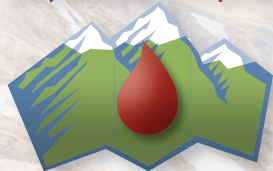


Rocky Mountain Hemophilia



& Bleeding Disorders Association



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.

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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

2016 RMHBDA Family Camp



July 29-31 2016

Flathead Lake United Methodist Camp
21339 Methodist Camp Road, Rollins, MT
(406) 844-3483 www.flatheadcamp.org

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!

For the parents and teens, we will have teambuilding programming led by our guest, hemophilia leadership expert, Pat Torrey and some time to relax with other families. 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

RMHBDA's Women's Retreat: Women's Escape

Friday-Sunday, November 6 - 8, 2015
Chico Hot Springs, Pray, MT

Ladies, you are invited to RMHBDA's "Women's Escape." Ladies, please leave the boys at home. ☺

We need help planning. Our committee includes: Christy Savage, Jane Robertson, Jodi Rudell, and Lisa Maxwell. Thank you for your time and support in planning this event. All of your Chico Hot Springs expenses will be covered. To RSVP or if you need fuel assistance, contact Brad: brad@rmhbda.org, 406.586-40500.



RMHBDA Education Weekend 2016

February 19- 21

Our Education Weekend will take place at the Holiday Inn, 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!



Message from the Executive Director

Hello Friends,

Thank you for joining us for our 4th Annual walk to support our chapter and families dealing with bleeding disorders in Montana & Wyoming. We had over 170 walkers at Zoo Montana in Billings. Good-natured and generous supporters helped raise over \$52,000 and expand awareness at our 4th annual walk. 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: St. Vincent's Healthcare, Barnard Construction, Baxalta, Bayer, Biogen, Bozeman Deaconess, Avitus Group, Fifth Street Design, First Interstate Bank, Grifols, HF Healthcare, Accredo, BioLife Plasma Services, Emergent BioSolutions, Optioncare, Octapharma, Fuller Family Medicine, Novo Nordisk, First State Bank of Malta, Pfizer, CVS Caremark, and Restore RX.



With gratitude and appreciation,
Brad Benne,
Executive Director

2015 Hemophilia Walk

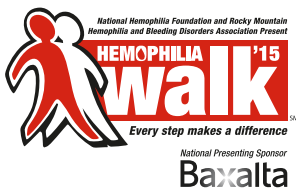
Participation was great for our 4th Annual Montana and Wyoming Walk for Hemophilia. Altogether, over \$52,000 was raised including these top fundraisers and teams — your work was awesome and deeply appreciated!

Top Fundraisers

1. Chris Graham \$4,300
2. John & Will Benne \$3,705.25
3. Campbell Hunter \$3,590
4. Dylan Hunter \$1,995
5. Kevin Amende \$1,395
6. Travis Bruyere \$1,150
7. Jodi Rudell \$940
8. Kristal Graham \$928
9. Lisa Maxwell \$770
10. Rose Woods \$619.75
11. Connor Ferriter \$500
12. Christy Berg \$375
13. Raven Card \$315
14. Forrest Berg \$300
15. Chris Hunter \$300
16. Jaxon Stafford \$258
17. Julane Wells \$250
18. Stephanie Hines-Hernandez \$220
19. Silent Donor \$200
20. Katie Schneider \$200

Top Teams

1. Ty's Crew III \$9,825
2. The Warriors \$6,685
3. Blood Brothers IV \$5,092.25
4. Bodacious Bleeders \$2,025
5. Best of the Bleed \$1,928
6. Clot Like an Amende \$1,570
7. VW Ladybugs Plus One \$1,265
8. RMHBDavitus \$1,150
9. MAXOUT \$870
10. Connor's Comrades \$700
11. Red Moon Walkers \$619.75
12. We Bleed Red & White \$470
13. Biolife Plasma Services \$465
14. WyoRed's15 \$303
15. Trot to Clot \$300
16. CohenourFive \$100
17. von Willebrand Walkers \$50
18. St. Vincent Healthcare Foundation \$25



Men's Retreat: Blood Brotherhood Event

The Chartered Fishing Trip on Flathead Lake from Lakeside, MT was held August 1. We held a dinner with Sharon Funk, PT, UC/HTC at Jagz in Kalispell where 23 people attended the dinner. Sharon shared her expertise with the group regarding the many benefits of physical therapy relating to those dealing with bleeding disorders.

