

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

- RMHBDA Education Weekend 2018 1
- Message from the Executive Director 1
- RMHBDA Walk — Billings Photos 2
- Men's Retreat 4
- calendar.rmhbda.org 4
- Mile High Colorado Camp 8
- FDA Grants Breakthrough Therapy Designation for BioMarin's Investigative Hemophilia A Gene Therapy 8
- Women's Retreat 9
- Accepting Scholarship Applications 10
- Montana RMHBDA License Plates 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/rmhbd



THE ROCKY MOUNTAIN



RMHBDA Education Weekend 2018

February 23–25, 2018, Bozeman, 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!

February is time for the 15th Annual Education Weekend for people affected by bleeding disorders in Montana and Wyoming!

You and your family are invited for a weekend of informative sessions, youth programming for all ages, and an opportunity to connect with others dealing with similar challenges.

Don't miss your chapter's annual meeting for all members on Saturday — important decisions will be made at this meeting and your input is needed! Lodging and meals will be provided to attending members, so don't hesitate to send your registration off today!

Don't miss this opportunity with your Chapter, Industries, HTC Staff, Accredited Speakers, and your family. It will be a special and rewarding weekend for all. ♦



Message from the Executive Director

Dear RMHBDA Supporters,

Thank you for joining us for our 6th Annual Walk to support our chapter and families dealing with bleeding disorders in Montana and Wyoming. We had over 125 walkers at Zoo Montana in Billings. Good-natured and generous supporters helped raise over \$46,000 and mission awareness. Our chapter also hosted our first walk in Kalispell, Montana. We had 60 walkers and raised over \$11,000. I want to send a very gracious thank you to our volunteers, team captains, and walkers for making our walk a tremendous success. We are so grateful for your participation.



We would also like to extend a very gracious thank you to our local and corporate sponsors: Advanced Dental Professionals, St. Vincent's Healthcare, Barnard, Shire, Bayer, Bioverativ, Bozeman Deaconess, Avitus Group, Fifth Street Design, First Interstate Bank, Grifols, Aptevo, Accredo, Fuller Family Health, Bridger Creek Dental, Kalispell Regional Specialists, Octapharma, CSL Behring, First Montana Title, Billings Clinic, Advanced Hydroseeding, Novo Nordisk, Pfizer, CVS Caremark, and Restore RX.



Sincerely,
Brad Benne,
Executive Director

RMHBDA Walk — Billings Photos





For adults and children with hemophilia A

REACH HIGHER

With the Long-lasting Protection of AFSTYLA

2x
WEEKLY
AVAILABLE

FDA-approved for dosing 2 or 3 times a week

ZERO
BLEEDS
(median AsBR*)

In clinical trials, whether dosed 2 or 3 times a week

COMPARABLE TO
NATURAL
FACTOR
VIII

Identical to natural Factor VIII once activated

Zero inhibitors observed—Low incidence of side effects in clinical trials

In clinical trials, dizziness and allergic reactions were the most common side effects.

Visit AFSTYLA.com to sign up for the latest news

*Annualized spontaneous bleeding rate in clinical trials (interquartile range [IQR]=0–2.4 for patients ≥12 years; 0–2.2 for patients <12 years).

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.

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.

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.

Please see the following brief summary of full prescribing information on the adjacent page, and the full prescribing information, including patient product information, at AFSTYLA.com.

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.

©2016 CSL Behring LLC 1020 First Avenue, PO Box 61501, King of Prussia, PA 19406-0901 USA
www.CSLBehring-us.com www.AFSTYLA.com AFS16-05-0084 5/2016

