

# THE ROCKY MOUNTAIN

Rocky Mountain Hemophilia



& Bleeding Disorders Association



RMHBDA is a 501(c)(3) nonprofit organization founded in 2000 and is a chartered chapter of the National Bleeding Disorders Foundation.

Our mission is to improve the quality of care and life for persons with inherited bleeding disorders, including hemophilia and von Willebrand Disease through education, peer support, resources, and referral.

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### Rocky Mountain Hemophilia & Bleeding Disorders Association

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www.rmhbda.org

Brad Benne, Executive Director,  
brad@rmhbda.org



www.facebook.com/rmhbd

## Note from the Executive Director

RMHBDA Family,

We raised more than \$69,000 at our 13<sup>th</sup> annual UNITE for Bleeding Disorders Walk. That is a new fundraising record for our chapter! Thank you to all who participated and donated. We had over 90 people attend our Walk, a larger crowd than 2023! Well done, RMHBDA! We still need your help, even if you can't walk in Billings



with us in 2025, please consider a small donation to YOUR chapter! In 2024, we distributed \$3,000 in scholarships and over \$19,000 in patient assistance. Please reach out to me if you have ideas or suggestions to make our walk more engaging for you and your family.

CSL Behring hosted our annual dinner and golf clinic the night before the Walk. We are grateful for CSL Behring's support. I want to personally send a very gracious "thank you" to our volunteers, team captains, and walkers for making our Walk beyond successful. I would be remiss to not mention our corporate sponsors: Billings Clinic, HF Healthcare, Takeda, Bayer Healthcare, Fifth Street Design, Drug Co, Genentech, Stillwater Hospice, Colburn Keenan Foundation, the University of Colorado – Hemophilia & Treatment Center, Octapharma, Optum, Sanofi, Intermountain Health, CSL Behring, Novo Nordisk, Pfizer, and Restore RX.

With gratitude,

Brad Benne, Executive Director



## Family Retreat 2025

April 4 – 6

Our Family Retreat will take place at Fairmont Hot Springs in Fairmont, Montana.



### We need help organizing!

Please contact Brad at 406.586.4050 if you are interested in serving on the Education Weekend committee.

This is **your** organization! 📌



## RMHBDA Women's Retreat

### Chico Hot Springs, November 1-3, 2024

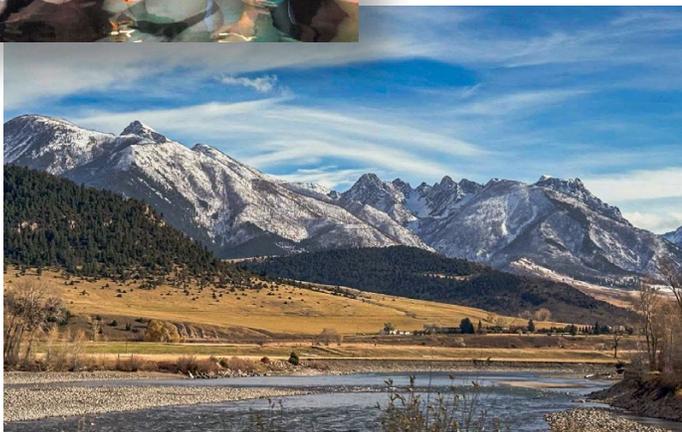
Twenty-eight women attended our annual women's retreat. The retreat evening began with a welcome and gathering of women from RMHBDA. Friday evening was a time for women to connect with our industry sponsors during exhibit time. We are deeply grateful for the sponsors of our women's retreat which include: CSL Behring, Novo Nordisk, Octapharma, Genentech, Bayer Healthcare, Takeda, Sanofi, Pfizer, HFA, and our UC-HTC.

Saturday morning's events began with eight of our industry sponsors giving an overview of their respective companies and products while the women enjoyed breakfast. Our two guest speakers rounded out the morning.

Saturday afternoon continued with half-hour massages, soaking in the hot springs, time to connect with others, and discussing what was learned and sharing stories. Dinner in the dining room capped off an eventful day of learning, sharing, and connection.

Sunday's brunch was the final goodbye and wishes for safe travel.

