

Women's Retreat

RMHBDA's first virtual women's retreat was on February 13, 2021. More than 30 women came together with Zoom to share laughs, catch up, and learn more about bleeding disorders from industry representatives, the HTC, and Amber Federizo, a nurse practitioner who specializes in bleeding disorders. Event boxes containing a fuzzy blanket, coffee and tea-fixings, spa items, and some treats were sent out prior to the event so that everyone could enjoy the normal luxuries of the women's retreat: relaxation, indulgence, and coziness. Even though the women of RMHBDA couldn't meet in person for this event due to the pandemic, everyone still had a lovely, rejuvenating time — all while being safe and respectful of each other's comforts.



► Continued on page 2

Education Weekend 2021

June 18–20, 2021

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! 💧

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.

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Rocky Mountain Hemophilia & Bleeding Disorders Association

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www.rmhbda.org

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brad@rmhbda.org



www.facebook.com/rmhbd

Note from the Executive Director

RMHBDA Family,

Connecting virtually this past year has become a way of life for nearly all of us due to COVID-19. While the chapter and our community experienced many hardships and challenges, we also saw a record number of women attend our virtual women's retreat, we hit a walk fundraising record, we were able to have an in-person family camp and have our annual Education weekend in-person. RMHBDA also had the best fundraising year in the history of RMHBDA thanks to a generous gift from the family of Alice and Fred Pitkin. This gift will sustain our scholarship program for many years to come.

RMHBDA is hoping we are in the "11th hour" in dealing with COVID-19. Our plans are to have an in-person/virtual hybrid Education Weekend at Fairmont Hot Springs the weekend of June 18–20, 2021. We are also planning our first "Teen Retreat," August 11-13, before our annual Family Camp August 13–15, 2021 at Flathead Lake Methodist Camp in Rollins, Montana.

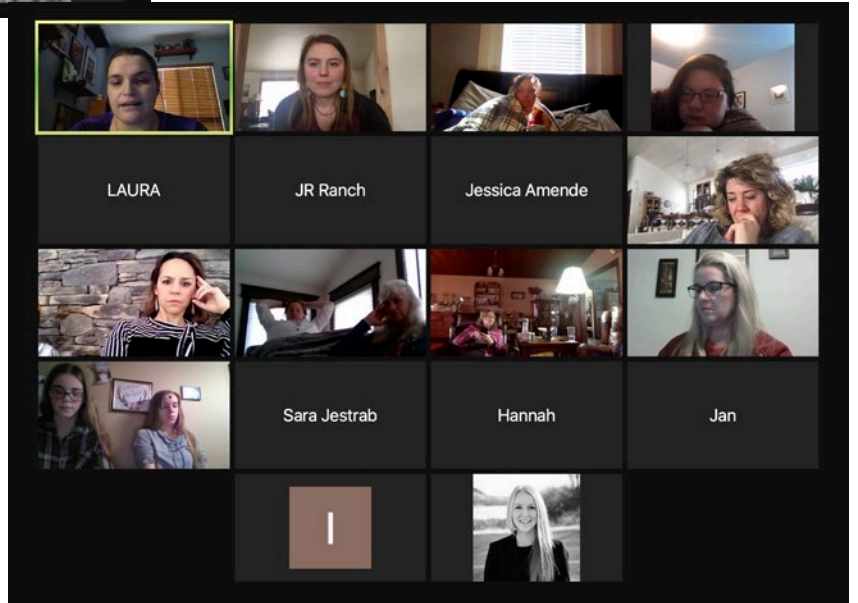
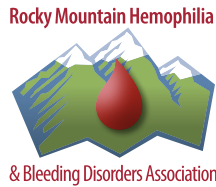
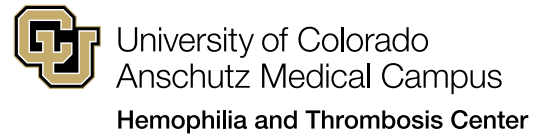
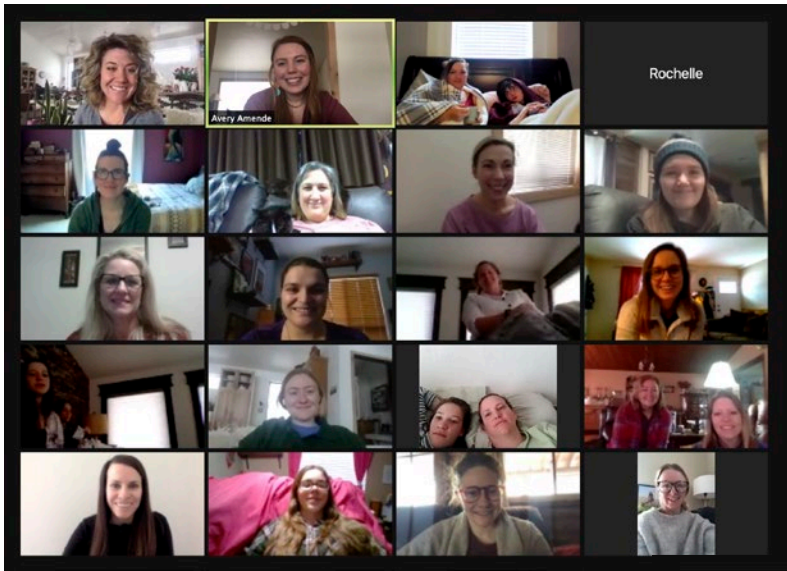
In this newsletter, we also provide a program schedule for all of our planned events in 2021. These programs and events would not be possible without your support. As we move through 2021, please consider empowering our chapter and community by participating and attending RMHBDA programs. While we are not quite out of the woods yet regarding COVID-19, I do believe the "best is yet to come" for our community and chapter.