AFSTYLA®
Antihemophilic Factor
(Recombinant), Single Chain

THE ROCKY MOUNTAIN

Men's Retreat

RMHBDA held the annual men's retreat at Quinn's Hot Springs the weekend of October 13–15. We had seven men attend the retreat. The weather was crisp, but we managed to enjoy a day guided flyfishing on Montana's Clark Fork River near St. Regis. Thank you to Novo Nordisk, Shire, Pfizer, and the Hemophilia Federation of America for making the event possible. 🍷



calendar.rmhbda.org

- 🔥 **January 19-21** **NACCHO Camp Conference**
- 🔥 **February 23-25** **RMHBDA Education Weekend & Annual Meeting, Bozeman**
- 🔥 **March 1-31** **Hemophilia Awareness Month**
- 🔥 **March 7-9** **NHF Washington DC Days**
- 🔥 **April 17** **World Hemophilia Day**
- 🔥 **April 26-29** **HFA Symposium, Cleveland, OH**
- 🔥 **May TBD** **Education Series**
- 🔥 **June TBD** **HTC Clinic, Billings**
- 🔥 **July 13-15** **Mile High Summer Camp Leadership Pre-Camp Retreat, Empire, CO**
- 🔥 **July 15-20** **Mile High Summer Camp Rocky Mountain Village, Empire, CO**
- 🔥 **August 10-12** **Family Camp, Flathead Methodist Camp, Rollins, MT**
- 🔥 **September 8** **RMHBDA Walk for Bleeding Disorders, Billings**
- 🔥 **September 15** **RMHBDA Walk for Bleeding Disorders, Kalispell**
- 🔥 **October 11-14** **National Hemophilia Foundation Conference, Orlando, FL**
- 🔥 **November TBD** **CSL Behring "Getting In the Game"**
- 🔥 **November 2-4** **Women's Retreat, Chico Hot Springs**



The calendar is always available on the website!

calendar.rmhbda.org



BAYER **access solutions**

Don't let insurance or financial challenges get between you and your treatment

Free Trial Program*

- Enroll today for up to 6 free doses†
- KOVALTRY®, Antihemophilic Factor (Recombinant), or KOGENATE® FS, Antihemophilic Factor (Recombinant), is delivered to your home free of charge
- Any patient who has not taken KOVALTRY® or KOGENATE® FS is able to participate, regardless of type of insurance or if you have insurance

Loyalty Program‡

Redeem points to receive KOVALTRY® or KOGENATE® FS at no cost if you experience gaps or challenges with insurance coverage

- **Introductory Enrollment Bonus—12 points:** Enroll now during the introductory period ending February 28, 2018, and get a year's worth of Loyalty points

\$0 Co-pay Program§

If you have private insurance, you may be eligible for the \$0 Co-pay Program

- You may be able to receive **up to \$12,000 in assistance** per year, regardless of income
- **Assistance is awarded per patient.** Multiple members of the same household can apply
- Enrollment can be started and completed in **one short phone call**

Live Helpline Support

- Consult with an expert in insurance
- Spanish-speaking Case Specialists are also available



Call **1-800-288-8374** 8:00 AM–8:00 PM (ET) Monday–Friday.

*The Free Trial Program is available to newly diagnosed patients and patients who are currently using other therapy. Patients currently using KOVALTRY® or KOGENATE® FS are not eligible for the respective Free Trial programs. Participation in the Free Trial Program is limited to 1 time only per treatment. The medication provided through this program is at no cost to patients and is not an obligation to purchase or use KOVALTRY® or KOGENATE® FS in the future. Reselling or billing any third party for the free product is prohibited by law.

†The Free Trial Program includes up to 6 free doses to a maximum of 5,000 IU for new patients and 40,000 IU for previously treated patients.

‡Patients who have government insurance (Medicaid, Medicare, Tricare, VA/DOD) are not eligible for the Loyalty Program. The program does not guarantee that patients will be successful in obtaining coverage for product. Support medication provided through Bayer's assistance programs is at no cost to patients and is not contingent on future KOVALTRY® or KOGENATE® FS prescriptions. Reselling or billing any third party for free product provided by Bayer's patient assistance programs is prohibited by law. Bayer reserves the right to determine eligibility, monitor participation, determine equitable distribution of product, and modify or discontinue the program at any time.