Thank you to all that provided support for this event. The women's retreat is an important program for the affected mothers, daughters, and caregivers, with most women being a combination of all. This retreat is about learning, sharing, and finding the time to recharge to be able to handle all that a lifelong bleeding disorder can throw at you. 💎



**SAVE THE DATE**  
**OCT 24-26, 2025**  
**WOMEN'S RETREAT**

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

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

# YOUR LIFE IS YOUR CANVAS

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

Keep Painting Your Story



Patient Portrayal



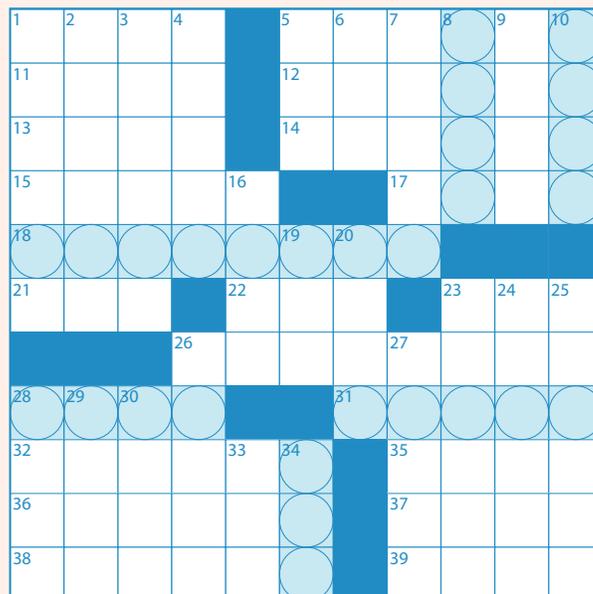
Get access to  
**Takeda Patient Support**



**CAN YOU SOLVE**

**FOR A DIFFERENT HEMOPHILIA A TREATMENT?**

**Test your HEMLIBRA knowledge**



**ACROSS**

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

\*According to IQVIA claims data from various insurance plan types from April 2020 - May 2021 and accounts for usage in prophylaxis settings in the US.

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

† Number of people with hemophilia A treated as of October 2021.

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

**DOWN**

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

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

**SOLUTIONS**

**Across:** 1. cask, 5. chasms, 11. Aden, 12. parish, 13. tore, 14. used to, 15. cruel, 17. nest, 18. HEMLIBRA, 21. yrs, 22. rue, 23. MCS, 26. passport, 28. zero, 31. three, 32. eyelid, 35. Oreo, 36. anose, 37. tall, 38. lessen, 39. oles  
**Down:** 1. catchy, 2. adorer, 3. serum, 4. kneel, 5. CPU, 6. has, 7. arena, 8. side, 9. MSTs, 10. shot, 16. lira, 19. bus, 20. rest, 23. mortal, 24. Creole, 25. steels, 26. polos, 27. photo, 28. zeal, 29. Eyre, 30. Reis, 33. ESE, 34. ten

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

**INDICATION & IMPORTANT SAFETY INFORMATION**

**What is HEMLIBRA?**

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

**What is the most important information I should know about HEMLIBRA?**

**HEMLIBRA increases the potential for your blood to clot. People who use activated prothrombin complex concentrate (aPCC; Feiba®) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots.**

**These serious side effects include:**

- **Thrombotic microangiopathy (TMA)**, a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs
- **Blood clots (thrombotic events)**, which may form in blood vessels in your arm, leg, lung, or head

Please see Brief Summary of Medication Guide on following page for Important Safety Information, including **Serious Side Effects**.



