

2020-21



**Midwest  
Hemophilia  
Association**

# **WELCOME!**

## **YOU BELONG HERE**

— with the *VIRTUAL* 28th Annual —  
**Family Education Weekend**  
September 19, 2020

1471 W. South Street, Suite F • Ozark, MO 65721

[info@midwesthemophilia.org](mailto:info@midwesthemophilia.org)

**[MidwestHemophilia.org](http://MidwestHemophilia.org)**



INNOVATIVE INFUSION SPECIALISTS, LLC.

[innovativeinfusion.net](http://innovativeinfusion.net)

## **WHY CHOOSE IIS?**

IIS is a Kansas-based company with experience providing the products you need, rather than a big corporate operation where patients are simply another number. The owners of IIS are closely involved with day to day operations and are committed to providing an optimal patient experience.

## **PERSONALIZED CARE PLANS**

At IIS we recognize that each individual patient requires a customized care plan. We work together with your provider, insurance and you, the patient, to meet your needs. We treat each individual as a person, not a number. IIS staff will regularly follow up with you to ensure you receive the care you deserve.

## **DELIVERED RIGHT TO YOUR DOOR!**

After establishing your therapy with IIS, we will arrange for delivery of your medication at a time and place that works best for you! We coordinate with you to deliver the medication, or if it is out of our delivery area, will ship the medication.

## **NEXT STEP?**

Ready to start treatment with us? Have more questions? Give us a call or go to [innovativeinfusion.net](http://innovativeinfusion.net) to setup an appointment online.

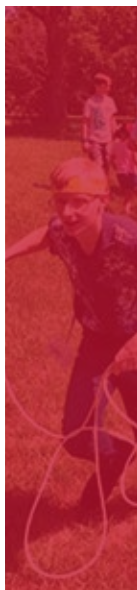
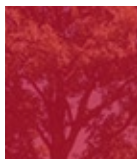
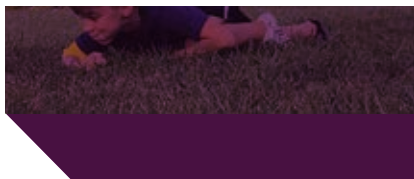


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CALL US AT: 316-613-8942 or 833-447-3733




# Table of Contents



**Midwest  
Hemophilia  
Association**

Welcome Letter .....	2
Board of Directors .....	3
<b>Fundraising Events:</b>	
Unite for Bleeding Disorders Walk-A-Thon .....	4
<b>Fundraising Events:</b>	
Annual Golf Tournament & Trivia Night.....	5
<b>Educational Events:</b>	
Summer Camp .....	6
<b>Educational Events:</b>	
Community Outreach .....	7
<b>Community Support:</b>	
Advocacy .....	8
<b>Community Support:</b>	
Scholarships.....	9
<b>Community Resource:</b>	
Financial Assistance Program.....	10 - 11
2019 Annual Report .....	12 - 13
<b>Family Education Virtual Agenda .....</b>	<b>14</b>
Family Education Weekend Sponsors.....	15
2020 Unite for Bleeding Disorders Walk.....	16 - 17



# **Welcome**

to the Midwest Hemophilia Association family! We believe you belong here. This brochure is intended to provide readers with a brief snapshot, a sort of family album, of our advocacy efforts, education programs, fundraising endeavors, the resources available to our bleeding disorders community and opportunities for you to get involved. Please browse through the pages and keep it as a reference tool to stay connected.

**Brief History.** Founded in 1990, the Midwest Hemophilia Association (MHA), a 501©3 non-profit, serves individuals and families in Kansas and Western Missouri with hemophilia, von Willebrand disease, and other bleeding disorders. Our mission is to improve the quality of life of those affected by bleeding disorders through education, advocacy, and support. We currently offer a range of programs and services, made possible through the generosity of individuals, corporations, and foundations with the belief that our mission to improve the quality of life, can also prevent disability and enable persons to live active, fulfilling lives.