With gratitude,

Brad Benne
Executive Director

THE ROCKY MOUNTAIN

► Women's Retreat



RMHBDA Education Scholarship 2021

For Undergraduate Students and Families Affected by Bleeding Disorders

Deadline: June 1, 2021

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. 📌



2021 Emergency Assistance & COVID-19 Assistance Program

What is the RMHBDA COVID-19 Assistance program?

The COVID-19 Pandemic has affected all Americans and has had an unprecedented negative impact on many. Those with health concerns, including bleeding disorders are some of the hardest hit. RMHBDA has recognized these effects and the Board of Directors has moved to provide assistance not otherwise available for those chapter members in need. Applicants must be residents of Montana or Wyoming.

How do families get identified/referred into the program?

- Families are encouraged to directly reach out to RMHBDA for assistance. Contacting any member of the Board of Directors or RMHBDA staff is encouraged.
- In some cases, verification of situations and circumstances may be required.
- The RMHBDA Board of Directors will determine the need based on the narrative received from the patient, family member, medical professional, or a social worker.
- The request can be granted for any reason, however, non-medical expenses should be the primary reason for application since medical expense relief typically can be applied for under the RMHBDA Patient Assistance program.

Is there a yearly cap per family/individual that applies?

The chapter will support a patient financially in the range of \$500-\$5,000 per grant depending on the patient's circumstances. All approvals and decisions are at the board's discretion.

How do I apply?

Please contact Brad Benne at brad@rmhbda.org or at 406.586.4050 if you would like to apply for the Emergency Assistance & COVID-19 Assistance program. This program is ONLY for the year of 2021.

Funding made possible by NHF, the COVID-19 Bridge Grant, The Hemophilia Alliance, the Frederick Pitkin Family and the University of Colorado Hemophilia & Treatment Center.

2021 Calendar

- April** World Hemophilia Day, April 17
- June** RMHBDA Education Weekend & Annual Meeting, June 18–20, Fairmont Hot Springs, Fairmont, MT
- July** Mile High Summer Camp Rocky Mountain Village, July 11–16, Empire, CO
- August** RMHBDA Teen Retreat, Flathead Methodist Camp, August 11-13, Rollins, MT
- RMHBDA Big Sky Family Camp, Flathead Methodist Camp, August 13-15, Rollins, MT
- September** RMHBDA UNITE WALK, Zoo Montana, September 11, Billings, MT,
- October** RMHBDA Men's Retreat, TBD
- November** RMHBDA Women's Retreat, November 5–7, Chico Hot Springs, Pray, MT



RMHBDA
2021
Emergency Assistance
& COVID-19
Assistance Program

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







BeneFix
 Coagulation Factor IX (Recombinant)
 Room Temperature Storage
*BeneFix was approved February 11, 1997.



EXPERIENCE MATTERS

BeneFix is FDA approved for **once-weekly prophylaxis** and **on-demand use** to fit your dosing needs—
 from the only recombinant factor IX supporting individuals with hemophilia B for more than 20 years.*

Not actual patients.

-  **More than 20 years* of experience**—the first recombinant treatment for individuals with hemophilia B
-  **Designed with viral safety in mind.** More than 150 quality control tests are done on each batch of BeneFix
-  **The convenience of the BeneFix Rapid Reconstitution (R2) Kit** with a range of vial sizes
-  **Ask your doctor about BeneFix dosing options** to meet your needs



What Is BeneFix?

BeneFix, Coagulation Factor IX (Recombinant), is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Your doctor might also give you BeneFix before surgical procedures.

BeneFix is **NOT** used to treat hemophilia A.

