



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**

- Family Camp 2014 1
- 2014 Walk for Hemophilia 1
- Education Weekend 2014 1
- First RMHBDA Scholarships Awarded 4
- MT & WY Hemophilia Walk Kickoff & Baxter True Identity Seminars 4
- Industry News 10
- National Hemophilia Foundation 11

**Rocky Mountain Hemophilia & Bleeding Disorders Association**

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brad@rmhbda.org



www.facebook.com/rmhbd



# THE ROCKY MOUNTAIN

## Family Camp 2014

Our annual Family Camp would not be possible without our generous



University of Colorado  
Anschutz Medical Campus  
Hemophilia and Thrombosis Center

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



RMHBDA Family Camp was held June 20–22, 2014 at Camp on the Boulder near McLeod, Montana at the base of the Beartooth Mountains. Eighteen families attended that included 29 youth and 36 adults. Thank you to all who attended.

Adults and youth ages 11–17 participated in a powerfully engaging program that is designed to inspire 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**.

Children ages 2–10 enjoyed numerous arts and crafts projects, games, and building forts in the woods, supported by wonderful counselors from the Camp on the Boulder staff.

Thank you to the camp committee and our chapter volunteers: **Ryan Smith, Billy Duckworth, Kent Pointer, Lisa Glass, Sue Riter, and Dr. Marilyn Manco-Johnson.** Your good work and valuable time made family camp a wonderful experience for everyone!

▶ *Continued on page 2*

## Education Weekend 2014

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, Baxter Healthcare, Biogen Idec Hemophilia, CSL Behring, CVS Caremark, HF Healthcare, Kedrion USA, Novo Nordisk, Pfizer Hemophilia and Walgreen Infusion Services.**

Education Weekend was held April 4–6, 2014 in Helena with 19 families attending (23 youth and 30 adults). Educational sessions included: infusion session, industry/product exhibits, “My Life Our Future,” living a healthier lifestyle, partnering with your school, and healthcare reform. All members visited our exhibitors to learn more about each company and their products.

RMHBDA welcomed three extraordinary additions to our Board of Directors: **Sean Jeffrey** of Missoula, **Van Savage** of Malta, and **Lisa Glass-Ferriter** of Helena (all in Montana). We are truly grateful to Sean, Van, and Lisa for volunteering their time to serve our community!

Special thanks to **Lisa Maxwell, Lisa Glass-Ferriter, Van Savage, and Ryan Carter** for assisting with the organization of the event!



More photos on page 6.

## 2014 Walk for Hemophilia

**Saturday, September 6, 2014**

**Zoo Montana, 2100 South Shiloh Road, Billings, MT 59106**

**Registration 8:00 AM**

**3k & 1.5k Walk 9:00 AM**

Contact: Hemophilia Walk Event Manager 406.586.4050

To be eligible for a special drawing prize, register as a Team Captain by July 30!

Visit [www.hemophilia.org/walk](http://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 \$14,000 as of June 30th!**

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 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!

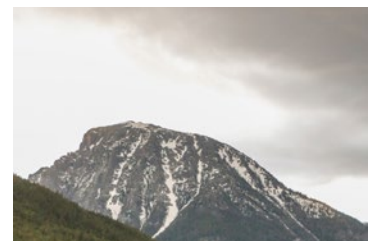
▶ *Continued on page 4*



► From page 1: Family Camp



## Photos from Family Camp 2014



A special thanks to Ryan Smith for helping with photography during Family Camp!



# Join the 4<sup>th</sup> Annual Bayer Virtual Walk for Hemophilia!

Help your local hemophilia chapter raise sponsorship funds by participating in the 4th annual Bayer Virtual Walk for Hemophilia.

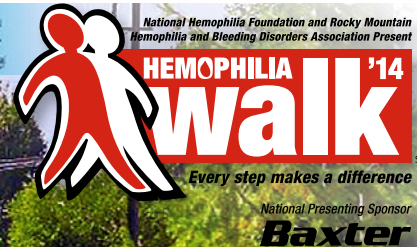
Spread the word to your friends and family. Every virtual walker brings your chapter one step closer to making a difference in the community!