**What is a bleeding disorders?** A bleeding disorder is a genetic blood clotting deficiency caused by the absence or inactivity of an essential blood clotting protein, or “factor.” This deficiency causes the body to form unstable blood clots that allow bleeding to continue longer than normal.

A person with a bleeding disorder can experience frequent and often spontaneous episodes of prolonged bleeding. The most severe cases can have extensive bleeding into joints, muscles, and vital organs, resulting in life-threatening emergencies and crippling long-term complications.

Hemophilia and related bleeding disorders, such as von Willebrand disease, are genetically inherited. However, one in three diagnosed cases of hemophilia results from a spontaneous genetic mutation where there is no family history of abnormal bleeding.

**What is the treatment?** Hemophilia treatment includes replacing the missing blood clotting factor so the blood can clot properly, typically done by injecting treatment products, called factor concentrates. Prophylactic care is recommended by the CDC and most clinicians to prevent bleeding episodes from occurring. It is possible for individuals and families to learn how to give their own factor clotting treatment products at home, resulting often in quicker treatment and less serious bleeding and fewer side effects. The kind of treatment for von Willebrand disease depends on the type and severity, but may include nasal spray, birth control, antifibrinolytic drugs, and/or factor replacement therapy.

# 2020 Board of Directors

## EXECUTIVE DIRECTOR

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**ANGELA BROWN**

*angela.brown@midwesthemophilia.org*

## 2020 BOARD OF DIRECTORS OFFICERS

---



**NORA ANCEL**  
**PRESIDENT**

*nora.e.ancel@gmail.com*



**BRIDGET CASTRO**  
**VICE PRESIDENT**

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**JACI COLTER HEITMAN**  
**TREASURER**

*treasurer@midwesthemophilia.org*

## 2020 BOARD OF DIRECTORS MEMBERS

---



**HEATHER INCE**

*Hince2013@gmail.com*



**JENNIFER RENTSCHLER**

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**DAKOTA ROSENFELT**

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*KRosenfelt@hotmail.com*



**MAREENA SNAREY**

*Snarey@gmail.com*



**CODY YORK**

*Cyxq6@mail.umkc.edu*

## Fundraising Events:

# UNITE for Bleeding Disorders Walk-A-Thon

The UNITE for Bleeding Disorders walk is an annual nationwide event held throughout the year in over 40 cities in the U.S. to raise funds and awareness for bleeding disorders.

As part of the UNITE for Bleeding Disorders fundraiser, our chapter hosts a walk in the Kansas City area bringing together the bleeding disorders community and their supporters to raise crucial funds for our organization. 100% of the donations raised go directly to MHA's services and programs which help us meet our mission to improve the quality of life for those affected by bleeding disorders with education, advocacy, resources, and support!

The 2020 Unite for Bleeding Disorders walk has transitioned to a virtual celebration to be held October 10th, with awards, recognition, and raffles. We welcome family, friends, neighbors, co-workers, teachers, coaches, leaders of our community and the general public to join us in our efforts! We also gladly accept individual and/or business sponsorships. To register and donate visit: **<https://midwesthemophilia.org/events/mha-2020-unite-walk/>**

\*The hope and plan for 2021 Unite for Bleeding Disorders is to be back in-person in the Kansas City area.





## Fundraising Events:

# Annual Golf Tournament & Trivia Night

In addition to the UNITE for Bleeding Disorders Walk-A-Thon, MHA hosts two additional fundraising events each year: Trivia Night held in the spring and the annual MHA Golf Tournament held in the fall.

The MHA Annual Golf Tournament is in its 22nd year of supporting our efforts for our bleeding disorders community. Open to everyone, the golf tournament offers another opportunity to support MHA's mission. Beginning with breakfast and a shotgun start, participants compete for team and individual prizes as well as raffles. An awards luncheon with bleeding disorder awareness follows at the conclusion of play. The 2020 contest was held at Winter Stone Golf Course in Independence, Missouri. To sponsor, participate or serve on the golf committee in September 2021, contact the MHA office.

