to keep a job, find low-wage hourly work the only option, are overlooked for promotions or raises, or regularly miss out on wages due to caregiving or medical needs.

In HFA's CHOICE Survey, a survey conducted by HFA several years ago to ask patients about their experiences, respondents with hemophilia A reported missing an average of 12 days of work because of their bleeding disorder. Respondents living with hemophilia A with inhibitors missed an average of 23 days. The American Journal of Hematology published a study in 2015 stating nearly 25 percent of patients with bleeding disorders ages 25 to 34 were unemployed compared to 6 percent in the general population in the same year.

FAMILY IMPACT

Bleeding disorders like hemophilia and vWD are usually hereditary, putting community members at risk of facing the intergenerational impacts of both trauma and financial insecurity. Families with bleeding disorders have faced traumatic experiences, including long and painful bleeding episodes when treatments weren't as effective, permanent complications, negative interactions with medical institutions, bankruptcy and debt caused by medical bills and insurance restrictions, the contamination of the blood supply, and stigma from neighbors, schools and employers.

While treatments have advanced and individuals with bleeding disorders are able to live long and productive lives, living with a chronic disorder still produces emotional, social medical, and financial challenges.

Some Helping Hands applicants face a short-term emergency, like insufficient savings to cushion the blow of temporarily lost income or an unexpected expense. With financial assistance, they soon get back on their feet. Other applicants face a financial emergency but are also in a cycle of debt or poverty due to employment challenges, medical/insurance setbacks, debt and credit card problems, or any number of issues outlined above.

Since its creation in 1997, Helping Hands has continuously evolved to meet the needs of our most vulnerable community members. The program started by providing bleeding disorder families with funds offering a brief respite from the daily grind of chronic illness. Over the years, Helping Hands has furnished thousands of families with assistance with urgent basic living expenses, medically necessary items, fitness support, medical travel and tutoring support. The program has also provided financial support to the bleeding disorders community affected by natural disasters such as hurricanes and floods through the Disaster Relief Fund to help for those impacted by the pandemic. But there is more to do.

PLAN TO END THE CYCLE OF FINANCIAL STRUGGLE

Our community members are experiencing physical, financial and mental stress on a daily basis. Many find themselves maxing out physically and emotionally with little left to field daily phone calls from bill collectors, re-apply for public benefit programs, research financial assistance programs, search for a job or job training, or strategize for financial sustainability.

The Helping Hands team proposed to-in addition to lending a “helping hand” to community members in crisis-develop a program to address the root causes of financial insecurity applicants face year after year, leading to the creation of the Helping Forward program, a program to empower community members to move forward from crisis into a sustainable future through career planning and financial management.

The current focus of Helping Forward is education, including:

- The Helping Forward webpage includes a robust set of resources to help community members understand their rights, options and resources related to employment and finances.
- The Employment Rights and Self-Advocacy courses on HFA’s Learning Central featuring videos, quotes and stories from 18 different community members. Lessons include an introduction to the topic of employment for people with bleeding disorders, the Americans with Disabilities Act (ADA), the Family and Medical Leave Act (FMLA) and tips for self-advocacy in the workplace.

Visit the website to sign up for the Helping Forward Network so you can learn and grow with the program.

Need help now or moving forward?

Helping Forward

www.hemophiliafed.org/HelpingForward

Helping Hands

www.hemophiliafed.org/helpinghands

Patient Assistance Portal

www.hemophiliafed.org/patientassistanceportal

Source: https://www.hemophiliafed.org/datetime/HFA_Dateline_2020_Q3_Fall/mobile/index.html#p=1



Making a difference in Peoples' lives

SERVICES INCLUDE:

- Nursing & Pharmacy 24/7
- Infusion Education & Training
- Reimbursement Specialists
- Direct Communication with the People You Know
- Same Day Delivery



Karen Price R.N., CLNC,
Clinical Infusion Specialist
kprice@superiorbiologics.com
314-954-4803



Judy Bagato RN, BSN
Hemophilia Specialist/Infusion Nurse
jbagato@superiorbiologics.com
618-558-1575

Office: 866.416.3655
Fax: 866.416.3656

Expertise in bleeding disorders

GO SEEK. GO EXPLORE. GO AHEAD.

PEOPLE LIKE YOU. STORIES LIKE YOURS.
Explore more at HEMLIBRAjourney.com



Discover your sense of go. Discover HEMLIBRA.

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.

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
 ©2018 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: 10/2018



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.
 ©2020 Genentech USA, Inc. All rights reserved. M-US-00007357(v1.0) 09/20

Genentech
 A Member of the Roche Group

Nationally Recognized, Centrally Located



Coming to Carbondale in 2021



9128 N Lindbergh Dr. Peoria, IL 61615 | 309.692.5337 | www.ilbcdi.org

Brittany Slossberg

Relationship builder

About Brittany

Brittany is a Hemophilia Community Liaison who has a passion for creating long-lasting relationships with others. She has built a strong comradery with many patients in the Colorado community.