Virtually walk for a cause TODAY at [www.walkforhemophilia.com](http://www.walkforhemophilia.com).



► From page 1: Hemophilia Walk

## 2014 Save the Date September 6 @ Zoo Montana in Billings



Rocky Mountain Hemophilia & Bleeding Disorders Association announces the 3rd 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 6, 2014, registration begins at 8:00 AM 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 RMHBDA.

### Top Fundraisers (as of June 30, 2014)

1. Jodi Rudell \$565
2. John & Will Benne \$100
3. Daniel Markham \$100
4. Chris Graham \$100
5. Lisa Maxwell \$25

### Top Teams (as of June 30, 2014)

1. The VW Ladybugs Plus One \$615
2. Blood Brothers III \$100
3. Ty's Crew 2 \$100
4. Biogen Idec \$100
5. MAX OUT \$25

Visit [www.hemophilia.org/walk](http://www.hemophilia.org/walk) for more information and to register and raise critical funds for our chapter of the National Hemophilia Foundation.

Using social media, online fundraising pages, and more, RMHBDA is leveraging the power of the web to raise funds. Visit [www.facebook.com/rmhbd](http://www.facebook.com/rmhbd), and become a fan today!

*Rocky Mountain Hemophilia & Bleeding Disorders Association, a chapter of the National Hemophilia Foundation, is a 501(c)(3) non-profit organization incorporated in 2000 to address the needs of the bleeding disorder community in Montana and Wyoming. RMHBDA's 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, and resource and referral. Contact Brad Benne at 406.586.4050 or [brad@rmhbda.org](mailto:brad@rmhbda.org) for fundraising support, questions, and comments. ♦*

## First RMHBDA Scholarships Awarded

Congratulations to the first RMHBDA scholarship recipients Jessica Amende and Lane Maxwell. 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 Lane 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*. From the generosity of many and due to the needs of our members, it has been a long time goal for us 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 the generous service and commitment of our members is the reason for the success of RMHBDA. With this scholarship program, 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 2015. ♦

## MT & WY Hemophilia Walk Kickoff & Baxter True Identity Seminars

**You Are Invited** to the Kickoff Celebration/Baxter Facts True Identity Education Seminars

We will have food and quality education provided by Baxter. 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 12**

**Bozeman August 13**

**Helena August 14**

**Kalispell August 15**

Please RSVP: Brad Benne, [brad@rmhbda.org](mailto:brad@rmhbda.org) or 406.586.4050

The **True Identity** program is an interactive, educational series that covers a wide variety of topics affecting the hemophilia community. True Identity seminars bring together hemophilia experts, caregivers, and those living with hemophilia to address issues and questions in an open, conversational setting. ♦




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For more information, contact your Baxter representative today:

Ryan Smith

Phone: (801) 450-7845

Email: [ryan\\_smith@baxter.com](mailto:ryan_smith@baxter.com)

  
 [Antihemophilic Factor (Recombinant),  
 Plasma/Albumin-Free Method]

► From page 1: Education Weekend



At CSL Behring  
**Innovation leads the way**

**Committed to making a difference in patients' lives**

As the industry leader in coagulation therapies, CSL Behring offers the most extensive portfolio of coagulation products for patients with factor deficiencies, including FII, FVIII, FIX, FXIII, and von Willebrand factor. And we continue to broaden our efforts with a number of recombinant factor therapies in development, including rFVIII, rFVIIa, rFIX, and rVWF.

For more information about our factor products for hemophilia, von Willebrand disease, and other rare bleeding disorders, or to learn about our innovative patient programs, please visit [www.cslbehring.com](http://www.cslbehring.com) or call consumer affairs at 1-888-508-6978.

