



THE ROCKY MOUNTAIN

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 2017 1
- RMHBDA in Washington 1
- Family Camp 2017 2
- Making the Connection Conference 2
- New Programs Coordinator: Lisa Maxwell 4
- Montana License Plates 4
- calendar.rmhbda.org 4
- Mile High Colorado Camp 2017 7
- Scholarships 9
- World Hemophilia Day 2017 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/rmhdbda

Education Weekend 2017

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, Shire, Bioerativ, CSL Behring, CVS Caremark, Grifols, HF Healthcare, Novo Nordisk, Octapharma, Restore RX, Aptevo, the National Hemophilia Foundation, the Hemophilia Federation of America, and Pfizer Hemophilia.



RMHBDA Education Weekend was held February 17–19 in Bozeman, Montana. Twenty-three families attended with a total of over 80 people in attendance. Educational sessions during the event included: infusion session and Breakout sessions for our Blood Brotherhood and Sisterhood programs. All chapter members spent time visiting our exhibitors and learned more about each company and their products.

Everyone enjoyed the chapter trip to the bowling alley. Children enjoyed field trips to the Spire Climbing Center.

Raffle Winners

- Wyatt Amende
- Connie Smith



RMHBDA in Washington

A fabulous team from Montana and Wyoming just recently stormed Capitol Hill March 9, 2017. Bozeman was well represented by Kevin, Avory, and Wyatt Amende, Jodi Rudell took on Wyoming, and I rounded out the team along with 480 other advocates from around the US. This was the largest group ever for NHF.



We personally meet with all four Senators and had good meetings with the legislative aids for both Representatives. We mainly focused on three policies that can greatly impact our community as Congress repeals/replace the ACA. We asked the members of Congress to support:

- Maintaining the elimination of lifetime caps and annual limits or caps on essential health benefits.

► Continued on page 2

► From page 1: **RMHBDA in Washington**

- Maintaining the federal requirements for essential health benefits.
- Maintaining the Medicaid expansion to ensure that Medicaid eligibility is preserved for single men and women meeting poverty standards. (Wyoming did not expand Medicaid)

It is important that we all continue to contact our senators and representatives to let the know how important these policies are and how they affect us. Phone calls are logged and counted. Please take the time to call:

- Senator Steve Daines (R-MT) (202) 224-2651
- Senator Jon Tester (D-MT) (202) 224-2644
- Senator John Barroso (R-WY) (202) 224-6441
- Representative Liz Cheney (R-WY) (202) 225-2311
- Senator Michael Enzi (R-WY) (202) 224-3424

— Lisa Maxwell
Programs Coordinator



Family Camp 2017

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!

June 16-18, 2017
Camp on the Boulder
 3916 Boulder Rd,
 P.O. Box 47, McLeod, MT 59052
www.campontheboulder.org
 (406) 932-6314



For the parents and teens, we will have teambuilding programming led by our guest, hemophilia leadership group, Gut Monkey, www.gutmonkey.com, and some time to relax with other families. For youth, Beyond Recreation will provide activities and programming. This is a great opportunity to learn from and share experiences with one another.

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

Call Brad with any questions at 406.586.4050

Making the Connection Conference

The "Making the Connection" conference is the first meeting designed for Type 3 VWD patients. This conference is being put together by the Global Blood Disorder Foundation (www.globalblooddf.org) and is being supported by Octapharma.



At the meeting, patients will have the opportunity to meet other Type 3 VWD patients, medical and health educator professionals, and representatives from national bleeding disorder support organizations. Presenters from all over the country will comprise the faculty that will offer attendees both medical and psycho-social information and resources to help manage living with Type 3 VWD.

The conference is free for a Type 3 patient and a companion in



Palm Beach Gardens, Florida
May 12-15, 2017.

For complete conference details and to register, please visit:
ce.creativegroupinc.com/#the-type-3-von-willebrand-disease-conference/welcome

We Love Donations!

Donations 2016
in honor of Andy Brinkley

Donations

Christy & Forrest Berg
 Jim Ferriter & Lisa Glass
 Linda Reichardt

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.



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



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



Want to Know More

about your factor options?

When it comes to your factor therapy, you have choices. And at Bioverativ, we recognize the importance of continued research as well as supporting the hemophilia community. See if now might be the right time for you to make a change—learn more about our therapy options as well as our range of financial, educational, and community support programs.



To learn more about these options, contact your CoRe Manager:

Becky Ybarra | **Phone:** 801.913.8204 | **E-mail:** becky.ybarra@bioverativ.com

**New Programs Coordinator:
Lisa Maxwell**



"We (RMHBDA) are beyond fortunate to announce the hiring Lisa Maxwell as our Programs Coordinator. Lisa's experience and commitment to our chapter and to our community on both a local and national level has been critical to the success of our chapter. Her past tireless work as a volunteer and as a board member will serve our chapter well as she transitions to being an extraordinary asset at RMHBDA," shared executive director Brad Benne.