On Saturday, ten men and their children went charter fishing on Flathead Lake. We had a beautiful day on the water and the kids had a wonderful time. 🍷



COMING SOON

KOVALTRY™

Antihemophilic factor (recombinant)



Register for updates at www.KOVALTRY.com

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Our vision for innovation, brighter than ever.

Baxalta

**For more than 60 years, we've consistently pursued
advancements in the treatment of bleeding conditions.**

Now, as Baxter's BioScience becomes Baxalta Incorporated, this proven heritage — along with the advancements we're making today to cultivate tomorrow's developments — fuels our global vision and promise: Our relentless desire to make a meaningful difference in the lives of real people — one person at a time. This promise to you can be seen in all we do, and helps to make us the company we are today.

Victor
Patient, Baltimore, MD

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June 2015 USBS/MG1/15-0589

2015 Mile Colorado Camp

An Empowering Experience

Mile High camp was a huge success again this year, nearly hundred children from Colorado, Montana, and Wyoming attended camp this year. A special "Thank you" to our University of Colorado Hemophilia Treatment Center and the Colorado Hemophilia Chapter for sponsoring

Mile High camp. The opportunity each camper encounters is empowering and life-changing. I want every kid dealing with bleeding disorders in Montana and Wyoming to experience Mile High Camp. Stay tuned for information about next year's camp in March of 2016! ♦



RMHBDA 2015 Program & Event Calendar

As of October 5, 2015.

♦ October

23–25 CSL Behring
"Getting In the Game"

♦ November

6–8 Women's Retreat
Chico Hot Springs
Pray, Montana

♦ December

TBD Pfi er Education Session
Bozeman



A treatment for hemophilia B

PROTECTION* FROM BLEEDS

Starting with at least a week
between prophylaxis infusions

Dosing regimen can be adjusted based on individual response.

*Protection is the prevention of bleeding episodes using a prophylaxis regimen.

To learn more, contact CoRe Manager **Becky Ybarra**
at becky.ybarra@biogen.com or call **801-913-8204**.



INDICATIONS AND IMPORTANT SAFETY INFORMATION

Indications

ALPROLIX, Coagulation Factor IX (Recombinant), Fc Fusion Protein, is a recombinant DNA derived, coagulation factor IX concentrate indicated in adults and children with hemophilia B for:

- Control and prevention of bleeding episodes
- Perioperative management
- Routine prophylaxis to prevent or reduce the frequency of bleeding episodes

ALPROLIX is not indicated for induction of immune tolerance in patients with hemophilia B.

Important safety information

Do not use ALPROLIX if you are allergic to ALPROLIX or any of the other ingredients in ALPROLIX.

Tell your healthcare provider if you have or have had any medical problems, take any medicines, including prescription and non-prescription medicines, supplements, or herbal medicines, have any allergies and all your medical conditions, including if you are pregnant or planning to become pregnant, are breastfeeding, or have been told you have inhibitors (antibodies) to factor IX.

Allergic reactions may occur with ALPROLIX. Call your healthcare provider or get emergency treatment right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.

Your body can also make antibodies called “inhibitors” against ALPROLIX, which may stop ALPROLIX from working properly.

ALPROLIX may increase the risk of formation of abnormal blood clots in your body, especially if you have risk factors for developing clots.

Common side effects of ALPROLIX include headache and abnormal sensation of the mouth. These are not all the possible side effects of ALPROLIX. Talk to your healthcare provider right away about any side effect that bothers you or does not go away, and if bleeding is not controlled using ALPROLIX.

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 Brief Summary of full Prescribing Information on the next page for additional safety information. This information is not intended to replace discussions with your healthcare provider.

ALPROLIX [Coagulation Factor IX (Recombinant), Fc Fusion Protein], Lyophilized Powder for Solution For Intravenous Injection.

FDA Approved Patient Information

ALPROLIX™ /all' pro liks/ [Coagulation Factor IX (Recombinant), Fc Fusion Protein]

Please read this Patient Information carefully before using ALPROLIX™ and each time you get a refill, as there may be new information. This Patient Information does not take the place of talking with your healthcare provider about your medical condition or your treatment.