Only in its second year, the annual Trivia Night Fundraiser is growing! Again, open to the public, our community, industry partners, and business sponsors there is no shortage of displays of knowledge, laughter, music, and food as teams battle for bragging rights of being the "Smarty Pants" team! Funds raised from entry fees and sponsorship donations benefit our local chapter! Grab your friends and be part of the fun! Visit our website for upcoming details.



## Educational Events:

# Summer Camp

In its 29th year, Camp Wilderness is our most beloved activity held every summer for kids ages 7-17 who are diagnosed as carriers, with hemophilia, von Willebrand disease, and/or platelet disorders. Our camp mission is to provide campers with a fun, safe, and educational experience along with opportunities to build relationships with others diagnosed with similar bleeding disorders. Camp is a unique place where kids can discuss and share their experiences of living with a bleeding disorder and know that they are heard and understood. For some, it is the only opportunity to meet peers who also have bleeding disorders. Campers receive onsite medical care and education, including supervised self-infusion skills, healthy habits, and the benefits of maintaining an active lifestyle.

Sadly, Camp Wilderness 2020 could not happen in person due to COVID-19. So, we have done our best to create an online virtual experience during Family Education Weekend where our beloved campers can chat, play camp games, receive health education, and support each other despite the circumstances. Campers also were able to sign up to receive a camp care package.





## Educational Events:

# Community Outreach

Health education relative to bleeding disorders is an imperative part of what MHA provides to our community. At times, that can be a challenge because MHA's coverage area spans over 100,000 square miles. In order to reach as many people as possible, MHA hosts Education Days and Community Outreach Programs by traveling to Garden City, KS, Wichita, KS, Springfield, MO, and Kansas City, KS/MO. A variety of topics are offered each year such as emergency preparedness, mental health, food and fitness, joint health, physical therapy, insurance, and many others.

With most of our 2020 events (and possibly some in 2021) being moved to a virtual platform due to the COVID-19 pandemic, we have been able to reach a larger portion of our community members together in one virtual space—including some who are unable to normally attend in-person outreaches. So, in a way, this aspect of the health crisis has been a positive experience for our MHA members.

Moving forward in 2020-2021, we will make every attempt to be in person (within health guidelines) as we greatly miss gathering as a family. At the same time, we are researching options to include a virtual portion to our live, in-person events as we saw the benefits for our outlying members to attend without the long travel.

Be sure to visit our website calendar for details of all our future events. **[www.midwesthemophilia.org](http://www.midwesthemophilia.org)**



## Community Support:

# Advocacy

Advocacy and awareness are essential aspects of support provided to our bleeding disorders community. Our advocacy committee and member representatives gather annually at both state and national levels to discuss important issues, needs and for access to care with elected officials and other government representatives. MHA collaborates with the Gateway Hemophilia Association in St. Louis, Missouri, to form the Missouri Bleeding Disorders Advocacy Coalition coming together in Jefferson City, Missouri, to address state issues. We also participate in the National Hemophilia Foundation's Washington Days in Washington D.C. along with representatives from the Hemophilia Federation of America and chapter leaders from across the United States. In 2020, our focus was continued funding for national programs and access to care to skilled nursing facilities.

We believe the most impactful way to advocate and bring awareness is when someone shares their bleeding disorder story with their family, a friend, a neighbor, teacher, coach, doctor or anyone that may cross their path. Each time these experiences are told, another step towards better understanding, general support, and needs-awareness is achieved. MHA has been following legislation in Kansas. We are needing to expand our advocacy efforts for our constituents there. If you or someone you know would like to be part of this group, please contact the MHA office.





## Community Support:

# Scholarship

From our inception as an organization in 1990, MHA has always believed in education. One way we encourage our younger community members to continue their education is by providing scholarships to assist with the costs of secondary education.

The Midwest Hemophilia Association Scholarship was established and has been offered for the past 25+ years. In 2016, the Board authorized a second scholarship, the Mark Dudley Scholarship, in honor of our past board treasurer. These two scholarships together have awarded over \$30,000 in educational funding.