Connect with Brittany

BTSO@novonordisk.com
(561) 289-3275



Hemophilia Community Liaison

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

Novo Nordisk is a registered trademark of Novo Nordisk A/S.

©2019 Novo Nordisk Printed in the U.S.A. US19HRBD00089 June 2019



The background of the top section of the page is a close-up photograph of several metal weight plates. The plates are arranged in a circular pattern, with some showing the number '25' and others '5'. The lighting is soft, highlighting the metallic texture and the edges of the plates.

Your Guide to Strength Training

Learn how to do weight workouts safely and effectively when you have a bleeding disorder.

Author: Matt McMillen

Strength training is an important part of a comprehensive exercise program, especially as you get older. It not only builds muscle and strengthens bones, but it also protects your joints. In addition to using dumbbells or weight machines at the gym, strength training can be done at home with kettlebells, resistance bands or even your own body weight. But before you embark on a new strength training program, it's important to understand the modifications your bleeding disorder may require you to make.

Talk to Your Physical Therapist and Physician

Your doctor or physical therapist can help you design a workout that your joints can handle. Your PT also can teach you how to do each exercise properly. Correct form is key to avoiding injury. Finally, because your joint health can fluctuate from day to day, ask your PT to show you how to rate your joints before each workout.

"You have to honestly assess which are your stronger joints and which need a more conservative approach during exercise," says Ruth Mulvany, PT, DPT, MS, retired associate professor of physical therapy and consultant to the University of Tennessee Hemophilia Treatment Center in Memphis.

Consider Classes

Guided group workouts also offer the benefits of connecting with others and the potential to make new friends. Or bring a friend with you. "You can motivate each other and enjoy being out and socially engaged in a very healthy activity," Mulvany says.

Use caution when picking a class, however. If you're a beginner, select classes that emphasize gentle, low-impact routines. If necessary, talk with the instructor about modifying your workout to account for target joints, and ask if he or she would be willing to discuss your needs with your PT. If not, try elsewhere. Even if you're a veteran of workout classes, you still want to talk to your PT before graduating to more intense classes.

"Group workouts are fun, energizing and beneficial if you have a good instructor who will modify instructions as needed," Mulvany says. "If you feel intimidated at first, find a spot in the back so you can pause or stop when you need to."

Exercise at Home

Turn on some music, a podcast, an audiobook or the TV as you lift or do body-weight exercises such as pushups and squats. Always warm up first for five to ten minutes by stretching and marching in place while swinging your arms back and forth or pedaling on a stationary bike at a moderate pace.

Plan Accordingly

If you use factor, protect your joints by timing your exercise session to coincide with the best period of factor coverage.

Pace Yourself

Don't ruin the fun with exercises that cause you joint pain or stress your joints. And don't forget to attempt to lift weights so heavy that you can't keep good, safe form. Plus, don't forget to stay well hydrated. And remember: Exercise brings on soreness, which often starts 24 to 72 hours after your workout. That's normal. But don't ignore pain, swelling and tenderness that signal a muscle or joint bleed.

"Start off well informed, pack away your competitive edge, make good decisions, be patient and go slow until you can see how you and your body respond to the challenges of strength training," Mulvany says. "Then enjoy the satisfaction of seeing your improvement."

Learn More:

Visit the National Hemophilia Foundation's **Steps for Living** website to find fitness videos and PT webinars, and to download the *Playing It Safe: Bleeding Disorders, Sports and Exercise* booklet.

Source: <https://hemaware.org/mind-body/your-guide-strength-training>

DONATIONS, HONORARIUMS, AND MEMORIALS

GHA gratefully acknowledges our donors who so generously contributed to the Chapter in the fourth quarter of 2020 with general donations, Honorariums, and Memorials.

\$3,000 - \$3,999

CSL Behring
Octapharma

\$2,000 - \$2,999

Bayer

\$1,000 - \$1,999

BioMarin
Genentech
Novo Nordisk
Takeda

\$500 - \$999

ARJ Infusion Services
FEFA
Medexus Pharma
Paragon Healthcare
Sanofi Genzyme

\$100 - \$499

Anonymous

Bagato, Judy
Bauman, Jake & Stephanie
Craven, Vicki
Duvall, Joe
Gindling, Judy
Johannes, Dan & Charla
Korte, Jennifer & Tom
Marema, Kristin & Brian
Miller, Mike & Kate
Nassif, Pat
Pratt, Rachel & Will
Pruitt, Don & Cheryl
Pustinger, Kim
Rodgers, Mark
Sampson, Steve & Sheri
Schroeder, Nikole
Shrout, Jeff
Sternberg, Denyse
Stringer, Trudy & Dirk
White, Lizzie

\$50 - 99

Amazon Smile
Brockmeyer, Steve
Dalton, Dave
Davis, Colby
Edler, Tracey
First National Bank of Carlyle
Klemmer, Jon
Miller, Stephanie & Byford
Pulcher, Amber
Schneider, Chris & Abby
Schuermann, Rich
The Wigge Family