What is ALPROLIX™?

ALPROLIX™ 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.

Your healthcare provider may give you ALPROLIX™ when you have surgery.

Who should not use ALPROLIX™?

You should not use ALPROLIX™ if you are allergic to ALPROLIX™ or any of the other ingredients in ALPROLIX™. Tell your healthcare provider if you have had an allergic reaction to any Factor IX product prior to using ALPROLIX™.

What should I tell my healthcare provider before using ALPROLIX™?

Tell your healthcare provider 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:

- are pregnant or planning to become pregnant. It is not known if ALPROLIX™ may harm your unborn baby.
- are breastfeeding. It is not known if ALPROLIX™ passes into breast milk or if it can harm your baby.
- have been told that you have inhibitors to Factor IX (because ALPROLIX™ may not work for you).

How should I use ALPROLIX™?

ALPROLIX™ should be administered as ordered by your healthcare provider. You should be trained on how to do infusions by your healthcare provider. Many people with hemophilia B learn to infuse their ALPROLIX™ by themselves or with the help of a family member.

See the Instructions for Use for directions on infusing ALPROLIX™. The steps in the Instructions for Use are general guidelines for using ALPROLIX™. Always follow any specific instructions from your healthcare provider. If you are unsure of the procedure, please ask your healthcare provider.

Do not use ALPROLIX™ as a continuous intravenous infusion.

Contact your healthcare provider immediately if bleeding is not controlled after using ALPROLIX™.

What are the possible side effects of ALPROLIX™?

Common side effects of ALPROLIX™ include headache and abnormal sensation in the mouth.

Allergic reactions may occur. Call your healthcare provider or get emergency treatment right away if you have any of the following symptoms: hives, chest tightness, wheezing, difficulty breathing, or swelling of the face.

ALPROLIX™ may increase the risk of forming abnormal blood clots in your body, especially if you have risk factors for developing blood clots.

Your body can also make antibodies called, "inhibitors," against ALPROLIX™, which may stop ALPROLIX™ from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

These are not all the possible side effects of ALPROLIX™. Talk to your healthcare provider about any side effect that bothers you or that does not go away.

How should I store ALPROLIX™?

Store ALPROLIX™ vials at 2°C to 8°C (36°F to 46°F). Do not freeze.

ALPROLIX™ vials may also be stored at room temperature up to 30°C (86°F) for a single 6 month period.

If you choose to store ALPROLIX™ at room temperature:

- Note on the carton the date on which the product was removed from refrigeration.
- Use the product before the end of this 6 month period or discard it. Do not return the product to the refrigerator.
- Do not use product or diluent after the expiration date printed on the carton, vial or syringe.

After Reconstitution:

- Use the reconstituted product as soon as possible; however, you may store the reconstituted product at room temperature up to 30°C (86°F) for up to 3 hours. Protect the reconstituted product from direct sunlight. Discard any product not used within 3 hours after reconstitution.
- Do not use ALPROLIX™ if the reconstituted solution is cloudy, contains particles or is not colorless.

What else should I know about ALPROLIX™?

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

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Biogen Idec Inc.
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Cambridge, MA 02142
U.S. License #1697

Wyoming Student Receives Scholarship through Baxalta's Education Advantage Scholarship Program

Baxalta

A student from Wyoming is among 60 people nationwide to receive a 2015–16 academic scholarship from Baxalta (formerly Baxter's Bioscience business). Forty scholarships were renewals, while 20 were new. The Education

Advantage scholarship program, now in its sixth year, is designed to help eligible students with hemophilia offset the costs of higher education, advance their careers, and pursue their dreams. Baxalta US Inc. is providing more than \$300,000 to this year's scholarship recipients nationwide.

Brandon Lasko from Cody is attending Patrick Henry College in Purcellville, VA. His major field of study will be strategic intelligence.

"We are honored and gratified to be able to support Brandon in his desire to get more out of life by continuing his education," said Barbara Pantazopoulos, senior director, Consumer Marketing US Hemophilia, Baxalta.

"He is representative of the extraordinary people who are passionate about making a difference in the world in general, and in the hemophilia community in particular."