MHA also offers the Georgia Northway Scholarship, which is managed by the Truman Heartland Community Foundation. The scholarship was established when MHA was named an estate beneficiary of Georgia Northway from the Wichita, Kansas area. Ms. Northway had two sons that had passed away due to complications from hemophilia. It was her wish that part of her estate be utilized to create a scholarship fund for individuals with bleeding disorders. Truman Heartland received \$423,924.87 in 2003 to start the scholarship. Each year, approximately 5% of the principal balance is available for scholarships, resulting in awards of \$293,188.44 in 113 scholarships to over 43 students. The great part of the Georgia Northway Scholarship is that it is renewable. Recipients can re-apply each year, potentially receiving funding beyond freshman year. In 2020-2021, a total of \$26,000 in scholarship funds were awarded.

Deadlines for all three scholarships are in late spring each year. Details and applications can be found on [MidwestHemophilia.org](http://MidwestHemophilia.org).

### **2020-2021 GEORGIA NORTHWAY SCHOLARSHIP RECIPIENTS:**

*William Carter, Ramsey Divine, Elizabeth Hancock,  
Alexander Ince, Claire Madden, Kolbe Madden*

### **2020-2021 MIDWEST HEMOPHILIA ASSOCIATION SCHOLARSHIP RECIPIENT:**

*Jacob Zink*

### **2020-2021 MARK DUDLEY ACADEMIC SCHOLARSHIP RECIPIENT:**

*Spencer Brown*

## Community Resource:

# Financial Assistance Program

It has been MHA's Board of Directors' vision and goal for several years for to create a resource to help families and individuals in our bleeding disorders community experiencing financial hardship. While researching and developing guidelines, fundraising for a program began in late 2019 with a successful Giving Tuesday online fundraiser

In April of 2020, the Board of Directors approved the Financial Assistance Program with guidelines, the application being added to the MHA website, and opened for requests. The chapter has been able to fully fund each request submitted thus far.

To be eligible for this program you must meet the following criteria:

- You must live within the geographical service area of MHA.
- You must be the parent or caregiver of a minor child who lives in your home and who has a diagnosis of a bleeding disorder; OR be an individual with a diagnosis of a bleeding disorder.
- You must have requested assistance from TWO (2) other agencies before applying to MHA and provide contact information for those agencies and the status of your requests.
- You must complete all sections of the application thoroughly and accurately.
- Because of limited funds, MHA reserves the right to take into consideration whether an applicant has been a "no show" as defined in its Event Registration and Attendance policy.

Financial assistance depends on the availability of funds and applicant eligibility. Funding is not guaranteed. Applicants should allow at least two weeks for MHA to process their request. Assistance is limited to a maximum of \$500 per household. MHA assistance is limited to once every two years. In the presence of special circumstances, the MHA Board of Directors will review exceptional requests.

Disbursements will be made only to creditors identified in the application and that have been verified by MHA. No payments will be made directly to applicants.

Applications and information pertaining to funding requests are considered confidential but may be use for statistical purposes, and for compliance with local, state, federal or affiliate organization requirements. No personal information will be used or disclosed for any purpose other than that for which it was collected. At no time will personal information be shared with any individual, company or organization outside of MHA.

## FINANCIAL ASSISTANCE PROGRAM REQUEST PROCESS:

1. Application forms are available by calling the MHA office at 816-479-5900, by emailing a request to [info@midwesthemophilia.org](mailto:info@midwesthemophilia.org), or by downloading from <https://midwesthemophilia.org/financial-assistance-program/>
2. Completed applications and a copy of the bill must be submitted by mail to:  
1471 W. South St, Suite F, Ozark, MO 65721  
OR email: [info@midwesthemophilia.org](mailto:info@midwesthemophilia.org)
3. The MHA staff will review applications for completeness, check references, and consider the date the funds are needed to determine urgency of the request.
4. Applications should be submitted directly to the MHA office by the applicant. If this is not possible and it is necessary for another person to submit the application on behalf of the applicant, MHA representatives will contact the applicant before the application will be processed.
5. MHA strongly encourages applicants to coordinate their request with the social worker (or nurse coordinator) at their hemophilia treatment center or other healthcare provider treating bleeding disorders.
6. Incomplete applications will be returned to the applicant with an explanation of why it was returned, and a description of the information still required.
7. Complete applications will be sent to the Financial Assistance Committee for review.
8. If the application is approved, MHA staff will notify the applicant, and payment will be issued to the creditor identified on the application.
9. If the application is rejected, MHA staff will notify the applicant with an explanation.
10. MHA staff will update its Financial Assistance Program records and add the applicant to the MHA database for future communications.

