

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 Hemophilia 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.

In This Issue

- Note from the Executive Director 1
- Education Weekend 2023 1
- RMHBDA Women's Retreat 2
- A Tribute to Val Bias 3
- Teen Retreat/Family Camp 2023 6
- Save the Date! 6
- 2023 Calendar 11
- RMHBDA Education Scholarship 2023 11

Rocky Mountain Hemophilia & Bleeding Disorders Association

1627 West Main Street, #142
Bozeman, Montana 59715
406.586.4050

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 \$65,000 at our 11th annual UNITE for bleeding disorders walk. That's a new walk fundraising record for our chapter! Thank you to all of you that participated and donated. That's the good news, the bad news is we had the smallest group of walkers we've ever had, and the lowest number of donations from our



chapter members that we've ever collected. I believe we can change that in 2023. We need your help, even if you can't walk in Billings with us in 2023, please consider a small donation to YOUR chapter! 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 dinner the night before the walk and a golf clinic with senior golf professional, Perry Parker. We are grateful for CSL Behring's support, and Perry is always a big hit the night before our walk. 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: Vensure, St. Vincent's Healthcare, Billings Clinic, Barnard, Takeda, Bayer Healthcare, Fifth Street Design, First Interstate Bank, Drug Co, Genentech, Stillwater Hospice, Jana Graham Photography, BioMarin, Colburn Keenan Foundation, the University of Colorado – Hemophilia & Treatment Center, Octapharma, CSL Behring, Novo Nordisk, Pfizer, Restore RX,

With gratitude,

Brad Benne, Executive Director



Education Weekend 2023

April 21 – 23

Our Education Weekend 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! 💧



Unite

for Bleeding Disorders

RMHBDA Women's Retreat

Chico Hot Springs, November 4-6, 2022

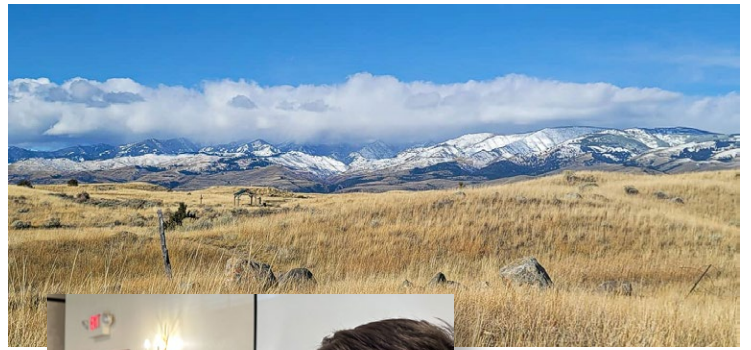
Twenty-seven women attended our annual women's retreat. The evening began with a welcome and gathering of women from RMHBDA. Friday evening was a time for women to connect with our industry sponsors during exhibit time. We are deeply grateful for our sponsors of our women's retreat which include: CSL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

Saturday mornings events began with seven of our industry sponsors giving an overview of their 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 breakfast was the final goodbye with 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 — most women being a combination of all. This retreat is about learning, sharing, and finding time to recharge to be able to handle all that a lifelong bleeding disorder can throw at you. 💖



A Tribute to Val Bias

Val transformed the NHF chapter network unifying and strengthening our voice and impact from the statehouse to the halls of Congress. His many notable contributions included establishing the first NHF Washington Days and championing the National AIDS Memorial's Hemophilia Circle. As CEO he led NHF into a new era of growth and service, he stabilized NHF funding and built programs to serve those who had been left behind. His lifelong commitment to families and youth was no more evident than through his commitment as a summer camp counselor and innovative summer camp programming in his service

as Camp Founder and Staff Director of Camp Hemotion: Camp for Children with Bleeding Disorders. He began his career with NHF in Washington championing the passage and funding of the Rick Ray Act and working to transform the regulatory framework to ensure the tragedy of HIV/AIDS would not repeat. His impact and the effect of his forceful advocacy will long be felt, from the halls of power at the U.S. Capitol Building, to the arts and crafts room at local summer camps. "The reason NHF and the inheritable blood disorders community has come so far is because of what Val was able to accomplish," said NHF President and CEO Len

Valentino. "I had the honor to walk alongside Val both professionally and personally and can say with certainty that what he has done throughout his life inspired change. His legacy will live on forever, and he will be greatly missed."

Mother of Ryan White, Jeanne-White Ginder said in tribute "I am most grateful to Val for including me in the hemophilia community and widening the circle to make sure everyone's voice was heard. He made sure our losses were not forgotten, especially through his efforts to include the hemophilia community in the National AIDS Memorial Grove. Val knew the hemophilia community

because he lived hemophilia alongside all of us. In spite of his own health battles and personal losses, he carried on with courage and strength that inspired us all, making him not only an accomplished leader but a role model that will never be forgotten."