Lisa's experience with RMHBDA includes:

- RMHBDA Board of Directors 2005-17
- RMHBDA Board President 2012-14
- Past Family Camp Director
- NHF Annual Meeting Co-Chair 2014, 2105
- Washington Days 2009-17

In regard to her new role with RMHBDA, Lisa offered, "This organization has given me and my family much needed education, support, and lifelong friendships. It is my hope to give back to other families all these blessings that this chapter has given me."

Lisa will work from her home base of Kalispell, Montana, and can be contacted at lisa@rmhbda.org.



**Montana License Plates
Now Available!**

The approval process has been longer and more involved than we anticipated, but the 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, 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/>

calendar.rmhbda.org



The calendar is always available on the website!

calendar.rmhbda.org



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

To patients on Helixate® FS

Antihemophilic Factor (Recombinant)



You can continue

Factor VIII treatment with

Kogenate® FS Antihemophilic Factor (Recombinant)

INDICATIONS

- Kogenate® FS Antihemophilic Factor (Recombinant) and Helixate® FS Antihemophilic Factor (Recombinant) are medicines used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A.
- Kogenate FS and Helixate FS are used to treat and control bleeding in adults and children with hemophilia A. Your healthcare provider may give you Kogenate FS or Helixate FS when you have surgery. Kogenate FS and Helixate FS can reduce the number of bleeding episodes in adults and children when used regularly (prophylaxis). Kogenate FS and Helixate FS can reduce the risk of joint damage in children without pre-existing joint damage when used regularly.
- Kogenate FS and Helixate FS are not used to treat von Willebrand disease.

IMPORTANT SAFETY INFORMATION

- You should not use Kogenate FS or Helixate FS if you are allergic to rodents (like mice and hamsters) or are allergic to any ingredients in Kogenate FS or Helixate FS.
- Tell your healthcare provider if you have been told you have heart disease or are at risk for heart disease.
- You could have an allergic reaction to Kogenate FS or Helixate FS. Call your healthcare provider right away and stop treatment if you get rash or hives, itching, tightness of the chest or throat, difficulty breathing, light-headed, dizziness, nausea or a decrease in blood pressure.

Mile High Colorado Camp 2017

SAVE THE DATE! July 16-21, 2017

Leadership Pre-Camp Retreat July 14-16, 2017

Camp forms are available online now at:

cohemo.org/what-we-do/mile-high-summer-camp/mile-high-summer-camp-forms.html/

The Hemophilia and Thrombosis Center (HTC) is proud to once again sponsor the summer camp program at **Rocky Mountain Village** July 14-21.



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 a non-refundable \$75.00 deposit. The remainder of the camp cost, approximately \$1000.00 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!

This summer make a dream come true. 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. ♦

Shire

Michelle
VWD
Nevada

Built on strength and experience. Powered by our commitment to you.

With over 60 years of dedicated history to the Hematology and rare disorders communities, Shire has even more resources to bring to the bleeding disorders community. Supported by the passion, commitment and innovation that make a difference, we'll continue to consistently pursue advancements in the treatment of bleeding disorders.

You can count on us because we're here ... stronger than ever.

To learn more about our commitment, visit us at BleedingDisorders.com

©2017 Shire US Inc., Lexington, MA 02421. All rights reserved. 1-800-828-2088. SHIRE and the Shire Logo are registered trademarks of Shire Pharmaceutical Holdings Ireland Limited or its affiliates. S28156 02/17

CoRe CONVERSATIONS

We invite you to join us for CoRe Conversations: opportunities for members of the hemophilia community to come together and discuss topics relevant to the issues we may face each day. We'll share stories, ways to navigate issues, and tips and resources to help guide the way.



THE POWER OF EMPOWERMENT

CRACKING THE CODE

MAPPING YOUR FUTURE

SETTING EDUCATIONAL EXPECTATIONS

BRAVING CHANGE

DECIDING IF YOU'RE CAMP READY

UNDERSTANDING THE VALUE OF GENOTYPING

GETTING READY FOR WHAT'S NEXT

NAVIGATING FINANCIAL AID

SPOTLIGHT ON UNAFFECTED SIBLINGS

THE EVOLVING LANDSCAPE OF HEMOPHILIA

AGING WITH HEMOPHILIA

HEMOPHILIA FROM A WOMEN'S PERSPECTIVE

GATEWAYS TO EDUCATION: EXPLORING OPPORTUNITIES THAT MAY BE RIGHT FOR YOU

PARENTING WITH HEMOPHILIA



Scholarships

As teens move toward adulthood, they face many choices for education and training for a future career. Education can be pricey. Add the costs of dealing with chronic bleeding disorder and students may not know where to start. There are several scholarships available that those with a bleeding disorder or their family members may qualify for. The links included here each have their own requirements and deadlines. Please read each carefully when considering application for scholarships.



