Rocky Mountain Hemophilia



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 2019 1
- Women's Retreat 1
- HTC's New Program Director 4
- HTC Montana Outreach Clinic Dates 4
- 2019 Calendar 4
- RMHBDA Education Scholarship 2019 9
- World Hemophilia Day 2019 9
- The Inhibitor Summits 2019 10
- Montana License Plates 10
- 2018 Junior National Championship (JNC) 10

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/rmhbda



THE ROCKY MOUNTAIN

Education Weekend 2019

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

University of Colorado Anschutz Medical Campus Hemophilia and Thrombosis Center

Thank you to our generous program funders: Accredo Health, Inc., Bayer Healthcare, Takeda, Sanofi Genzyme, CSL Behring, CVS Caremark, Spark Therapeutics, HF Healthcare, Diplomat, Genentech, Octapharma, Restore RX, Aptevo, Pfizer, the National Hemophilia Foundation, and the Hemophilia Federation of America.

RMHBDA Education Weekend was held February 22–24 in Bozeman, Montana. We had ninety-three people in attendance from our community and an additional dozen 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, and a discussion on "legal tools to avoid poverty" for individuals with bleeding disorders. We also watched the new film "Bombardier Blood." All chapter members spent time visiting our exhibitors as they learned more about each company and their products.

Everyone enjoyed the chapter trip to the bowling alley. Children some educational opportunities in the morning and enjoyed a field trip to Laser Dash on Saturday afternoon.

Cooky Luten

Raffle Winners

- Amanda Glass
- Sue Scott
- Patricia Liming
 Samantha Fulton
- ...



Continued on page 9

Women's Retreat

We hosted a Women's retreat November 2–4, 2018 at Chico Hot Springs in Pray, Montana. The event was a wonderful success with 24 women attending from Kalispell to Cheyenne, Woming. 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, Nancy Spomer, and Sonji Wilkes for their insightful expertise and the time they shared with the group.



NOW APPROVED

FOR PEOPLE WITH HEMOPHILIA A WITH OR WITHOUT FACTOR VIII INHIBITORS

GO SEEK. GO EXPLORE. GO AHEAD.

Discover your sense of go. Discover HEMLIBRA®.

HEMLIBRA.com

What is **HEMLIBRA**?

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

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

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. HEMLIBRA may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

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



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

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

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

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

- Thrombotic microangiopathy (TMA). This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
 - confusion

- stomach (abdomen)
- weakness

- or back pain
- swelling of arms and legs
- nausea or vomiting
- yellowing of skin and eyes
- 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 legspain or redness in your
- cough up blood
 feel faint
- headache
- roath
- shortness of breath
 chest pain or tightness

arms or legs

fast heart rate

- numbness in your face
- ss eye
- 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

HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan ©2018 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 : 10/2018



© 2018 Genentech USA, Inc. All rights reserved. EMI/061818/0106 HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan. The HEMLIBRA logo is a 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.



HTC's New Program Director



If you were able to attend some of our recent events, you may have met our new Program Director, Angela Blue. Angie joined us six months ago and has become a vital part of our HTC staff. She comes to us from the Children's Hospital of Minnesota's Hemophilia Center where she worked as their Program Manager for nine years. Before that she worked for six years at the University of Minnesota's Center for Bleeding and Clotting Disorders as their Hemophilia Pharmacy Coordinator. Her experience is a huge asset for our HTC and her wonderful personality brings calm energy to our staff.

She shared her thoughts with us on what brought her to working with the bleeding disorders community:

"When I was young, one of my favorite teachers had a son my age who had hemophilia. Sadly, this boy passed away when we were 11 years old from HIV which he contracted through contaminated factor products. I remember feeling so shocked and scared when that happened. Ten years later, I was working as a pharmacy technician at the University of Minnesota and had the opportunity to work with the hemophilia pharmacy program. I was interested because I knew someone who had suffered the worst fate and was hoping I could do something to help these patients and families.

After I started working at the HTC at the University of Minnesota, I realized what a special area of medicine this is, because the whole team was so involved and would pour their hearts into the care they were giving. Even more so, the patients and families that I met and got to know were the most resilient and incredible people I had ever met. It is the same here at the HTC in Colorado, as I believe it is across the entire country. The staff at HTCs are, in my opinion, the best of the best in the medical field, and the patients are the most brave and resilient group of people I could ever imagine. I've seen kids and teens (and adults) overcome their biggest fears time and time again, it never ceases to amaze and inspire me."