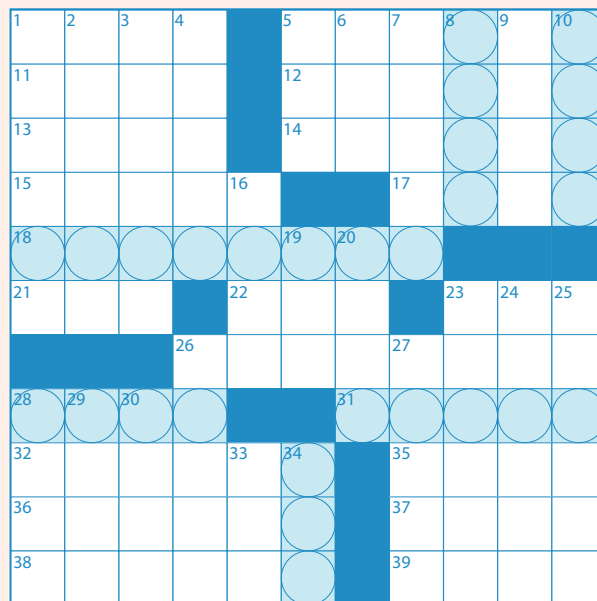
NHF and the community are heartbroken over this sudden loss. Val served as NHF's CEO for over a decade and carved the path for the organization's continued growth and sustainability. NHF extends sincere condolences to Val's beloved son Langston, his loving wife of twenty years, Robin, and his entire family.



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. ruel, 23. M.C.S, 26. passport, 28. zero, 31. three, 32. eyelid, 35. Oreo, 36. anise, 37. tall, 38. lessen, 39. oles
 Down: 1. catchy, 2. adorer, 3. serums, 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. polo, 27. photo, 28. zeal, 29. Eyre, 30. Reis, 33. ESE, 34. ten

Discover more at HEMLIBRA.com/answers

INDICATION & IMPORTANT SAFETY INFORMATION

What is HEMLIBRA?

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

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

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

These serious side effects include:

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

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



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

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

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

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

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

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

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

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

What is HEMLIBRA?

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

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

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

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

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

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

How should I use HEMLIBRA?

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

- Use HEMLIBRA exactly as prescribed by your healthcare 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
©2021 Genentech, Inc. All rights reserved.

For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised: 12/2021



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.
©2022 Genentech USA, Inc. All rights reserved. M-US-00011998(v2.0) 03/22

Genentech
A Member of the Roche Group

Teen Retreat/Family Camp 2023

Each summer, RMHBDA invites affected families living in Montana and Wyoming to attend a teen retreat and family weekend retreat. The long weekend is packed full of education, bonding, and fun!

Teen Retreat August 10–11 Family Camp, August 11–13

Flathead Lake Methodist Camp, 21339 Methodist Camp Road, Rollins, Montana 59931 www.flatheadcamp.org

For parents and teens, we will have teambuilding programming led by our guest, hemophilia leadership group, Gut Monkey (www.gutmonkey.com) and some time to relax with other families. This is a great opportunity to learn from and share experiences.

We also have many great activities planned for our campers including arts and crafts projects, field games, and educational sessions for children with bleeding disorders and their siblings. Infusion classes will be offered from our HTC.

Call Brad with any questions at 406.586.4050 📞



Save the Date!

September 9, 2023, Zoo Montana, Billings, MT

Dinner on September 8 sponsored by CSL Behring, all walk attendees will be provided hotel lodging and childcare on September 8.



Unite
for Bleeding Disorders

We Love Donations!

RMHBDA is a 501 (c)(3) nonprofit organization which means that contributions are tax deductible; check with your tax professional to determine how this specifically affects you.

We appreciate your consideration.

Welcome to **amazon smile**

You shop. Amazon gives. AmazonSmile (smile.amazon.com) Amazon's way of letting Amazon customers enjoy their convenient online shopping plus the benefit of the AmazonSmile Foundation donating 0.5% of the price of eligible purchases to the charitable organizations selected by customers.

PayPal™

Safe & secure donation at no cost to RMHBDA or the donor; just visit rmhbda.org on Donate/Join page.

goodsearch

Search the internet with the patent-protected, Yahoo!-powered search engine (just like you'd search on any other search engine), and we'll donate about a penny for nearly all searches to your selected cause. www.goodsearch.com

Craig Price

Patient turned proponent

About Craig

Craig is a Hemophilia Community Liaison who lives with hemophilia himself, and has almost 20 years of experience in the hemophilia field. He has two brothers with the condition and parents who are actively involved in hemophilia advocacy. Craig is eager to share his perspective with others in Utah.

Hobbies

- Exercising
- Camping

“My favorite thing about the hemophilia community is how close and tight-knit it is. There’s a lot of love, and people are committed to helping each other.”

