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.**586.405**0

www.rmhbda.org

Brad Benne, Executive Director brad@rmhbda.org



www.facebook.com/rmhbda

RMHBDA Education Weekend 2016

A special "Thank you" to our HTC for co-sponsoring our Education Weekend!



Thank you to our generous program funders: Accredo Health, Inc., Bayer Healthcare, Baxter Healthcare, Biogen Idec Hemophilia, CSL Behring, CVS Caremark, Grifols, HF Healthcare, Alnylam, Novo Nordisk, Octapharma, Restore RX,

Emergent Biosolutions, HFA, Pfizer Hemophilia and Option Care Bleeding Disorders Program.

RMHBDA Education Weekend was held February 19—21 in Bozeman, Montana. Twenty-one families attended with a total of seventy people in attendance. Educational sessions during Education Weekend included: infusion session, Breakout sessions for our Blood Brotherhood and Sisterhood programs. All

chapter members spent time visiting our exhibitors as they 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

Cary Bell, Candie Whitworth, Emily Dugan, Mary Brinkley, and Sally McEldery. ▶

Dads in Action



Using Fitness to Fight Back

Date: **April 16, 2016**Time: **12:00 p.m.**

Speakers: Grace Hernandez, Physical Therapist

Myles Ganley, Severe Hemophiliac.

Location: Teton County/Jackson Parks and Recreation Center,

155 E. Gill, Jackson, Wyoming

Are you affected with a bleeding disorder, or are you a caregiver for someone dealing with a bleeding disorder? Please join us for some family fun, lunch, education, and the **Hydra tube**!

Please RSVP with Brad at 406-586-4050 or brad@rmhbda.org ▶





From Our Executive Director

Welcome to the 2016 RMHBDA Bleeding Disorders Walk!

The **RMHBDA Bleeding Disorders Walk** is about the power of community and hope for a cure. Coming together for a cause empowers us. We are much stronger when we stand together.

Our walk is also an amazing way to raise money to fund education, advocacy, and research leading to better treatments and a cure.

Raising money through the walk isn't hard to do. Friends and family want to help; all you have to do is ask them. Get started by registering today at walk.rmhbda.org and register your team.

You can do even more by forming a team. The more who participate, the more fun we have and the more we raise; come together with your friends and family and join in on the excitement today.

Help get us off to a good start. Join the RMHBDA Walk today!

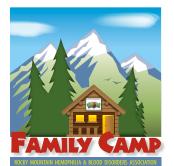
Be sure to call, text, or email everyone you know and ask for support. Ask 10 people today for a donation — you will be well on your way. Or better yet, ask them to join you at the Walk and start a team — get them to register today to get started!

Graciously, Brad R. Benne



Family Camp 2016 July 29–31, 2016 | United Methodist Camp | Rollins, Montana

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 more information, visit www.flatheadcamp.org.



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

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. 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 questions 406.586.4050.

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.

amazonsmile

You shop. Amazon gives.

Amazon Smile (smile.amazon.com) Amazon's way of letting Amazon customers enjoy their convenient online shopping plus the benefit of the Amazon Smile 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.

<u>∞</u> goodsearch

Search the internet with the patent-protected, Yahool-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

Washington Days

"This year's Wash Days was a hoot! The visits were overwhelmingly successful as I was able to visit with each of my senators and representative in person. The visits I had with them were all very personal and from the heart, and I will be planning follow-up visits with them in Cheyenne in the very near future.

I was told that both of the Wyoming Senators were even part of the bill that provided additional funding for causes such as ours, which is another huge bonus!

March 2016 is the 30-year anniversary of President Reagan's proclamation of a National (then Hemophilia) and now all bleeding disorders awareness month. This year, NHF is promoting a Red Tie Challenge on social media to raise awareness for all bleeding disorders. This is similar to the ALS Challenge that you all might be more familiar with. You are all challenged by me to challenge your social media outlets to promote the awareness by using #redtiechallenge:)"



Red Tie Challenge

The **Red Tie Challenge** is a movement created by the bleeding disorders community and their advocates at the National Hemophilia Foundation (NHF) to start a conversation about inheritable bleeding disorders and support March 2016 as the first Bleeding Disorders Awareness Month.

