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

- Education Weekend 2020 1
- Women's Retreat 1
- Mile High Summer Camp 2
- Big Sky Family Camp 2
- UNITE Walk 2
- Women's Retreat 2
- Washington Days 6
- Dear CSL Behring 6
- Governor's Proclamation 6
- General Scholarship Information 11
- RMHBDA Education Scholarship 2020 11
- Dear Hemophilia: Finding Hope Through Chronic Illness 11
- Montana License Plates 12

Rocky Mountain Hemophilia & Bleeding Disorders Association

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www.facebook.com/rmhbda

RMHBDA Newsletter CKY MOUNTAL

Education Weekend 2020

A special "Thank You" to our HTC for co-sponsoring our Education Weekend!



University of Colorado Anschutz Medical Campus Hemophilia and Thrombosis Center

Octapharma

Restore RX

Aptevo

Pfizer

Thank you to our generous program funders:

- Accredo Health
- Optum
- HF Healthcare
- Bayer Healthcare Takeda
- Sanofi Genzyme
- CSL Behring
- Novo Nordisk Genentech

Diplomat

- the National Hemophilia Foundation
- and the Hemophilia Federation of America

RMHBDA Education Weekend was held February 21 – 23 in Bozeman, Montana. We had eighty people in attendance from our community and an additional twenty sponsors and exhibitors. Educational sessions during Education Weekend included:

- Infusion session
- Breakout sessions for our Blood Brotherhood and Sisterhood programs
- A VWD presentation
- Gene therapy and emerging medicines,
- A discussion on the "ADA" for individuals with bleeding disorders

All chapter members spent time visiting our exhibitors as they learned more about each company and their products.

Many people enjoyed the chapter trip to the "Brawl of the Wild" basketball game, Montana vs. Montana State. The children had some educational opportunities in the morning and enjoyed a field trip to Laser Dash on Saturday afternoon.



Women's Retreat

We hosted a Women's retreat November 1-3, 2019 at Chico Hot Springs in Pray, Montana. The event was a wonderful success with twenty-five women attending from Kalispell to Cheyenne, Wyoming. Thank you to all of those that attended our program, your feedback on your surveys will be very beneficial in planning future programs. We are truly grateful to Amber Federizo and Nancy Spomer for their educational support. We are also thankful to our sponsors of our Women's Retreat.







Dates to Remember in 2020

With our next event not until May, as of now, we are anticipating holding our summer activities as scheduled, which include:

Mile High Summer Camp

July 12-17

Rocky Mountain Village, Empire, Colorado

The purpose of camp is to learn about bleeding disorders, develop skills, and have fun! Campers will have the opportunity to meet new friends and participate in a variety of traditional camp activities. As always, we have included educational components with the goal of encouraging self-confidence and independence

A Message From NHF Colorado: As of now, we are planning to move forward as scheduled with all summer activities, which includes Mile High Summer Camp. However, we are delaying the registration process for these events as we continue to monitor the situation. We will evaluate this rapidly changing situation at the end of this month with the goal of making registrations live in early April, a delay of approximately one month from the typical process.



Big Sky Family Camp

August 21-23

Flathead Methodist Camp, Rollins, MontanaT

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



UNITE Walk

September 12

Zoo Montana, Billings



Rocky Mountain Hemophilia & Bleeding Disorders Association announces our Annual Montana and Wyoming UNITE WALK, benefiting those suffering from bleeding disorders in Montana and Wyoming communities. •

Women's Retreat

November 6-8

Chico Hot Springs, Pray, Montana 🌢



▶ Education Weekend Photos



DEDICATION and **PERSONAL SUPPORT**

Your Pfizer Patient Affairs Liaison is a professional dedicated to serving you and the hemophilia community by connecting patients and caregivers with Pfizer Hemophilia tools and resources. We are committed to continuing Pfizer's more than 20 years of listening to the hemophilia community and working to meet its needs.



Patty Eastin AZ, NM, NV, UT, CO, ID, WY, MT

"Having worked at Pfizer for 14 years, I am passionate about supporting and educating the amazing rare disease community."