Connect with Craig

CGPR@novonordisk.com
(801) 556-9409

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 EXTENDED-HALF-LIFE rFVIII WITH PROVEN PROTECTION AND UNIQUE STEP-WISE DOSING^{1,2}

For patients ≥ 12 years

Start simply	TWICE WEEKLY	For all prophylaxis patients: Recommended starting regimen is Jivi twice weekly (30-40 IU/kg) ¹
Step up	EVERY 5 DAYS	Based on bleeding episodes: Less frequent dosing of Jivi every 5 days (45-60 IU/kg) can be used ¹
Fine tune		Based on bleeding episodes: The dosing frequency may be further adjusted up or down ¹

IU, international units; kg, kilograms; rFVIII, recombinant Factor VIII.

INDICATIONS

- Jivi is an injectable medicine used to replace clotting factor (Factor VIII or antihemophilic factor) that is missing in people with hemophilia A.
- Jivi is used to treat and control bleeding in previously treated adults and adolescents (12 years of age and older) with hemophilia A. Your healthcare provider may also give you Jivi when you have surgery. Jivi can reduce the number of bleeding episodes in adults and adolescents with hemophilia A when used regularly (prophylaxis).
- Jivi is not for use in children below 12 years of age or in previously untreated patients.
- Jivi is not used to treat von Willebrand disease.

IMPORTANT SAFETY INFORMATION

- You should not use Jivi if you are allergic to rodents (like mice and hamsters) or to any ingredients in Jivi.
- Tell your healthcare provider about all of your medical conditions that you have or had.
- Tell your healthcare provider if you have been told that you have inhibitors to Factor VIII.
- Allergic reactions may occur with Jivi. Call your healthcare provider right away and stop treatment if you get tightness of the chest or throat, dizziness, decrease in blood pressure, or nausea.
- Allergic reactions to polyethylene glycol (PEG), a component of Jivi, are possible.
- Your body can also make antibodies, called “inhibitors,” against Jivi, which may stop Jivi from working properly. Consult your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.



FEEL EMPOWERED
to step up to the challenge
with Jivi[®]

Ask your doctor if Jivi[®] may be right for you. Learn more at www.jivi.com.

IMPORTANT SAFETY INFORMATION (CONT'D)

- If your bleeding is not being controlled with your usual dose of Jivi, consult your doctor immediately. You may have developed Factor VIII inhibitors or antibodies to PEG and your doctor may carry out tests to confirm this.
- The common side effects of Jivi are headache, cough, nausea, and fever.
- These are not all the possible side effects with Jivi. Tell your healthcare provider about any side effect that bothers you or that does not go away.

For additional important risk and use information, please see the Brief Summary on the following page.

You are encouraged to report side effects or quality complaints of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

References: 1. Jivi[®] Prescribing Information. Whippany, NJ: Bayer LLC; 2018.
2. Data on file. Tx Review 0918. Bayer; 2018.

Bayer, the Bayer Cross, and Jivi are registered trademarks of Bayer.
© 2019 Bayer. All rights reserved. Printed in USA 01/19 PP-JIV-US-0386-2


antihemophilic factor
(recombinant) PEGylated-aucl
LET'S GO

**HIGHLIGHTS OF
FDA-Approved Patient Labeling
Patient Information**

Jivi (JHIV-ee)
antihemophilic factor (recombinant), PEGylated-aucl

This leaflet summarizes important information about Jivi with vial adapter. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about Jivi. If you have any questions after reading this, ask your healthcare provider.

Do not attempt to self-infuse, unless your healthcare provider or hemophilia center has taught you how to self-infuse.

What is Jivi?

Jivi is an injectable medicine used to replace clotting factor (Factor VIII or antihemophilic factor) that is missing in people with hemophilia A (congenital Factor VIII deficiency).

Jivi is used to treat and control bleeding in previously treated adults and adolescents (12 years of age and older) with hemophilia A. Your healthcare provider may also give you Jivi when you have surgery. Jivi can reduce the number of bleeding episodes in adults and adolescents with hemophilia A when used regularly (prophylaxis).

Jivi is not for use in children < 12 years of age or in previously untreated patients.

Jivi is not used to treat von Willebrand disease.

Who should not use Jivi?

You should not use Jivi if you

- are allergic to rodents (like mice and hamsters).
- are allergic to any ingredients in Jivi.

What should I tell my healthcare provider before I use Jivi?

Tell your healthcare provider about:

- All of your medical conditions that you have or had.
- All of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies.
- Pregnancy or planning to become pregnant. It is not known if Jivi may harm your unborn baby.
- Breastfeeding. It is not known if Jivi passes into the milk.
- Whether you have been told that you have inhibitors to Factor VIII.

What are the possible side effects of Jivi?