*Note: This program is intended to help individuals and families who have exhausted all other sources of assistance and for whom no other funds are available.*

Individual donations, grants and other fundraisers currently support this fund. Additional contributions can be made at **[midwesthemophilia.org](https://midwesthemophilia.org)** by clicking the donate button. Contributions can also be mailed to P.O. Box 412866, Kansas City, MO 64141 or to the physical office at 1471 W. South St, Suite F, Ozark, MO 65721.





# 2019 Annual Report

## Where the Money Comes From

Event & Newsletter  
Sponsors

**\$156,376**

Donations,  
Memorials  
& Misc.

**\$4,796**

Fundraisers

**\$42,334**

Activity  
Fees & Dues

**\$700**

Interest Income

**\$10,155**

**TOTAL INCOME**

**\$214,361**

## Where the Money Goes

Educational Services

**\$119,442**

Operating  
Costs

**\$41,144**

Supporting  
Services

**\$70,130**

Scholarships

**\$26,000**

**TOTAL EXPENSES**

**\$256,716**

## Event Breakdown by Dollars



### UNITE WALK

**INCOME:** \$ 15,697

**EXPENSE:** \$ 3,989

**PROCEEDS:** \$ 11,708



### GOLF TOURNAMENT

**INCOME:** \$ 22,522

**EXPENSE:** \$ 11,567

**PROCEEDS:** \$ 10,955



### TRIVIA NIGHT

**INCOME:** \$ 4,115

**EXPENSE:** \$ 1,333

**PROCEEDS:** \$ 2,782

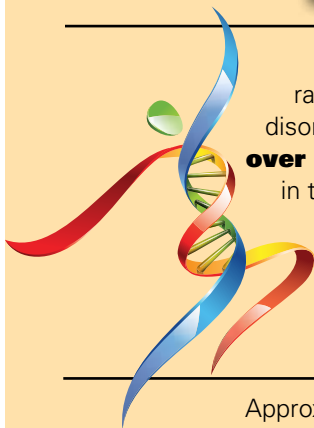


The Midwest Hemophilia Association supports the bleeding disorders communities in **KANSAS** and **WESTERN MISSOURI**.

Number of  
events hosted  
by MHA  
in 2019

13

Hemophilia is a  
rare inherited blood  
disorder which affects  
**over 20,000 people**  
in the United States.



Approximate number of  
people reached through MHA's  
annual programs & resources

460



**Midwest  
Hemophilia  
Association**



**NATIONAL HEMOPHILIA FOUNDATION**  
*for all bleeding disorders*



Midwest Hemophilia  
Association is a proud  
Member Organization of  
the Hemophilia Federation  
of America (HFA) and  
an affiliated chapter of  
the National Hemophilia  
Foundation (NHF).