§People with private, commercial health insurance may receive KOVALTRY® or KOGENATE® FS co-pay or co-insurance assistance based on eligibility requirements. The program is on a first-come, first-served basis. Financial support is available for up to 12 months. Eligible patients can re-enroll for additional 12-month courses. The program is not for patients receiving prescription coverage for product under any federal-, state-, or government-funded insurance programs, or where prohibited by law. All people who meet these criteria are encouraged to apply. Bayer reserves the right to discontinue the program at any time.

Bayer, the Bayer Cross, KOVALTRY, and KOGENATE are registered trademarks of Bayer.

© 2017 Bayer. All rights reserved.
Printed in USA 07/17 PP-775-US-0794



antihemophilic factor (recombinant)



Antihemophilic Factor (Recombinant)



Science matters. Because patients matter.™

It's because of this belief that we:

Brought the leading extended half-life therapies to people with hemophilia—innovation that has changed the way hemophilia can be managed.

Sponsor free genetic testing for people with hemophilia and carriers through *My Life, Our Future*. Together with program co-founders the American Thrombosis and Hemostasis Network, Bloodworks Northwest, and the National Hemophilia Foundation, we are advancing disease understanding and research for the entire community.

Transformed humanitarian aid in hemophilia, with Sobi, by committing to donate up to one billion IUs of factor therapy over 10 years to help close the treatment gap in the developing world. More than 12,300 people have been treated through the WFH Humanitarian Aid Program, which is receiving 500 million IUs over five years.

We not only believe great science can conquer the toughest medical challenges, we live it every single day.

Bioverativ.com

Bioverativ 

HEM-US-1906 07/2017

Mile High Colorado Camp

July 15–20, 2018

Leadership Pre-Camp Retreat

July 13–15, 2018

Camp forms will be available in March 2018 at <https://goo.gl/36FDzb> or from our rmhbda.org

When and Where?

The Hemophilia and Thrombosis Center (HTC) is proud to once again sponsor the summer camp program:

- July 15–20, 2018 (13–15 for Leadership Pre-Camp Retreat)
- Rocky Mountain Village, Empire Colorado.

Who Should Attend?

- Children with hemophilia or other bleeding disorders
- Siblings of the above groups
- Mile High Colorado Camp is for ages 7–18. Programming is determined by age. Check back with us soon to learn about the different programs we offer at camp!

Why Attend Camp?

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.

Many campers have learned to perform self-infusion, experienced teamwork, and discovered new skills during the week of camp. Staff at the Hemophilia & Thrombosis Center (HTC) and Rocky Mountain Village wants this to be a wonderful experience that creates a wealth of fond memories for your camper.

What does it cost?

Each family is required to pay only a non-refundable \$75 deposit. The remainder of the camp cost, approximately \$1,000 per camper, is underwritten by other sources. If you have questions or need additional information, please call Brad Benne at 406.586.4050. Scholarship forms are available. Scholarships will be granted on an individual basis.

Help send a child to camp!

Make a dream come true this summer! Your contribution will send a youth to hemophilia summer camp at Mile High Camp in Colorado. Your support makes a lasting difference in the lives of children with a bleeding disorder. ♦



FDA Grants Breakthrough Therapy Designation for BioMarin's Investigative Hemophilia A Gene Therapy

The U.S. Food and Drug Administration (FDA) recently granted “breakthrough” therapy designation for valoctocogene roxaparvovec (formerly BMN 270), an investigational hemophilia A gene therapy candidate developed by BioMarin Pharmaceuticals.

The breakthrough status was granted in light of positive results of phase 1/2 clinical study that focused on the safety and efficacy of valoctocogene roxaparvovec. Breakthrough drugs are put on a fast-track approval program and given intensive guidance from the FDA. The therapy was granted a similar designation by the European Medicines Agency (EMA), the FDA's counterpart in Europe, earlier in 2017.

Valoctocogene roxaparvovec uses adeno-associated viruses (AAVs) as delivery vehicles, or vectors, to carry the genetic codes that prompt the production of the factor VIII (FVIII) protein that is deficient in people with hemophilia A. These AAVs are designed to deliver genetic material into living cells to sustain therapeutic effect without causing disease or triggering significant immune responses.