\$1 - \$49

Belle, Megan
Case, Corey & Kristin
Craven, Kelly
Driemeyer, Rich
Escrip
Flores, Tony & Danielle

Hakenyos-Rizzi, Lenore
Hanse, Austin & Maria
Hepburn, Angela
Herbig, Lauren
Hileman, Kisha
Hoke, Nathalie
Kafai, Natasha
Kroupa, Dan
Leathers, Jeff
Litteken, Bill
McCaffrey, Brandon
McMahon, Melidan
McNamee, Jen
Mercurio, Erin
Moellenhoff, Kari
Moore, Chad & Lori
Noel, Rob & Chris
Norman, Todd
Nuetzel, Kelly
Orr, Jen
Paypal Giving Fund



Exploring the science behind gene therapy research

Gene therapy research has the potential to bring an entirely new option to people with specific genetic conditions. Many gene therapies are in clinical trials to evaluate the possible risks and benefits for a range of conditions, including hemophilia. HemDifferently is here with gene therapy education, providing accurate information on the basics and beyond.

What questions do you have? Get them answered. Explore gene therapy at [HemDifferently.com](https://hemdifferently.com)

No gene therapies for hemophilia have been approved for use or determined to be safe or effective.

BiOMARIN

© 2020 BioMarin Pharmaceutical Inc. All Rights Reserved. MMRC-GTH-0226 1120

Penning, Dawn
 Perez, Vanessa
 Petersen Williams, Brittany
 Powers, Nina
 Pratt, Abe
 Prewitt, Keith & Kim
 Rhodes, Lauren
 Robbins, Becca
 Robertson, Robin
 Ryan, Lindsay
 Sampson, Jordan
 Sandt, Louis & Rose
 Schweitzer, Keith
 Searcy, Melinda
 Sims, Janet & Bryan
 Stafford, Brandy
 Stringer, Andrew
 Taras, Lisa
 Trollinger, Amelia
 Tyrey, Bridget
 United Healthcare
 Watson, Sharon
 West, Brad
 West, Monika
 Woffard, Tiffany

Yoey, Kristin
 Yoey, John

Thank You
FACEBOOK FUNDRAISERS!

Gabi Flores
Steve Lirette
Jen McNamee
Stephanie Miller
Carmen Morales
Trudy Stringer
Monika West
Kristian Zack



Facebook Fundraisers are a great way to raise awareness of bleeding disorders and an easy way to raise money to support GHA! Facebook takes no fees from their fundraisers, so all money raised goes to GHA!

3 Easy Ways to Support GHA!

1

Schnucks E-Scrip Card

GHA gets \$\$ every time you shop!



1. Pick up a free E-Scrip card at your local Schnucks
2. Visit escrip.com to enroll and select GHA as your charity
3. Give the cashier your E-Scrip card at checkout

2

Amazon Smile

Amazon donates 0.5% of the price of your eligible Amazon Smile purchases to GHA!



1. Visit smile.amazon.com
2. Sign in to your amazon account (or create an account for free)
3. Select GHA as your charitable organization
4. Start shopping!

3

Fresh Thyme Giving Bags

\$1 from the sale of each Giving Bag will be donated to GHA!

1. Visit any Fresh Thyme Farmer's Market location
2. Purchase a reusable Giving Bag featuring a Giving Tag
3. Direct your donation to GHA!
4. Use your Giving Bag when you shop and help the environment!



Thank you 2020 Major Donors

\$10,000+

Hemophilia Alliance
 National Hemophilia Foundation

\$5,000+

Carney's Kids Foundation

\$2,500+

Boeing
 Hemophilia Federation of America
 Washington University

\$1,000+

Colburn-Keenan Foundation
 Bob & Gina Eschbacher
 FasterHouse
 Tom Guignon
 Kori & Julie Kleppe

Terry & Elena Larson

Midland Optical

MIDSCI

Paul Roderick

Andrew Stringer

Swink Coplen

\$750+

Jay Charpentier

Creative Supply Chain Solutions

Jeff Day

Dave Heyl

Dan & Charla Johannes

Jeff Karpel

Kristin & Brian Marema

Chris & Abby Schneider

500+

David & Kristi Campbell

Brian Hurst

Kiwanis Club of Hampton-Midtown

Scott Kupcho

Barbara Roderick

State Farm - Josh Arnold

Jamie Strange

UMB Bank

Tim & Colleen Walls

Patrick Welch

Jeff Witt





4976 Eichelberger Street
St. Louis, Missouri 63109
314.482.5973
www.gatewayhemophilia.org

Presort Standard
US Postage
PAID
St. Louis, MO
Permit No.

Email us at: info@gatewayhemophilia.org

GHA's Adult Retreat

April 16-18, 2021

The Lodge of 4 Seasons
315 Four Seasons Dr.
Lake Ozark, MO 65049

GHA's Adult Retreat is for adults age 19+ with a bleeding disorder and caregivers. Each adult may bring one significant other.

Register at gatewayhemophilia.org/adult-retreat
by March 26th.