The common side effects of Jivi are headache, cough, nausea and fever.

Allergic reactions may occur with Jivi. Call your healthcare provider right away and stop treatment if you get tightness of the chest or throat, dizziness, decrease in blood pressure, or nausea. Allergic reactions to polyethylene glycol (PEG), a component of Jivi, are possible.

Your body can also make antibodies, called “inhibitors”, against Jivi, which may stop Jivi from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.

If your bleeding is not being controlled with your usual dose of Jivi, consult your doctor immediately. You may have developed Factor VIII inhibitors or antibodies to PEG and your doctor may carry out tests to confirm this.

These are not all the possible side effects with Jivi. You can ask your healthcare provider for information that is written for healthcare professionals.

Tell your healthcare provider about any side effect that bothers you or that does not go away.

How do I store Jivi?

Do not freeze Jivi.

Store Jivi at +2°C to +8°C (36°F to 46°F) for up to 24 months from the date of manufacture. Within this period, Jivi may be stored for a period of up to 6 months at temperatures up to +25°C or 77°F.

Record the starting date of room temperature storage clearly on the unopened product carton. Once stored at room temperature, do not return the product to the refrigerator. The product then expires after storage at room temperature for 6 months, or after the expiration date on the product vial, whichever is earlier. Store vials in their original carton and protect them from extreme exposure to light.

Administer reconstituted Jivi as soon as possible. If not, store at room temperature for no longer than 3 hours.

Throw away any unused Jivi after the expiration date.

Do not use reconstituted Jivi if it is not clear.

What else should I know about Jivi and hemophilia A?

Medicines are sometimes prescribed for purposes other than those listed here. Do not use Jivi for a condition for which it is not prescribed. Do not share Jivi with other people, even if they have the same symptoms that you have.

This leaflet summarizes the most important information about Jivi that was written for healthcare professionals.

Resources at Bayer available to the patient:

For Adverse Reaction Reporting, contact Bayer Medical Communications 1-888-84-BAYER (1-888-842-2937)

To receive more product information, contact Jivi Customer Service 1-888-606-3780

Bayer Reimbursement HELpline 1-800-288-8374

For more information, visit <http://www.Jivi.com>

Bayer HealthCare LLC
Whippany, NJ 07981 USA

U.S. License No. 0008

© 2021 Genzyme Corporation. All rights reserved. MA1-US-2100170-V1.0-01/2021

SANOFI GENZYME 

Here for you.

As a CoRe Manager, I'm here to be a source of education for you and others living with hemophilia.

Heather Williams
CoRe Manager for Minnesota, Montana, North Dakota, South Dakota, Wisconsin, Wyoming

Let's connect.

608-977-0785
heather.williams@sanofi.com
rareblooddisorders.com
f @HemophiliaCoRes



2023 Calendar

- ◆ **March** HEMOPHILIA AWARENESS MONTH
- ◆ **April/May** World Hemophilia Day, April 17

Education Weekend & Annual Meeting, April 21–23, Fairmont Hot Springs, Fairmont, MT
- ◆ **May** Education & Dinner Seminars, Cody, WY and Kalispell, MT – Dates TBD
- ◆ **July** Mile High Summer Camp, Teens: July 21–23, Camp for Kids 7–18: July 23–27 Rocky Mountain Village, Empire, CO
- ◆ **August** Teen Retreat, Flathead Methodist Camp, August 10–11, Rollins, MT

Big Sky Family Camp, Flathead Methodist Camp, August 11–13, Rollins, MT
- ◆ **September** UNITE Walk Dinner & Golf or Swim Clinic, September 8, Location TBD, Billings, MT

UNITE Walk, September 9, Zoo Montana, Billings, MT
- ◆ **October** Education & Dinner Seminars, Cody, WY and Kalispell, MT – Dates TBD
- ◆ **November** Women's Retreat, November 3–5, Chico Hot Springs, Pray, MT

RMHBDA Education Scholarship 2023

For Undergraduate Students and Families Affected by Bleeding Disorders

Deadline: June 1, 2023

The Rocky Mountain Hemophilia and Bleeding Disorder Association is a chapter located in Bozeman, MT that is dedicated to representing, educating, supporting and helping those patients with bleeding disorders and their families in Montana and Wyoming. Having an association with the National Hemophilia Foundation, we gain support from the NHF, national and local corporate partners and local individuals. Our mission is to provide ongoing support through education, family camp and financial means as well as other specific programs to meet the needs of the individuals we serve.

Visit www.rmhbda.org to apply. ◆



Rocky Mountain Hemophilia



& Bleeding Disorders Association

1627 West Main Street, #142
Bozeman, Montana 59715

Address Correction Requested

Non Profit Org.
US Postage
Paid
Bozeman, MT
Permit No. 94

WINTER 2023