“The news of the FDA granting breakthrough therapy designation coupled with EU PRIME designation granted in early 2017 by EMA, demonstrates the strong support of global health authorities for valoctocogene roxaparvovec and its expedited development and registration pathway,” said Hank Fuchs, MD, President, Worldwide Research and Development at BioMarin. “There is a tremendous need to achieve normal steady state factor VIII levels to eliminate spontaneous bleeding, to avoid the complications of sub optimally corrected bleeding disorder, to improve quality of life and enable patients to live to their fullest potential.”

BioMarin has indicated that patient enrollment for phase 3 clinical studies will begin before the end of 2017.

Source: BioMarin press release dated October 26, 2017 ♦

We Love Donations!

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 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 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

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.

Women's Retreat

Twenty-two women braved the snowy roads to attend the Women's retreat. The evening began with a welcome and short introduction. Dr. Marilyn Manco-Johnson started the Friday evening's education with an overview of the My Life Our Future program, which ends this December. This program offers free genotyping to participants to gain a greater understanding of hemophilia, while helping to advance the breakthrough treatments of tomorrow. Dr. Manco-Johnson coordinated with the women interested in participating in the program and set up blood draws for Sunday morning.

Saturday morning's events began with three of our industry sponsors giving an overview of each of their companies and products while the women enjoyed breakfast. The two guest speakers rounded out the morning. Sonji Wilkes, Hemophilia Federation of America, gave an informative talk on being in control of your health and included the website tabs for HFA's toolkit, a downloadable resource for various subjects. Amber Federizo, RN, MSN, FNP-BC, gave a frank, amazing talk on women's health and intimacy. Amber also met with the young women, ages 16 to 18, after lunch for a private rap session. These young ladies noted that one hour could have turned into four hours easily.

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

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

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



Accepting Scholarship Applications

We are currently accepting applications for the Beth Carew Memorial Scholarship. We use an online application process provided by International Scholarship and Tuition Services, Inc. (ISTS). The application link is: <https://aim.applyISTS.net/ColburnKeenan/>

The application deadline is Monday, February 19th. Deadline extensions will not be provided. ♦



Montana RMHBDA License Plates

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, we hope that the more will want one!

Have a look on the Montana State website:

<https://dojmt.gov/driving/plate-designs-and-fees/service-organizations-associations/> or <https://goo.gl/j8GGq5>, which is the same place, just easier to type. ♦



Now Available!



NUWIQ[®]
Antihemophilic Factor
(Recombinant)



Want to Learn More?

Contact your
Octapharma Representative:

KEN WAGG

PHONE:
505-414-7173

EMAIL:
Kenneth.Wagg@octapharma.com

©2016, Octapharma USA Inc. All rights reserved.
Date of preparation: 1/2016. NUW-017-CAD-e

octapharma[®]
For the safe and optimal use of human proteins

MAKE A NOTE

REBINYN®:

COMING
SOON

AVAILABLE IN 2018



Register for updates
at rebinyn.com



Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.

Rebinyn® is a registered trademark of Novo Nordisk Health Care AG.

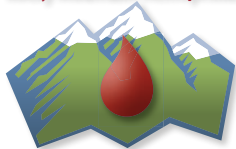
Novo Nordisk is a registered trademark of Novo Nordisk A/S.

© 2017 Novo Nordisk All rights reserved. USA17BI002514 October 2017

rebinyn®

*Coagulation Factor IX
(Recombinant), GlycoPEGylated*

Rocky Mountain Hemophilia



& Bleeding Disorders Association

1627 West Main Street, #142
Bozeman, Montana 59715

Address Correction Requested

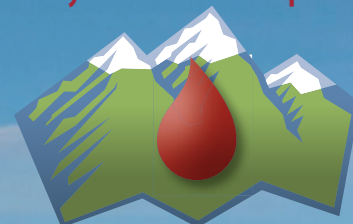
Non Profit Org.
US Postage
Paid
Bozeman, MT
Permit No. 94

3-46

FALL/WINTER 2017



Rocky Mountain Hemophilia



& Bleeding Disorders Association