**Medication Guide**  
**HEMLIBRA® (hem-lee-bruh)**  
**(emicizumab-kxwh)**  
**injection, for subcutaneous use**

**What is the most important information I should know about HEMLIBRA?**

**HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.**

**HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:**

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
  - confusion
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - stomach (abdomen) or back pain
  - nausea or vomiting
  - feeling sick
  - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - swelling in arms or legs
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - trouble seeing

**If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.**

**Your body may make antibodies against HEMLIBRA, which may stop HEMLIBRA from working properly. Contact your healthcare provider immediately if you notice that HEMLIBRA has stopped working for you (eg, increase in bleeds).**

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

**What is HEMLIBRA?**

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

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

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

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

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

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

**How should I use HEMLIBRA?**

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

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

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

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

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

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

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

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

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

**How should I store HEMLIBRA?**

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

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

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

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

**What are the ingredients in HEMLIBRA?**

**Active ingredient:** emicizumab-kxwh

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

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

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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: 12/2021



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# BD SUMHAC

Bleeding Disorders Substance Use & Mental Health Access Coalition



## Resources for People with Bleeding Disorders & Their Loved Ones

If you or a loved one has been denied access to an inpatient/residential mental health or substance use disorder treatment facility because of a BD, don't give up! BD SUMHAC has tools to help get you the treatment you need and deserve.



## Resources for Providers Who Work With People with Bleeding Disorders

BD SUMHAC has developed a toolkit for medical providers that has recommendations for overcoming common barriers to behavioral health access.

# NHF IS NOW NBDF!

NATIONAL BLEEDING DISORDERS FOUNDATION



### Save the Date!

**September 6, 2025, ZooMontana, Billings, Montana**

**Dinner on September 5** sponsored by CSL Behring, all walk attendees will be provided hotel lodging September 6 and childcare on September 7. 



**Unite**  
for Bleeding Disorders

### 2025 Calendar

-  **January 17–19** RMHBDA Education Weekend, Bozeman Health, Bozeman, Montana
-  **March** Hemophilia Awareness Month
-  **April 17** World Hemophilia Day
-  **April 4–6** RMHBDA Family Retreat, Fairmont Hot Springs, Fairmont, Montana
-  **May** (dates TBD) Education & Dinner Seminars, (locations TBD)
-  **July** (dates TBD) Mile High Summer Camp: Teens, Rocky Mountain Village, Empire, Colorado
-  **July** (dates TBD) Camp for Kids: Kids 7–18, Rocky Mountain Village, Empire, Colorado
-  **July** (date TBD) 2<sup>nd</sup> Annual Pickleball Fundraiser, Jackson, Wyoming
-  **September 5** RMHBDA UNITE Walk Golf Clinic & Dinner, Yegen Golf Club & Dinner (Hampton Inn), Billings, Montana
-  **September 6** RMHBDA UNITE Walk, ZooMontana, Billings, Montana
-  **October** (dates TBD) Education & Dinner Seminars, (locations TBD)
-  **October 24–26** RMHBDA Women's Retreat, Boulder Hot Springs, Boulder, Montana



# Matthew Chapman

Patient advocate

## About Matt

Matt is a Novo Nordisk Rare Blood Community Liaison who is motivated by meaningful work and enjoys making music, being outside, and gardening. Having grown up in the hemophilia space, he has held many different positions within it and is passionate about serving his community.

## Connect with Matt

[MVHP@novonordisk.com](mailto:MVHP@novonordisk.com)  
(541) 420-5796

## Rare Blood Community Liaison

OR, WA, AK, ID

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**Register now for *Symposium 2025!***