# Family Education Weekend Agenda

## Saturday, September 19

8:45am	<b>Zoom Login Open</b>
9:00am	Welcome and Opening Ceremony <b>RAFFLE!</b>
9:30am	<b>Room 1: Adversity, Strength, &amp; Resilience</b> <i>Presented by Jeff McFall</i> <b>Room 2: Braving Change</b> <i>Presented by Danielle Kempker</i>
10:15am <i>Visit our virtual sponsors</i>	<b>BREAK 1: Sponsor Recognition &amp; MHA News Brief</b> <b>RAFFLE!</b>
10:30am	<b>Room 3: Haciendo el Grado/Making the Grade (Spanish Session)</b> <i>Presented by Annabelle Garcia</i> <b>Room 4: How to Communicate with Your Child's School</b> <i>Presented by Penni Smith</i>
11:15am <i>Visit our virtual sponsors</i>	<b>BREAK 2: Sponsor Recognition &amp; MHA Trivia</b> <b>RAFFLE!</b>
11:30am	<b>Room 5: Who Am I?</b> <i>Presented by Amber Federizo, APRN, FNP-BC</i> <b>Room 6: Hiding Behind 'Normal'</b> <i>Presented by John Vieke</i>
12:15am <i>Visit our virtual sponsors</i>	<b>BREAK 3: Lunch Break</b> <b>RAFFLE!</b>
12:45pm	Kansas City Regional HTC Update <i>Presented by Dr. Lauren Amos, MD</i> <b>Awards &amp; Recognition (Adult Closing)</b> <b>RAFFLE!</b>
1:30-2:30pm <i>Visit our virtual sponsors</i>	<b>Session A: Camp Wilderness Virtual Bonfire</b> <i>Ages 7-12 years</i>
3:00-4:30pm <i>Visit our virtual sponsors</i>	<b>Session B: Camp Wilderness Virtual Bonfire</b> <i>Ages 13-17 years</i>



# Family Education Weekend Sponsors

## PLATINUM

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CSL Behring  
Octapharma  
Pfizer  
Takeda

## GOLD

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Novo Nordisk  
Sanofi Genzyme

## SILVER

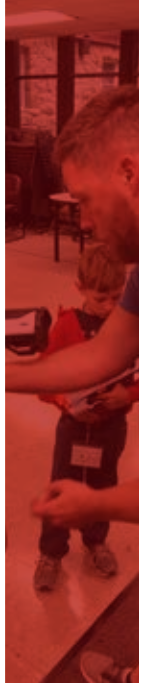
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Accredo  
Bayer  
BioMarin  
Brother's Healthcare  
CVS Specialty  
Genentech

## BRONZE

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ARJ Infusion Services  
Soleo Health



# Unite



for Bleeding Disorders

Join us ***VIRTUALLY***  
**October 10, 2020 @ 10:00am**  
to **UNITE** in celebration &  
for chances to win raffle prizes!

Each year, the Midwest Hemophilia Association hosts an annual Walk to bring together the bleeding disorders community of Kansas and Western Missouri and their supporters to raise crucial funds for the organization! The donations raised go directly to MHA's services and programs like Camp Wilderness, Family Education Weekend & Outreach Programs.

**WE HAVE SET OUR GOAL  
TO RAISE \$20,020 IN 2020!**

***WE BELIEVE YOU  
CAN HELP US DO IT!***

**REGISTER TODAY!**

Visit [www.uniteforbleedingdisorders.org](http://www.uniteforbleedingdisorders.org) and click "Find a Walk". Search for walks in Kansas. Once on the local page, click **REGISTER NOW** to form your team!



# **WE ARE ASKING 500 PEOPLE TO REGISTER & DONATE \$10, THEN ASK TWO PEOPLE THEY KNOW TO DONATE \$10.**

We know things are financially tough for some,  
but believe there are those who can and  
want to give to a great cause like MHA.

If you can give, great! Consider “spotting”  
an extra \$10 for someone who cannot right now.

If you can't financially give, you can still be part  
of the experience by registering. Then invite your friends,  
family, neighbors, coaches, teachers,  
and others to give \$10 to your team.

Share on social media, in an email, be creative!

## **2020 INCENTIVE PROGRAM**

Recognition and prizes for **Top Individual Fundraiser**,  
**Top Team Fundraisers**, and **Largest Team** (based on # of registered  
team members under one team captain).  
Plus fundraising incentives!