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Steve McKell

**Phone:** (801) 395-4670

**E-mail:** [steven\\_mckell@baxter.com](mailto:steven_mckell@baxter.com)

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**ALPROLIX™**  
[Coagulation Factor IX  
(Recombinant), Fc Fusion Protein]

# Now Available

A new treatment for hemophilia B

ALPROLIX provides 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**

E: [becky.ybarra@biogenidec.com](mailto:becky.ybarra@biogenidec.com) T: 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](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.

**Please see Brief Summary of full Prescribing Information on the next page. 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' prō 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.

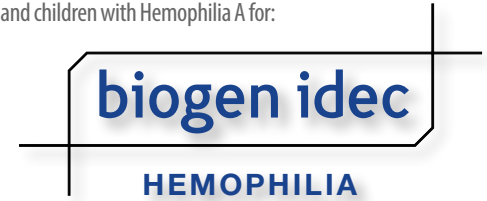
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## Industry News

### Biogen Idec

ELOCTATE will be available by prescription in mid July 2014. You'll be among the first to know about product availability and updates. ELOCTATE is now FDA approved based on the results from a clinical trial of 164 previously-treated patients. ELOCTATE is a recombinant-DNA-derived, antihemophilic factor indicated in adults and children with Hemophilia A for:

- Control and prevention of bleeding episodes
- Perioperative management (surgical prophylaxis)
- Routine prophylaxis to prevent or reduce the frequency of bleeding episodes.
- ELOCTATE is not indicated for the treatment of von Willebrand disease.



### Bayer

#### FDA Approves Bayer's Kogenate® FS Antihemophilic Factor VIII (recombinant) for Routine Prophylaxis in Adults with Hemophilia A



May 12, 2014 – Bayer HealthCare announced today that the U.S. Food and Drug Administration (FDA) has approved a new indication for Bayer's Kogenate® FS antihemophilic factor VIII (recombinant), for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults with hemophilia A. The approval is based on data from the SPINART study, in which 84 patients ages 15 to 50 were randomized to either prophylaxis (25 IU/kg three times per week) or on-demand treatment.

### Baxter

Many members of the Hemophilia community are struggling with the high costs of healthcare. Baxter remains committed to the community and recognizes our responsibility to develop new approaches to help improve access to therapies. The Baxter Hemophilia Co-Pay/Co-Insurance Assistance Program is a financial needs-based initiative which serves the hemophilia community by providing eligible patients with financial support toward the purchase of Baxter factor or inhibitor products.



People who are enrolled in the program will receive support with their insurance expenses specific to co-payment/co-insurance for Baxter Hemophilia treatment for up to 12 months.

Patients are **eligible** to apply for the program if

- They have mild, moderate, or severe Hemophilia A or B, or have an inhibitor
- They currently have private health insurance

Patients are **not** eligible to apply if

- They are presently on public insurance including, but not limited to, Medicare, Medicaid, TriCare, DOD, and PCIP

### CSL Behring

King of Prussia, PA — 9 May 2014

- Leading-edge science at the core of \$250 million expansion to drive long-term growth in promising bleeding disorders portfolio
- CSL Behring to commercialize therapies produced in part at the facility, pending required approvals
- Opening taking place in advance of World Federation of Hemophilia 2014 Congress in Melbourne, Australia

## CSL Behring

CSL Limited (ASX:CSL), parent company of CSL Behring which is based in King of Prussia, PA, today opened the CSL Behring Biotechnology Manufacturing Facility in Melbourne, Australia. The new facility, located adjacent to the site's manufacturing plant for plasma products, is the centerpiece of CSL's \$250 million expansion at its Broadmeadows site and will play an increasingly important role in the company's global operations, particularly in the late-stage development of new types of hemophilia products. It is one of the largest and most advanced facilities of its kind in the world and will produce novel recombinant therapies on a large scale for international clinical trials.