# **HFA 2025** **SYMPOSIUM**

Navigating the Future, Together  **San Diego**

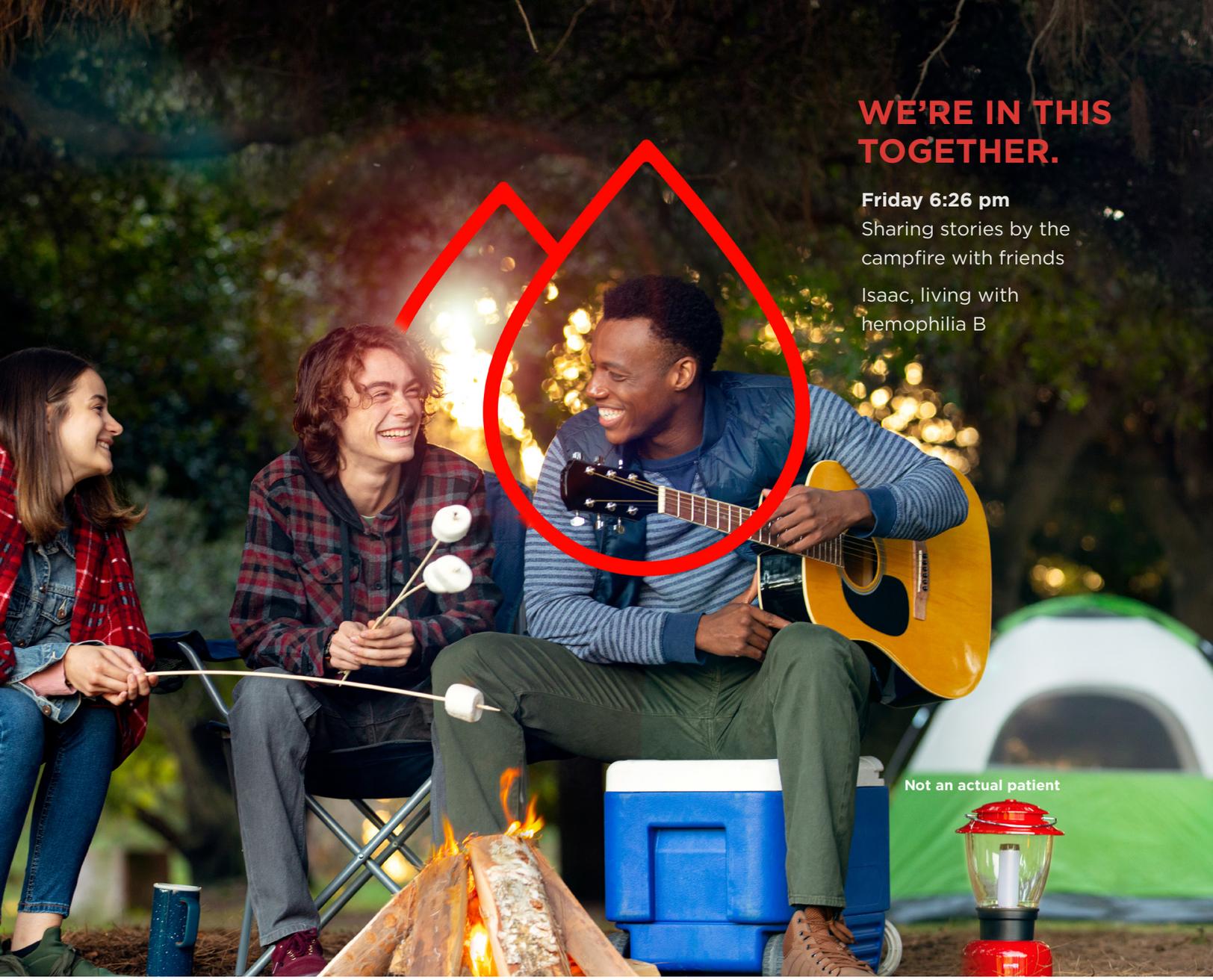
**Connect with your community at one of America's most beautiful locations!**

- Valuable educational sessions for severes, milds, rares and more.
- Rap sessions and information for men, women, parents and Spanish-speaking community members.
- Connect with friends, who are like family, and end with a fun Final Night Event!

Scan QR to stay connected and register.



**[www.hfasymposium.org](http://www.hfasymposium.org)**



## WE'RE IN THIS TOGETHER.

Friday 6:26 pm

Sharing stories by the campfire with friends

Isaac, living with hemophilia B

Not an actual patient

### Let's make today brilliant.

Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world is stronger than ever.

 [bleedingdisorders.com](https://bleedingdisorders.com) | 



# #TreatmentForAll

Help shape a future where all people with inherited bleeding disorders are diagnosed and have access to care, regardless of type of bleeding disorder, gender, or where they live.

## Support our work:

Become a  
Global Champion!



Scan the QR code  
or [click here!](#)

Join us in Madrid for the  
WFH 2024 World Congress:



Scan the QR code  
or [click here!](#)





**Doing our part by sharing what we have.  
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Dedicated Professionals.**

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**WINTER 2024-25**



Rocky Mountain Hemophilia



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