2020 Unite Walk Tshirt  
**Raise \$25 or more**



Thermal Cooler  
**\*\*Raise \$250-\$499**



Bluetooth Wireless Headphones  
**\*\*Raise \$500-\$999**



Bluetooth Wireless Speaker  
**\*\*Raise \$1,000-\$2,499**



Rolling Duffel Bag  
**\*\*Raise \$2,500 or more**

# HELPFUL NUMBERS

**Kansas City Regional Hemophilia Center**  
1-816-302-6869 • 1-800-236-1713

**University Of Missouri Hospital & Clinics  
Hemophilia Treatment Center**  
1-573-882-9355

**National Hemophilia Foundation (NHF)**  
1-800-42-HANDI • [www.hemophilia.org](http://www.hemophilia.org)

**Hemophilia Federation Of America (HFA)**  
202-675-6984 • [www.hemophiliafed.org](http://www.hemophiliafed.org)

**Washington University  
St. Louis, MO**  
314-721-2084



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# HemDifferently

## 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 in a way you can understand.

Let's explore gene therapy together at  
**HemDifferently.com**

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

**BioMARIN**

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# To me, it's personal.

As a Community Relations and Education Manager for Sanofi Genzyme, I'm here to help provide support and resources for you and the Missouri hemophilia community.

Vicki Oberkrom  
CoRe Manager of Missouri



## Let's connect.

Call, text, video chat: 660-281-9518  
Email: [vicki.oberkrom@sanofi.com](mailto:vicki.oberkrom@sanofi.com)  
Facebook: @HemophiliaCoRes

**SANOFI GENZYME** 

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HEM-US-7108 3/20



# Jivi® Extension Study

Explore the study design and see the safety and efficacy data from patients who were part of the study.

► Dive in at [JiviExtensionStudy.com](https://www.JiviExtensionStudy.com)



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**CSL**

**Driven by  
Our Patients**

CRP-0067-APR19

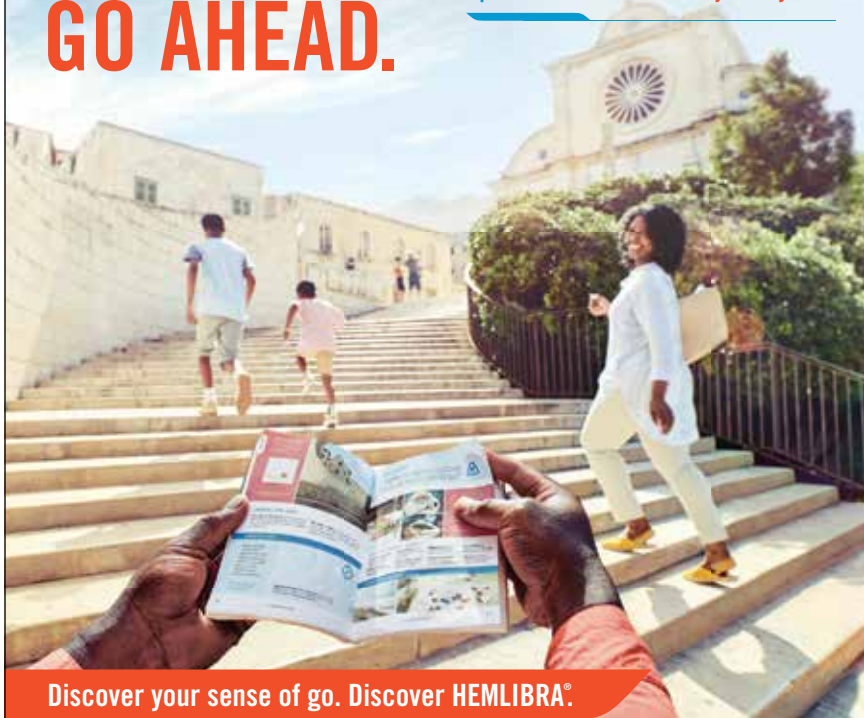


LEARN MORE AT  
**IDELVION.COM**

IDL-0350-JUL19

GO SEEK. GO EXPLORE.  
**GO AHEAD.**

PEOPLE LIKE YOU. STORIES LIKE YOURS.  
Explore more at [HEMLIBRAjourney.com](https://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. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. HEMLIBRA may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). 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.**

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 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,  
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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: 10/2018



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