Important Safety Information

- BeneFix is contraindicated in patients who have manifested life-threatening, immediate hypersensitivity reactions, including anaphylaxis, to the product or its components, including hamster protein.
- Call your health care provider right away if your bleeding is not controlled after using BeneFix.
- Allergic reactions may occur with BeneFix. Call your health care provider or get emergency treatment right away if you have any of the following symptoms: wheezing, difficulty breathing, chest tightness, your lips and gums turning blue, fast heartbeat, facial swelling, faintness, rash, or hives.
- Your body can make antibodies, called “inhibitors,” which may stop BeneFix from working properly.
- If you have risk factors for developing blood clots, such as a venous catheter through which BeneFix is given by continuous infusion, BeneFix may increase the risk of abnormal blood clots. The safety and efficacy of BeneFix administration by continuous infusion have not been established.
- Some common side effects of BeneFix are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness, and rash.

Please see the Brief Summary for BeneFix on the next page.

**FOR ONCE-WEEKLY PROPHYLAXIS
 AND ON-DEMAND USE**



R_x only

Brief Summary

See package insert for full Prescribing Information. This product's label may have been updated. For further product information and current package insert, please visit www.Pfizer.com or call our medical communications department toll-free at 1-800-438-1985.

Please read this Patient Information carefully before using BeneFix and each time you get a refill. There may be new information. This brief summary does not take the place of talking with your doctor about your medical problems or your treatment.

What is BeneFix?

BeneFix is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Your doctor might also give you BeneFix before surgical procedures.

BeneFix is **NOT** used to treat hemophilia A.

What should I tell my doctor before using BeneFix?

Tell your doctor and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal medicines.

Tell your doctor about all of your medical conditions, including if you:

- have any allergies, including allergies to hamsters.
- are pregnant or planning to become pregnant. It is not known if BeneFix may harm your unborn baby.
- are breastfeeding. It is not known if BeneFix passes into the milk and if it can harm your baby.

How should I infuse BeneFix?

The initial administrations of BeneFix should be administered under proper medical supervision, where proper medical care for severe allergic reactions could be provided.

See the step-by-step instructions for infusing in the complete patient labeling.

You should always follow the specific instructions given by your doctor. If you are unsure of the procedures, please call your doctor or pharmacist before using.

Call your doctor right away if bleeding is not controlled after using BeneFix.

Your doctor will prescribe the dose that you should take. Your doctor may need to test your blood from time to time. BeneFix should not be administered by continuous infusion.

What if I take too much BeneFix?

Call your doctor if you take too much BeneFix.

What are the possible side effects of BeneFix?

Allergic reactions may occur with BeneFix. Call your doctor or get emergency treatment right away if you have any of the following symptoms:

wheezing	fast heartbeat
difficulty breathing	swelling of the face
chest tightness	faintness
turning blue (look at lips and gums)	rash
	hives

Your body can also make antibodies, called "inhibitors," against BeneFix, which may stop BeneFix from working properly.

Some common side effects of BeneFix are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness and rash.

BeneFix may increase the risk of thromboembolism (abnormal blood clots) in your body if you have risk factors for developing blood clots, including an indwelling venous catheter through which BeneFix is given by continuous infusion. There have been reports of severe blood clotting events, including life-threatening blood clots in critically ill neonates, while receiving continuous-infusion BeneFix through a central venous catheter. The safety and efficacy of BeneFix administration by continuous infusion have not been established.

These are not all the possible side effects of BeneFix.

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

How should I store BeneFix?

DO NOT FREEZE the BeneFix kit. The BeneFix kit can be stored at room temperature (below 86°F) or under refrigeration. Throw away any unused BeneFix and diluent after the expiration date indicated on the label.

Freezing should be avoided to prevent damage to the pre-filled diluent syringe.

BeneFix does not contain a preservative. After reconstituting BeneFix, you can store it at room temperature for up to 3 hours. If you have not used it in 3 hours, throw it away.

Do not use BeneFix if the reconstituted solution is not clear and colorless.

What else should I know about BeneFix?

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

If you would like more information, talk with your doctor. You can ask your doctor or pharmacist for information about BeneFix that was written for healthcare professionals.

This brief summary is based on BeneFix® [Coagulation Factor IX (Recombinant)] Prescribing Information LAB-0464-12.0, revised June 2020.

Jodi Rudell is NHF Advocate of the Year



Jodi Rudell from Cheyenne, Wyoming is NHF Advocate of the Year. She has been a member of our Chapter since 2012 and both of her daughters as well as herself have VwD. Jodi has been to Washington Days to advocate for bleeding disorders 6 times and has even testified in front of the Wyoming Medicaid Board which helped secure access to choice of medication for the Wyoming

bleeding disorders community. She has also secured proclamations from her Wyoming Governors declaring March as Bleeding Disorder awareness Month on several occasions.

Her emotional family story has garnered not only the ears of the Wyoming delegation in Washington DC but numerous others in the Congress and Senate as well as others in our community.