Through the first six years of the program, Baxalta has awarded more than \$1.4 million in 112 merit- and financial need-based scholarships. ♦

FDA Approves Octapharma's NUWIQ to Treat Hemophilia A

The FDA has approved Octapharma's NUWIQ, antihemophilic factor (recombinant), an IV therapy for adults and children living with hemophilia A. The approval includes on-demand treatment and control of bleeding episodes, routine prophylaxis to

reduce the frequency of bleeding episodes and perioperative management of bleeding.

NUWIQ is the first B-domain–deleted recombinant factor VIII (FVIII) derived from a human cell line, not chemically-modified or fused with another protein, designed for

the treatment of patients with hemophilia A, congenital FVIII deficiency.

Up to 16,000 individuals in the United States have hemophilia A. Although there are already therapies for hemophilia A, significant challenges remain, including



development of inhibitors and the need for multiple infusions on a prophylactic basis, the company said. ♦

HTC's Next Billings Clinics

November 9, 2015

Our next clinic in Billings, MT will be a follow-up clinic on November 9th. Dr. Marilyn Manco-Johnson and Nancy Spomer will be attending that clinic and providing interim visits for patients that need follow-up from earlier visits.

Save the Date: June 6-8, 2016

The next full staff clinic visit to Billings, MT is already scheduled.



Find Us Online

For more details, head to our calendar of local and national/international events on our website. <http://www.ucdenver.edu/academics/colleges/medicalschoo/centers/HemophiliaThrombosis/resources/Pages/Events.aspx> or <http://goo.gl/QFXT8c> for the same URL.

HTC Newsletter

We will have printed copies of this content available in the clinic and a link to the digital version at our website. If you have questions, corrections, or feedback, please contact us at HTC.Newsletter@ucdenver.edu. ♦

We Love Donations!

Donations 2015 in honor of Andy Brinkley

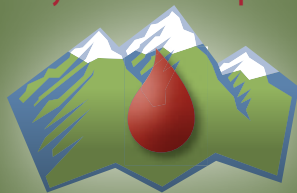
Donations

Christy & Forrest Berg • Gary & Judith Hughes • Rona Matheson • Oracle

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.

Rocky Mountain Hemophilia



& Bleeding Disorders Association

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COAGULATION

Baxalta

**THE
COUNTDOWN
HAS BEGUN.**

For more information
and updates, sign up at
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ADYNOVATE
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(Recombinant), Pegylated]

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Montana Health and Economic Livelihood Partnership (HELP) Program Waiver

The Plasma Protein Therapeutics Association (PPTA) appreciates the opportunity to comment on the Montana Health and Economic Livelihood Partnership (HELP) Program Waiver. PPTA applauds this reform effort and its goal to expand access to health coverage for over 70,000 new adults in Montana. This newly covered population may contain individuals who use a plasma protein therapy. PPTA would like to share its health reform principles to help Montana best care for this unique population.

PPTA is the standard setting and global advocacy organization that represents plasma donation centers and manufacturers of plasma-derived therapies and their recombinant analogs (collectively known as “plasma protein therapies”). Our North American members include: Baxalta, Biotest, CSL Behring, Grifols, and Kedrion Biopharma. PPTA members provide more than 75% of the plasma protein therapies used in the United States.

Plasma protein therapies are used to treat rare, life-threatening diseases, including hemophilia and other bleeding disorders, primary immune deficiency, and Alpha-1 antitrypsin deficiency. A rare disease or disorder is one that affects fewer than 200,000 people in the United States. It is estimated that 28,000 individuals have hemophilia, 16,000 have a primary immune deficiency, and 6,500 have alpha-1 antitrypsin deficiency; PPTA estimates that approximately 105 Montanans have hemophilia, 90 Montanans have a primary immune deficiency, and 20 Montanans have alpha-1 antitrypsin deficiency.

Patients need affordable health care insurance.

PPTA believes patients deserve access to appropriate public and private health insurance coverage regardless of health or disability, employment status, age, or medical predisposition. Specifically, PPTA urges state governments to adopt legislation and/or regulations that protect patients from health insurance industry practices that impose punitive cost-sharing requirements upon patients with rare, chronic diseases and disorders. PPTA supports Montana’s plan to limit premiums and copayments for all new beneficiaries.