## NATIONAL HEMOPHILIA FOUNDATION

www.hemophilia.org

### **The Need For Qualified, Experienced Specialty Pharmacy Providers and Competition**

*“Competition is not only the basis of protection to the consumer, but is the incentive to progress.”  
Herbert Hoover*

NHF has long advocated for the hemophilia community to have access to more than one qualified specialty pharmacy provider experienced in handling individuals with hemophilia or related bleeding disorders and preferably more than one delivery method for providing these services, specialty pharmacy and 340B. As explained more fully below, having access to more than one provider and delivery method (where available) ensures access, quality services, and patient safety. Thus, NHF will continue to advocate to states to adopt policies that ensure access in such a manner, and to adopt certain quality standards to ensure qualified, experienced providers in the market.

#### **Background on Specialty Pharmacies**

Individuals with hemophilia or other inherited bleeding disorders rely on FDA-approved blood clotting factor therapies, either recombinant or plasma-derived, as life-sustaining treatments for the entirety of their lives. These products fall in a class commonly known as “specialty drugs,” which because of their properties, require specialized storage and handling. Given these special handling and storage requirements, someone with hemophilia cannot go to a traditional neighborhood pharmacy to obtain their life-saving medications. Instead, they receive their medication from what is known as a specialty pharmacy.

Specialty pharmacies include separate pharmacy divisions owned by your traditional, national retail chains; independent specialty pharmacies; pharmacies at hemophilia treatment centers (HTCs) who have elected to participate in the 340B federal discount drug program (340B pharmacies); and, more recently, specialty pharmacies owned by insurers. Because most individuals self-infuse their medications at home, specialty drugs are typically delivered to patients via mail or other home-delivery options. Unlike your traditional pharmacy, specialty pharmacies provide a range of support services targeted at patient education, care coordination, assay management and disease management.

Because hemophilia requires effective prophylactic treatment, adherence and optimal service from qualified providers knowledgeable about hemophilia, it is important the specialty pharmacy providers serving the hemophilia and related bleeding disorders community meet certain standards. Accordingly, NHF’s Medical and Scientific Advisory Council (MASAC)<sup>1</sup> developed MASAC 188: *Recommendation Regarding Standards of Service for Pharmacy Providers of Clotting Factor Concentrates for Home Use to Patients with Bleeding Disorders.*<sup>2</sup>

MASAC 188 sets minimum standards that all specialty pharmacies should adhere to in order to ensure: (1) patient safety; (2) avoid unnecessary, adverse health incidents; (3) good health outcomes; and (4) more predictable costs.

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<sup>1</sup> MASAC is comprised of scientists, hematologists other treatment professionals, US government agencies and patient representatives that are internationally regarded as experts in the broad field of bleeding disorders research and care, AIDS, hepatitis, other infectious diseases and blood safety. MASAC recommendations set the standard of care around the world; are referred to by an international array of physicians, medical schools, pharmacists, emergency room personnel, and insurance companies; and address a wide array of treatment issues.

<sup>2</sup> Adopted by MASAC on November 15, 2008. MASAC #188 can be located at:

<http://www.hemophilia.org/NHFWeb/MainPgs/MainNHF.aspx?menuid=57&contentid=1107>

Rocky Mountain Hemophilia



& Bleeding Disorders Association

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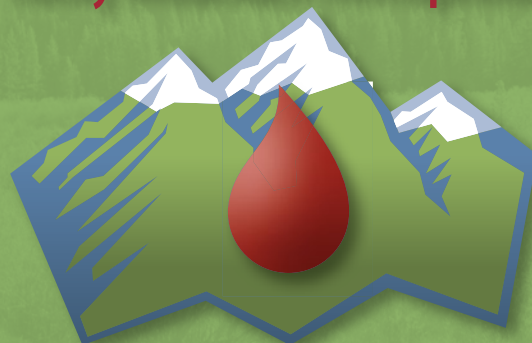
**SUMMER 2014**

# We **Love** 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.

**Now donate at our new domain name [www.rmhbda.org](http://www.rmhbda.org) with PayPal.**

**Rocky Mountain Hemophilia**



**& Bleeding Disorders Association**