| Name | Amount(s) | Description | 2017 Deadline |
|---|-----------------|--|---------------|
| RMHBDA | \$1,000 | Through the RMHBDA we recognize the many individuals including the board of directors, governance bodies, donators, sponsors and each and every member as a reason to exist as well as the reason we do exist. Due to the generosity of many and the needs of our members it has been a long time goal to be able to offer scholarships to our membership. | |
| Eric Dostie Memorial College Scholarship | \$1,000 | For persons with bleeding disorders, or a family member. | March 1 |
| Beth Carew Memorial Scholarship Program | \$4,000 | For persons with hemophilia, von Willebrand disease or other inherited bleeding disorders. | April 15 |
| Biogen Idec Hemophilia Scholarship | \$2,500–\$7,000 | For persons with hemophilia A or B. | April 16 |
| Baxalta Education Advantage Scholarships | \$150–\$7,000 | For persons with hemophilia A or B, or von Willebrand disease. | April 29 |
| | \$7,000 | University Scholarship | |
| | \$1,000 | Community College and Technical Scholarship | |
| | \$150 | GED Assistance | |
| HFA Educational Scholarship | \$2,000 | For persons with bleeding disorders seeking post-secondary education from a college, university or trade school. | April 30 |
| HFA Medical/Health Services Educational Scholarship | \$4,000 | For persons with a bleeding disorder, or persons related to someone with a bleeding disorder, and pursuing a degree in the medical/healthcare services field. | April 30 |
| HFA Parent/Sibling/Child Educational Scholarship | \$2,000 | For parents/siblings/children of a person with a bleeding disorder seeking post-secondary education from a college, university or trade school. | April 30 |
| Professor Ulla Hedner Scholarship | \$7,000 | For persons with bleeding disorders, no age limit. | April 30 |
| Novosecure Scholarship | \$2,000–\$5,000 | For persons with hemophilia or their caregivers seeking college or vocational education. | May 1 |
| NHF Colorado Chapter Academic Scholarship | \$2,500 | For persons with a bleeding disorder or family members, living in Colorado. | TBA |
| Emergent B More Scholarship | \$2,000 | For persons with hemophilia B. (Scroll down the page to find the link for the scholarship application) | May 5 |
| Pfizer Soozie Courter Hemophilia Scholarship | \$2,500 & \$400 | For persons with hemophilia A or B; graduate or college & vocational school applicants. | May 6 |
| HF Healthcare Nate Slack Scholarship | \$1,000 | For persons with hemophilia or related bleeding disorder, or persons in the immediate family of a person with hemophilia or related bleeding disorder. | May 20 |
| NHF Kevin Child Scholarship | \$1,000 | For persons with hemophilia A or B. | June |
| Education is Power Scholarship | \$500–\$2,000 | For persons with hemophilia or von Willebrand disease. | June 1 |
| Eric Delson Memorial Scholarship Program 1 | \$2,500 | For persons with hemophilia or von Willebrand disease to attend college, vocational or technical school. | July 1 |
| Eric Delson Memorial Scholarship Program 2 | \$1,500 | For persons with hemophilia or von Willebrand disease who are attending private school, grades 7–12. | July 1 |
| Joshua Gomes Memorial Scholarship Fund | \$1,000 | For persons living with HIV/AIDS accepted or enrolled in a college in the United States. | July 15 |
| Matrix Health Group: Memorial Scholarship Program | \$1,000 | Several scholarships available with varying criteria, but most with either hemophilia, von Willebrand Disease or other bleeding disorders. | August 1 |

The HTC strives to keep these links as updated as possible for ease of our patients and families. Please contact the scholarship provider directly for questions pertaining to a particular scholarship. If you find a broken link or an error on this page, please feel free to contact us and we will work to make a correction as soon as possible.

Please also check with these resources when searching for scholarships as there may be others you qualify for that are not listed. 💡

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

World Hemophilia Day 2017

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. 📌





is now brought to you by

Aptevo Therapeutics— a company that's anything but ordinary



At Aptevo, we pride ourselves on:

Providing high-quality, specialized therapies for people with rare conditions

Connecting with people to learn about their needs

Developing empowering programs that enrich peoples' lives

Learn more at IXINITY.com

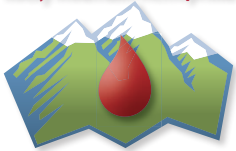


Aptevo BioTherapeutics LLC, Berwyn, PA 19312

IXINITY [coagulation factor IX (recombinant)], and any and all Aptevo BioTherapeutics LLC brand, product, service and feature names, logos, and slogans are trademarks or registered trademarks of Aptevo BioTherapeutics LLC in the United States and/or other countries.

©2016 Aptevo BioTherapeutics LLC. All rights reserved. CM-FIX-0061B

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

SPRING 2017

Rocky Mountain Hemophilia



& Bleeding Disorders Association