Patients need unfettered access to drugs and biologics.

PPTA supports patient access to all medically appropriate, life-saving plasma protein therapies. Each plasma protein therapy is a unique biologic to which patients respond differently. Each therapy is approved by the FDA for distinct clinical indications, and each has distinct contraindications. Treating these therapies as interchangeable directly contradicts expert clinical recommendations as well as the determinations made under FDA guidelines, which have undergone years of review.

There are two groups of expert providers and researchers who develop best practice guidelines for plasma protein therapies. The American Academy of Allergy, Asthma & Immunology (AAAAI) makes recommendations for the use of Immune Globulin therapy in treating primary immune deficiency, and the National Hemophilia Foundation’s Medical and Scientific Advisory Council (MASAC) makes recommendations for the use of clotting factor therapies in treating bleeding disorders such as hemophilia. Both groups have issued recommendations on the non-interchangeability of plasma protein therapies:

The eighth principle of AAAAI’s Eight Guiding Principles for Effective Use of Intravenous Immune Globulin (IVIg) for Patients with Primary Immunodeficiency states “IVIg is not a generic drug and IVIg products are not interchangeable. A specific IVIg product needs to be matched to patient characteristics to ensure patient safety. A change of IVIg product should occur only with the active participation of the prescribing physician.” This principle holds true for subcutaneous immune globulin (SCIG) therapies as well.

MASAC Recommendation #159 states, “Clotting factor therapies are neither pharmacologically nor therapeutically equivalent and vary based upon purity, half-life, recovery, method of manufacture, viral removal and inactivation processes, potential immunogenicity, and other attributes. The characteristics of each product and the resultant product choice for an individual patient require a complex decision making process with the ultimate product being agreed upon by the patient and their respective healthcare provider. It is critical that the bleeding disorders community has access to a diverse range of therapies and that prescriptions for specific clotting factor concentrates are respected and reimbursed.”

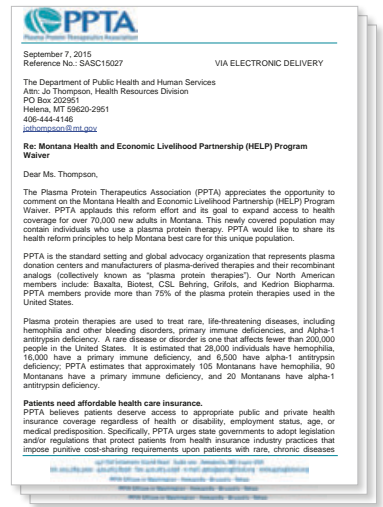
PPTA shares Department’s stated goal of ensuring, “All Montanans have access to quality health-care.” Unfortunately, some health care payers in the United States use cost-containment strategies that limit patient access to quality health-care. An example of this is step-therapy. Under a step therapy protocol, insurers will require a diagnosed and properly treated beneficiary to switch from a medically appropriate therapy to one that is preferred on the company’s formulary. It may be a therapy the beneficiary has never tried before, or a therapy that the beneficiary tried in the past with poor results. This protocol violates continuity of care by forcing a beneficiary to change from the medically appropriate therapy that was determined in consultation between the patient and the prescriber. It is also not cost-effective nor quality care because in failing on a PPTA suggests that Montana not allow its Third Party Administrator to implement a step-therapy protocol for these therapies.

Patients need access to quality providers.

PPTA believes state Medicaid programs should consider the needs of individuals with rare, chronic conditions when implementing health reform. Not every provider has the training and experience necessary to provide these patients with quality care. Nearly all of the diseases and disorders treated with a plasma protein therapy require a physician with a sub-specialty in the specific disease. For this reason, PPTA suggests Montana Medicaid establish standards that allow Medicaid recipients access to hemophilia treatment centers and specialty pharmacies that comply with MASAC Recommendation 188.

PPTA appreciates your consideration of our principles and welcomes the opportunity to discuss them further. Should you have any questions or require additional information please do not hesitate to contact Brenna Raines (braines@pptaglobal.org or 443-458-4667) at the association.

Sincerely, Brenna Raines Senior Manager, Health Policy Plasma Protein Therapeutics Association



Rocky Mountain Hemophilia



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