As the Program Director, Angie works with various HTC staff and organizations, coordinating with research, quality improvement, and supporting the community events, such as those led by NHF Colorado or the Rocky Mountain Hemophilia and Bleeding Disorders Association. She is involved in the planning and support of our outreach clinics, special training programs at the HTC, and works to compile data and reports for HTC grants and research projects. She is paying particular attention to expanding our outreach efforts, and is working with the regional HTCs to help find ways to continually improve the quality of care for patients in our area.

Angie is a creative person who loves music, playing piano, singing, and attending concerts. She loves Broadway musicals and even got to see *Hamilton* when it was in Denver earlier this year! She loves outdoor concerts and is looking forward to experiencing the fun venues we have in town. She likes to bike, ski, run, and rollerblade. She's even done rollerblading marathons! She likes that she's closer to skiing now, but also enjoys travel.

We at the HTC are thrilled to welcome Angie to our HTC and are so happy she's working with us! You can meet Angie at our Bleeding Disorder Parent Support Group, at upcoming NHF events, or other HTC-sponsored activities.

HTC Montana Outreach Clinic Dates

June 24–28
 July 31–August 2
 Dates are tentative.

Billings, Montana **Missoula**, Montana

University of Colorado Anschutz Medical Campus Hemophilia and Thrombosis Center

**** alenda SUNDAY THESDAY WEDN 2 3 9 10 16 17 15 24 21 22 23 25 24 28 21

2019 Calendar

left March	Hemophilia Awareness
♦ March 27–29	NHF Washington Days, D.C.
♦ April 4–7	HFA Symposium, San Diego, CA
🌢 April 17	World Hemophilia Day
🌢 April 24	RMHBDA Education Series: Shire, Bozeman, MT
🌢 April 25	RMHBDA Education Series: Shire, Billings, MT
lay 13	RMHBDA Education Series: Octapharma, Cody, WY
♦ June 14–16	RMHBDA Family Camp, Fairmont Hot Springs, Anaconda, MT
♦ June TBD	HTC Clinic
♦ July 14–19	Mile High Summer Camp, Rocky Mountain Village, Empire, CO
August TBD	Dads in Action, Flathead Lake, MT
September 7	RMHBDA UNITE WALK, Zoo Montana, Billings, MT
• September 14	RMHBDA UNITE WALK, Lawrence Park, Kalispell, MT
♦ October 3–6	NHF Conference, Anaheim, CA
November TBD	CSL Behring "Getting in the Game"
November 1–3	RMHBDA Women's Retreat, Chico Hot Springs, MT



The Ender Dragon Awaits at Hemophilia Village



Adventure and education in a virtual world

We've blended education with adventure to bring you an experience that emphasizes the importance of staying prepared and sticking to a treatment plan. Craft an infusion kit, keep an eye on your "factor bar," and share your game strategy with friends and family—but beware of the Ender Dragon!

Visit www.hemophiliavillage.com to learn more about HEMOCRAFT and start your own adventure

HEMOCRAFT is a trademark of Pfizer Inc.

HEMOCRAFT is provided for educational purposes only and is not intended to replace discussions with a health care provider, nor is it intended for curing, treating, seeking treatment for, managing, or diagnosing a specific disease, disorder, or any specific health condition.

Intended for US audiences only.



KOVALTRY[®], Antihemophilic Factor (Recombinant): THE CONFIDENCE TO TAKE CONTROL

For children, adolescents, and adults with hemophilia A

For more information, visit YourKOVALTRY.com

INDICATIONS

- KOVALTRY[®] is a medicine used to replace clotting factor (Factor VIII or antihemophilic factor) that is missing in people with hemophilia A.
- KOVALTRY[®] is used to treat and control bleeding in adults and children with hemophilia A. KOVALTRY[®] can reduce the number of bleeding episodes in adults and children with hemophilia A when used regularly (prophylaxis). Your healthcare provider may give you KOVALTRY[®] when you have surgery.
- KOVALTRY[®] is not used to treat von Willebrand Disease.

IMPORTANT SAFETY INFORMATION

- You should not use KOVALTRY[®] if you are allergic to rodents (like mice and hamsters) or any ingredients in KOVALTRY[®].
- Tell your healthcare provider if you have heart disease or are at risk for heart disease.
- The common side effects of KOVALTRY[®] are headache, fever, and itchy rash.
- Allergic reactions may occur with KOVALTRY[®]. Call your healthcare provider right away and stop treatment if you get tightness of the chest or throat, dizziness, decrease in blood pressure, and nausea.
- Your body can also make antibodies, called "inhibitors," against KOVALTRY®, which may stop KOVALTRY® 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.