She often tells people that she has a loud voice from a small population state. She loves her family, being an advocate and Wyoming. We are proud of her and are extremely happy she is in our Chapter! ♦

Washington Days Update

We met with the following representatives and staff member virtually:

Montana

- Senator Tester, staff, Katie Rubinger
- Senator Daines, staff, Rachel Green
- Representative Rosendale, staff, Dawn Marie Sullivan

Wyoming

- Senator Lummis office, Ryan and Parker (staff)
- Senator Barrasso office, Senator Barrasso and staff Jay Eberle
- Representative Cheney office, Linnea (staff)

RMHBDA and NHF want members of congress and the senate to not approve co-pay accumulator programs and we want all co-pays to count towards a person's OOP Max and deductibles, regardless of what plan they have or if they use co-pay assistance programs. By not being able to take advantage of that, a person may be forced to make a decision on whether or not they need the meds because they cannot afford it. That leads to higher health costs down the road, if a bleed doesn't get treated, or worse. ♦

RMHBDA and Uganda Continue Twinning Partnership with the World Federation of Hemophilia through A Pandemic

RMHBDA enters the second year in our twinning partnership with the Uganda Hemophilia Foundation. The year 2020 was a tough year to carry out all our twinning partnership goals and objectives. However, we did collaborate on creating a Uganda newsletter that was printed and mailed all over the country, and we were still able to conduct a couple regional awareness and outreach programs in Uganda.



The Twinning Program creates short-term collaborative partnerships between medical professionals as well as patient and youth leaders in developing and developed countries for a period of two to four years. Hemophilia treatment centers, patient organizations and youth groups can participate in this program, helping improve treatment and care for people living with an inherited bleeding disorder in developing countries. ♦



ADAPTING TO CHANGE

Sustaining care in a new world



APRIL 17
2021

WORLD
HEMOPHILIA
DAY

#WHD2021
wfh.org/whd2021




WFH

WORLD FEDERATION OF HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOFILIE
FEDERACIÓN MUNDIAL DE HEMOFILIA

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.

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antihemophilic factor
(recombinant) PEGylated-aucI
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

Governor's Proclamation



BLEEDING DISORDERS AWARENESS MONTH

WHEREAS, this designation will formalize and expand upon the designation in March 1986 as "Hemophilia Awareness Month" by President Ronald Reagan; and

WHEREAS, the federal Department of Health and Human Services designated March 2021 as National Bleeding Disorders Month; and

WHEREAS, these bleeding disorders, which share the inability to form a proper blood clot, are characterized by extended bleeding after injury, surgery, trauma or menstruation and can lead to significant morbidity and can be fatal if not treated effectively; and

WHEREAS, many individuals with hemophilia became infected with HIV and Hepatitis C in the 1980s due to the contamination of the blood supply and blood products; and

WHEREAS, this Awareness Month in the State of Wyoming will generate greater awareness and understanding of not only hemophilia but all inheritable bleeding disorders, including von Willebrand disease—which alone impacts an estimated one percent of the U.S. population or more than 3.2 million individuals; and

WHEREAS, this Awareness Month will foster a greater sense of community and shared purpose among individuals with all inheritable bleeding disorders; and

WHEREAS, this Awareness Month will elevate awareness of and engagement in the inheritable bleeding disorders journey beyond our community to the general public, enabling the prevention of illness, unnecessary procedures, and disability.

NOW, THEREFORE, I, MARK GORDON, Governor of the State of Wyoming, do hereby proclaim March 2021, as

BLEEDING DISORDERS AWARENESS MONTH

in the State of Wyoming.

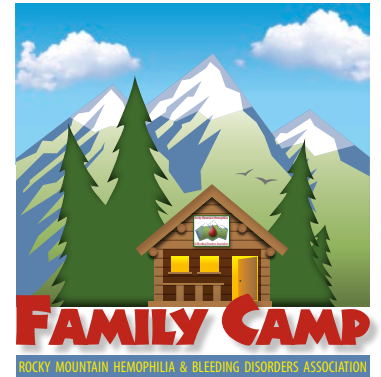
IN WITNESS WHEREOF, I have hereunto set my hand and caused the Executive Seal of the Governor of Wyoming to be affixed this 24th day of February, 2021.



The Honorable Mark Gordon
33rd Governor of the Great State of Wyoming

Family Camp

Flathead Methodist Camp
August 13-15
Rollins, Montana



Save the Dates!

Mile High Summer Camp

July 11-16
Rocky Mountain Village
Empire, Colorado

NEW!
RMHBDA Teen Retreat

August 11-13
Flathead Methodist Camp
Rollins, Montana

Rocky Mountain Hemophilia



& Bleeding Disorders Association

1627 West Main Street, #142
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Address Correction Requested

Non Profit Org.
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Permit No. 94

SPRING 2021

Rocky Mountain Hemophilia



& Bleeding Disorders Association