480-734-4011 patricia.d.eastin@pfizer.com

MY WORK IS GUIDED BY:

Compassion

Listening to your needs and addressing questions and concerns that you may have

Commitment

Educating you about Pfizer's tools and resources, including the Pfizer Community Connections Program, the HemMobile® app for logging bleeds and infusions, B2B materials, and more

Connection

Connecting you with hemophilia advocacy groups and programs like Leading Edge, the National Hemophilia Foundation, the Coalition for Hemophilia B, and others

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HemMobile is not intended for curing, treating, seeking treatment for, managing, or diagnosing a specific disease, disorder, or any specific health condition. Pfizer will not have access to any personal information you enter into HemMobile.

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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.

HEMLIBRA

emicizumab-kxwh | 150

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 HFMI IBRA:
 - 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

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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



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Washington Days

Washington Days had more than 450 participants this year! We are asking legislators to support these policies::

- Co-sponsor H.R., 5952, the Hemophilia SNF Access Act to improve access to skilled nursing facility care for Medicare beneficiaries with bleeding disorders
- Support federal hemophilia programs at CDC, HRSA, and NIH that provide funding for comprehensive care, research, surveillance and prevention activities that benefit the bleeding disorders community.
- Co-sponsor S. 3233, the Hemophilia SNF Access Act to improve access to skilled nursing facility care for Medicare beneficiaries with bleeding disorders.
- Support federal hemophilia programs at CDC, HRSA, and NIH that provide funding for comprehensive care, research, surveillance, and prevention activities that benefit the bleeding disorders community.





Dear CSL Behring

I want to thank you for giving me the opportunity to attend Junior National Championship (JNC) this year! I had an amazing time and met a lot of nice people. I loved competing and practicing with Jose in the golf competition. I attend a lot of bleeding disorders events, and JNC is by far the best event I've ever attended. I wish I could go every year, but I want other kids from Montana and Wyoning to enjoy the experience.

Will Benne









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 used¹

Fine tune



Based on bleeding episodes:

The dosing frequency may be further adjusted up or down¹

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.

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LET'S GO

HIGHLIGHTS OF FDA-Approved Patient Labeling

Patient Information

Jivi (*JIHV-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 $+2^{\circ}$ C to $+8^{\circ}$ 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 $+25^{\circ}$ 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

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We appreciate your
consideration.

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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 patentprotected, 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

General Scholarship Information

NHF/HANDI provides this current list of scholarships for gene information purposes only. Prospective candidates will need check with the individual sponsor or administrator of a given scholarship program for more details on specific criteria or procedures for submitting an application.



www.hemophilia.org/Community-Resources/Scholarships

RMHBDA Education Scholarship 2020

For Undergraduate Students & Families Affected by Bleeding Disorders Deadline: June 1, 2020

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.

TVisit www.rmhbda.org to apply.

Dear Hemophilia: Finding Hope Through Chronic Illness

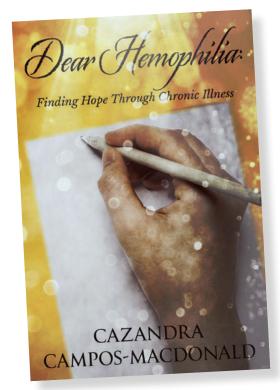
Our stories are powerful. Our experiences are unique. And sharing our lives can transform the world. Cazandra Campos-MacDonald's new book, *Dear Hemophilia: Finding Hope Through Chronic Illness*, is her story of raising two sons with Severe hemophilia A with inhibitors. Her journey is filled with despair and heartache, yet hope is always the center of her world. Cazandra invites the reader into her life as she raises her sons and uncovers the truth about her older brother's untimely death. With raw, even painful honesty, she shows us that even those with the strongest faith can lose sight of what is important. For more information and to follow Cazandra's journey, visit www.cazandracmacdonald.com. Her book is now available at Amazon.

"Travel with Cazandra and share her love, even anger, and above all commitment to God as she boldly confronts a rare bleeding disorder, and eventually finds peace with it in the end."

-Laureen A. Kelley author, *Raising a Child with Hemophilia*

"The two most powerful warriors are patience and time" said Leon Tolstoy. He must have never met the mother of a child with a chronic health condition and certainly not Cazandra Campos MacDonald. Behold the warrior! If we could all be as brave, as determined and as undaunted as Cazandra this world would be a significantly better place. Cazandra bares her soul and her plight for herself and for her children in this superbly written account of her story.

—Jorge de la Riva Former Chairman of the Board, National Hemophilia Foundation



& Bleeding Disorders Association

1627 West Main Street, #142 Bozeman, Montana 59715

SPRING 2020