KOVALTRY®:

Designed to closely match your body's natural Factor VIII

Based on a primary protein structure with more than 20 years of experience

Offers the potential for as few as 2 infusions per week

KOVALTRY® Dosing: The recommended dose for routine prophylaxis in adults and adolescents is 20 to 40 IU of KOVALTRY® per kg of body weight 2x/week or 3x/week. The recommended dose for routine prophylaxis in children 12 years old and younger is 25 to 50 IU of KOVALTRY® per kg of body weight 2x/week, 3x/week, or every other day according to individual requirements.

IMPORTANT SAFETY INFORMATION (CONT'D)

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

Call your healthcare provider right away if bleeding is not controlled after using KOVALTRY®.

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

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

Talk to your doctor to see if KOVALTRY® is right for you.



HIGHLIGHTS OF FDA-Approved Patient Labeling Patient Information KOVALTRY (KOH-vahl-tree) Antihemophilic Factor (Recombinant)



This leaflet summarizes important information about KOVALTRY 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 KOVALTRY. If you have any questions after reading this, ask your healthcare provider.

Do not attempt to self-infuse unless you have been taught how by your healthcare provider or hemophilia center.

What is KOVALTRY?

KOVALTRY is a medicine used to replace clotting factor (Factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia). Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

KOVALTRY is used to treat and control bleeding in adults and children with hemophilia A. Your healthcare provider may give you KOVALTRY when you have surgery. KOVALTRY can reduce the number of bleeding episodes in adults and children with hemophilia A when used regularly (prophylaxis). KOVALTRY is not used to treat yon Willebrand Disease.

Who should not use KOVALTRY?

You should not use KOVALTRY if you

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

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

- Tell your healthcare provider about all of your medical conditions.
- Tell your healthcare provider 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 remedies.
- Tell your healthcare provider if you have been told you have heart disease or are at risk for heart disease.
- Tell your healthcare provider if you have been told that you have inhibitors to Factor VIII (because KOVALTRY may not work for you).

What are the possible side effects of KOVALTRY?

The common side effects of KOVALTRY are headache, fever and itchy rash. Allergic reactions may occur with KOVALTRY. Call your healthcare provider right away and stop treatment if you get tightness of the chest or throat, dizziness, decrease in blood pressure, and nausea.

Your body can also make antibodies, called "inhibitors," against KOVALTRY, which may stop KOVALTRY 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.

These are not all the possible side effects with KOVALTRY. 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.

Reference: KOVALTRY® [prescribing information]. Whippany, NJ: Bayer HealthCare Pharmaceuticals, Inc; 2016.

Bayer, the Bayer Cross, and KOVALTRY are registered trademarks of Bayer. © 2017 Bayer. All rights reserved. Printed in USA 04/17 PP-675-US-0800

How do I store KOVALTRY?

Do not freeze KOVALTRY.

Store KOVALTRY at +2°C to +8°C (36°F to 46°F) for up to 30 months from the date of manufacture. Within this period, KOVALTRY may be stored for a period of up to 12 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 12 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 KOVALTRY as soon as possible. If not, store at room temperature for no longer than 3 hours.

Throw away any unused KOVALTRY after the expiration date.

Do not use reconstituted KOVALTRY if it is not clear.

What else should I know about KOVALTRY and hemophilia A?

Finding veins for injections may be difficult in young children. When frequent injections are required, your healthcare provider may propose to have a device surgically placed under the skin to facilitate access to the bloodstream. These devices may result in infections.

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

This leaflet summarizes the most important information about KOVALTRY. If you would like more information, talk to your healthcare provider. You can ask your healthcare provider or pharmacist for information about KOVALTRY 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 KOVALTRY Customer Service 1-888-606-3780

Bayer Reimbursement HELPline 1-800-288-8374 For more information, visit www.KOVALTRY-us.com

Bayer HealthCare LLC Whippany, NJ 07981 USA U.S. License No. 8



RMHBDA Education Scholarship 2019

For Undergraduate Students and Families Affected by Bleeding Disorders

Deadline: June 1, 2019

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.

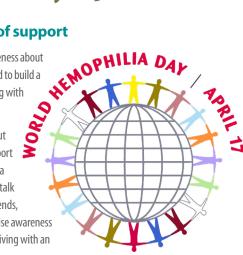
Visit www.rmhbda.org to apply.

World Hemophilia Day 2019

Building a family of support

Join us on April 17 to raise awareness about bleeding disorders and the need to build a family of support for those living with them.

Families come in many forms but they all share the ability to support and advocate. World Hemophilia Day provides an opportunity to talk to your extended family and friends, colleagues, and caregivers to raise awareness and increase support for those living with an inherited bleeding disorder.



You can also go one step further and have a local landmark, a light in your home or office, or your front porch light lit in red on April 17 to show your commitment to the bleeding disorder community.

