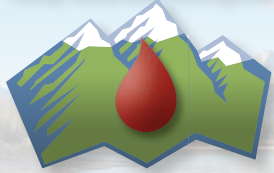


THE ROCKY MOUNTAIN



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.

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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/rmhdbda

RMHBDA Family Camp Recap

Our annual Family Camp would not be possible without our



University of Colorado
Anschutz Medical Campus
Hemophilia and Thrombosis Center

generous program funders: **CVS Caremark, Bayer, Baxter, Biogen, CSL Behring, Grifols, Novo Nordisk, Pfizer Hemophilia, and Walgreens Infusion Services.**



RMHBDA Family camp was held June 19–21, 2015 at Fairmont Hot Springs near Anaconda. Fourteen families attended that included 34 youth and 30 adults. Thank you to all who attended!

Adults and youth ages 11–17 participated in a powerfully engaging program that inspires adults and kids to believe in their own ability to function at their optimal level and challenge them to grow, presented by Pat Torrey, and made possible by Pfizer Hemophilia.

► Continued on page 2

Men's Retreat: Blood Brotherhood Event

August 1

Chartered Fishing Trip @ Flathead Lake, 688 Lakeside Boulevard, Lakeside, Montana. Meet at A ABLE at 7 am. Dinner with Sharon Funk, Physical Therapist, UC-HTC, at 6:30 pm at Jagz in Kalispell. Please RSVP for both events to Brad at brad@rmhbda.org or 406.586.4050. ♦



2015 Hemophilia Walk

Rocky Mountain Hemophilia & Bleeding Disorders Association announces the **4th Annual Montana and Wyoming Walk for Hemophilia**, benefitting those suffering from bleeding disorders in the Montana and Wyoming community.



We are hosting a walk in Billings, Montana on September 12 registration beginning at 9:00 a.m. at Zoo Montana. Team and Personal Fundraisers compete for the Top Team and Personal Fundraiser Awards in the state from Montana and Wyoming. All proceeds from these fundraising efforts will benefit Rocky Mountain Hemophilia & Bleeding Disorders Association.

Using social media, online fundraising pages, and more Rocky Mountain Hemophilia & Bleeding Disorders is leveraging the power of the web to raise funds. Visit our new Facebook page, and become a fan today!

Can't make it? We understand! But you can still participate and contribute by hosting a "mini walk," BBQ, small party, or event in your community, or search out "virtual walkers" who can't

► Continued on page 3

Saturday, September 12
Zoo Montana
2100 South Shiloh Road
Billings, MT

9:00 am Registration
10:00 am Walk 1.5k

Contact: Walk Event Manager 406.586.4050

To be eligible for a special drawing prize, register as a Team Captain by July 24!

Visit www.hemophilia.org/walk to create or join a walk team; click on the "MT" link, then click on your preference: "Register," "Donate," "Create a team," or "Join a Team." We've raised over \$15,000 as of June 30th!

THE ROCKY MOUNTAIN

► From page 1: Family Camp



Children ages 2–10 enjoyed numerous activities and games. Thank you to the camp committee and our chapter volunteers and counselors: Weston Stafford, Zoe Dugan, Lane Maxwell, Bailey Hill, Ryan Smith, Billy Duckworth, Becky Ybarra, Hailey Ybarra, Steve Petty and Nancy Spomer. Your good work and valuable time made family camp a wonderful experience for everyone! 🍓





HOW WE SPELL COMMITMENT

Actions are louder than words.

When it comes to commitment, we believe you are either “all in” or you’re not. There’s no in-between.

For a quarter-century, the people of **Bayer HealthCare** have been committed to helping people with hemophilia A and their families with a wide array of community programs and support services.

For information on Bayer’s Educational Patient and Community Resources, contact your Hematology Account Executive by calling **1-888-79-BAYER.**

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► From page 1: **2015 Walk**

attend as well! Tell them they can, “sleep in, save gas, get a t-shirt,” and make a big difference for your family and families throughout Montana and Wyoming. Also, call Brad Benne to find out how you can help! Your support is appreciated, this is your organization!

Top Fundraisers
(as of June 30, 2015)

Top Individual Fundraisers

1. Jodi Rudell \$790.00
2. John & Will Benne \$100.00
3. Kevin Amende \$100.00

4. Connor Ferriter \$100.00
5. Silent Donor \$25.00

Top Teams

1. VW Ladybugs Plus One \$1,015.00
2. Blood Brothers IV \$100.00
3. Clot Like an Amende \$100.00
4. Connor’s Comrades \$100.00

Visit www.hemophilia.org/walk for more information and to register to raise critically-need funds for our chapter of the National Hemophilia Foundation. Contact Brad Benne at 406.586.4050 or brad.rmhbda@gmail.com for fundraising support, questions, and comments. 📌

2015 Save the Date September 12 @ Zoo Montana in Billings



Our enduring commitment, 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.

Miriam
Caregiver, Miami, FL

Baxalta is a trademark of Baxalta Incorporated.
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June 2015 USBS/MG1/15-0381

Give Big Gallatin Valley

On Tuesday, May 5th, RMHBDA participated in Give Big Gallatin Valley, a one-day-only online giving event presented by the Bozeman Area Community Foundation.



RMHBDA raised over \$750. The donations went directly to our Scholarship Fund and Patient Assistance fund. In 2014, RMHBDA distributed over \$19,000 in Scholarship and Patient Assistance funds.

Thank you to the following donors

Jessica & Kevin Amende	Lisa Glass
Brad Benne	Derek Nelson
Ken & Patricia Benne	Katy Tortorici
Irene Benne	Susan Welker
Kevin & Jill Ellison	

RMHBDA Scholarships

Congratulations to our 2nd Annual RMHBDA Scholarship recipients Jessica Amende and Hunter Hart. They each received \$1,000 from RMHBDA to pursue their career and educational aspirations.



On behalf of the RMHBDA Board of Directors and the RMHBDA family, we wish Jessica and Hunter great success and happiness as they pursue their goals.

Through the RMHBDA, we recognize the many individuals including the board of directors, governance bodies, donors, 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.

We believe that knowledge and understanding is the key to the future for the bleeding disorders community. We also understand that generous service and commitment of our members is the reason for the success of RMHBDA. With this scholarship we want to recognize those individuals who have shown commitment to the bleeding disorders community through their actions. We look to all those within our reach; those with bleeding disorders, parents, siblings, etc. We want to reward those who show courage, understanding and a commitment to the betterment of the lives of those affected. We wish all students the very best of luck in their endeavors. Stayed tuned for details regarding the RMHBDA scholarship application in the spring of 2016. ♦

RMHBDA's Women's Escape

Ladies, you are invited to "RMHBDA's Women's Escape"

We need to organize, please contact Brad if you are interested in attending and planning our program. *Ladies, please leave the boys at home* 😊

Our Women's Escape 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 expenses at Chico Hot Springs will be covered. If you need fuel assistance, please talk with Brad.

When: Friday, November 6 – Sunday, November 8, 2015

Where Chico Hot Springs, Pray, Montana

Please RSVP to Brad Benne, brad@rmhbda.org, (406) 586-4050 ♦



MT & WY Hemophilia Walk Kickoff

Help Your Walk Team Be A Star Fundraiser



You Are Invited to the Kickoff Celebration/Biogen Core Conversations Education Seminars

We will have food and quality education provided by Biogen, and, of course, loads of helpful information on how to make your walk team make the last two weeks of fundraising really count! We can't wait for you to join us.

Billings August 25 and Bozeman August 26

Please RSVP: Brad Benne, brad@rmhbda.org or 406.586.4050 ♦

biogen idec

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
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We Love Donations!

**Donations 2015
in honor of Andy Brinkley**

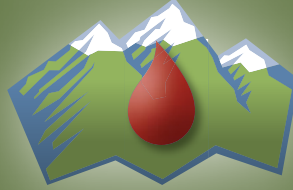
Donations

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

Welcome to
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You shop. Amazon gives.

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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



Ajay - 2015



Thank you...
for helping Ajay pay for school
fees and medication this past
year!

Ajay Velayudhan Vellaramkuzhi is eight years old and in second grade. He missed ten days of school due to bleeds last year. His favorite subject is English. He enjoys watching television and riding his bike in his free time. Ajay celebrated his birthday this past year with his family at home.

Ajay experienced fifteen bleeding episodes last year and visited the clinic where he received multiple infusions of factor concentrate.

Ajay lives with his parents and older brother, age 15. His father is a laborer and earns \$100 per month. They live in a three-room home in the village. The home is generally in good condition.

Contact: Paul Nettikkadan
Partner:: Hemophilia Society Angamaly, India
Email: hsakerala@yahoo.co.in
Sponsor: Rocky Mountain Hemophilia & Bleeding Disorder Assoc. Code: IN AG 025

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COAGULATION

Ajay - 2015



RMHBDA 2015 Program & Event Calendar

As of March 31, 2015. The chapter is still determining exact dates for several programs and events for the community.

◆ July

- 10–12 Mile High Summer Camp Leadership Pre-camp Retreat
- 12–17 Mile High Summer Camp, Rocky Mountain Village, Empire, Colorado

◆ August

- 1 Blood Brotherhood Event, Chartered Fishing on Flathead Lake, 7 am
- 1 Dinner with Sharon Funk, Jagz Restaurant, Kalispell, MT, 6:30 pm
- 13–16 NHF Annual Meeting, Dallas, Texas
- 25, 26 Biogen Core Conversations & Walk Kickoff, Billings 25th, Bozeman 26th

◆ September

- 11 Walk Welcome Dinner and Education Presentations, sponsored by Octapharma and Pfizer 6:30 pm
- 12 RMHBDA Walk for Hemophilia, Billings, Registration 9:00 am, Walk Begins 10:00 am

◆ October

- 14 Pfizer Education Session, Bozeman
- 23–25 CSL Behring “Getting In the Game”

◆ November

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





Baxalta

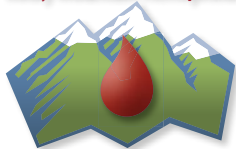
**THE
COUNTDOWN
HAS BEGUN.**

For more information
and updates, sign up at
ADYNOVATE.com


ADYNOVATE
[Antihemophilic Factor
(Recombinant), Pegylated]

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SUMMER 2015

Rocky Mountain Hemophilia



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