This year connect the global bleeding disorder family on the World Federation of Hemophilia social media network and encourage your online community to join the global family.

From page 1: Education Weekend





RMHBDA Loves 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.

amazonsmile

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 and secure donation at no cost to RMHBDA or the donor — just visit www.rmhbda.org on the 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

The Inhibitor Summits 2019

The Inhibitor Summits have been held for more than a decade, providing families affected by inhibitors with the education and support they often need as they face this serious complication. NHF will continue this tradition in 2019, by hosting three Inhibitor Summits:

- ♦ June 6–9. Sunday–Thursday
- Indianapolis, Indiana
- June 27–30, Thursday–Sunday

Seattle, Washington

♦ August 1–4, Thursday–Sunday

Boston, Massachusetts



NATIONAL HEMOPHILIA FOUNDATION www.hemophilia.org

Montana License Plates



RMHBDA Montana

license plates are ready to have a place on your vehicle.

Please keep this in mind for your upcoming Montana license renewal and as an easy way of supporting your chapter. The more people who see it, the more people will want one!

Have a look on the Montana State website:

https://dojmt.gov/driving/plate-designs-and-fees/service-organizations-associations/



2018 Junior National Championship (JNC)

Dear RMHBDA,

I wanted to sincerely and gratefully thank you for sending me to the JNC this year!!! I had an absolutely amazing time, met so many people, and loved competing and practicing baseball! I came in 3rd overall, so I won a \$500 donation to your chapter, so be on the lookout for that!

Please pass on to your chapter how incredibly honored I was to have been selected and to have represented Montana and Wyoming!

Sincerely, Keegan



Developed by CSL Behring, the Gettin' in the Game Junior National Championship (JNC) was the first and is currently the only national golf, baseball, and swimming competition designed specifically for the bleeding disorders community. The JNC features accomplished Gettin' in the Game Athletes, who themselves have been diagnosed with bleeding disorders, such as hemophilia and von Willebrand Disease.

CSL Behring

Biotherapies for Life[™]





Biotherapies for Life[®] CSL Behring





FDA approved for dosing 2 to 3 times a week



Regardless of age and dosing schedule



In previously treated people

AFSTYLA was studied in 258 adults, adolescents, and childrenthe largest hemophilia A pivotal trial program to date

*AsBR=Annualized spontaneous bleeding rate.

Important Safety Information

AFSTYLA is used to treat and control bleeding episodes in people with hemophilia A. Used regularly (prophylaxis), AFSTYLA can reduce the number of bleeding episodes and the risk of joint damage due to bleeding. Your doctor might also give you AFSTYLA before surgical procedures.

AFSTYLA is administered by intravenous injection into the bloodstream, and can be self-administered or administered by a caregiver. Your healthcare provider or hemophilia treatment center will instruct you on how to do an infusion. Carefully follow prescriber instructions regarding dose and infusion schedule, which are based on your weight and the severity of your condition.

Do not use AFSTYLA if you know you are allergic to any of its ingredients, or to hamster proteins. Tell your healthcare provider if you previously had an allergic reaction to any product containing Factor VIII (FVIII), or have been told you have inhibitors to FVIII, as AFSTYLA might not work for you. Inform your healthcare provider of all medical conditions and problems you have, as well as all medications you are taking.

Ask your doctor if twice-weekly dosing is right for you

Immediately stop treatment and contact your healthcare provider if you see signs of an allergic reaction, including a rash or hives, itching, tightness of chest or throat, difficulty breathing, lightheadedness, dizziness, nausea, or a decrease in blood pressure.

Your body can make antibodies, called inhibitors, against FVIII, which could stop AFSTYLA from working properly. You might need to be tested for inhibitors from time to time. Contact your healthcare provider if bleeding does not stop after taking AFSTYLA.

In clinical trials, dizziness and allergic reactions were the most common side effects. However, these are not the only side effects possible. Tell your healthcare provider about any side effect that bothers you or does not go away.

Please see full prescribing information at AFSTYLA.com.

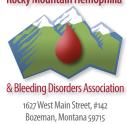
You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

AFSTYLA is manufactured by CSL Behring GmbH and distributed by CSL Behring LLC. AFSTYLA® is a registered trademark of CSL Behring Recombinant Facility AG. Biotherapies for Life® is a registered trademark of CSL Behring LLC.

©2018 CSL Behring LLC 1020 First Avenue, PO Box 61501, King of Prussia, PA 19406-0901 USA www.CSLBehring.com www.AFSTYLA.com AFS-0198-JAN18



Rocky Mountain Hemophilia



SPRING 2019

Address Correction Requested

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