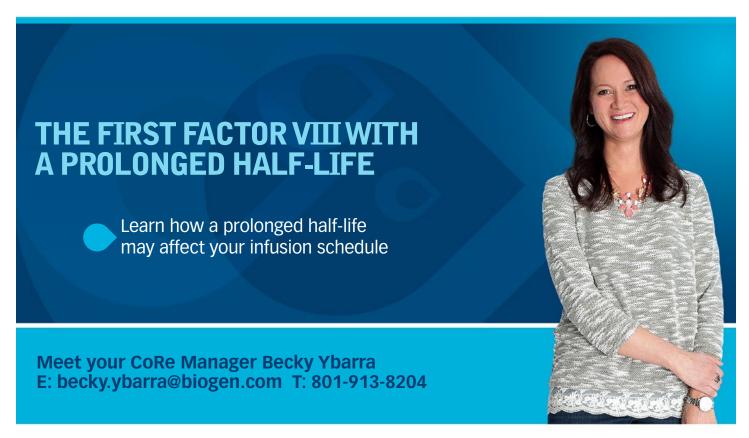




The calendar is always available on the website!

calendar.rmhbda.org





Indications

ELOCTATE, [Antihemophilic Factor (Recombinant), Fc Fusion Protein], is a recombinant DNA derived, antihemophilic factor indicated in adults and children with Hemophilia A (congenital Factor VIII deficiency) for: on-demand treatment and control of bleeding episodes, perioperative management of bleeding, and routine prophylaxis to reduce the frequency of bleeding episodes. ELOCTATE is not indicated for the treatment of von Willebrand disease.

Important Safety Information

Do not use ELOCTATE if you have had an allergic reaction to it in the past.

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, are breastfeeding, are pregnant or planning to become pregnant, or have been told you have inhibitors (antibodies) to Factor VIII.

Allergic reactions may occur with ELOCTATE. 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 ELOCTATE, which may stop ELOCTATE from working properly.

The most frequently occurring side effects of ELOCTATE are headache, rash, joint pain, muscle pain and general discomfort. These are not all the possible side effects of ELOCTATE. Talk to your healthcare provider right away about any side effect that bothers you or that does not go away, and if bleeding is not controlled after using ELOCTATE.

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.

This information is not intended to replace discussions with your healthcare provider.



FDA-Approved Patient Labeling Patient Information ELOCTATE® /el' ok' tate / [Antihemophilic Factor (Recombinant), Fc Fusion Protein]

Please read this Patient Information carefully before using ELOCTATE 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 ELOCTATE?

ELOCTATE is an injectable medicine that is used to help control and prevent bleeding in people with Hemophilia A (congenital Factor VIII deficiency).

Your healthcare provider may give you ELOCTATE when you have surgery.

Who should not use ELOCTATE?

You should not use ELOCTATE if you had an allergic reaction to it in the past.

What should I tell my healthcare provider before using ELOCTATE?

Talk to your healthcare provider about:

- Any medical problems that you have or had.
- All prescription and non-prescription medicines that you take, including over-the-counter medicines, supplements or herbal medicines.
- Pregnancy or if you are planning to become pregnant. It is not known if ELOCTATE may harm your unborn baby.
- Breastfeeding. It is not known if ELOCTATE passes into the milk and if it can harm your baby.

How should I use ELOCTATE?

You get ELOCTATE as an infusion into your vein. Your healthcare provider will instruct you on how to do infusions on your own, and may watch you give yourself the first dose of ELOCTATE.

Contact your healthcare provider right away if bleeding is not controlled after using ELOCTATE.

What are the possible side effects of ELOCTATE?

You can have an allergic reaction to ELOCTATE. Call your healthcare provider or emergency department 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 ELOCTATE. This can stop ELOCTATE from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

Common side effects of ELOCTATE are headache, rash, joint pain, muscle pain and general discomfort.

These are not the only possible side effects of ELOCTATE. Tell your healthcare provider about any side effect that bothers you or does not go away.

How should I store ELOCTATE?

- Keep ELOCTATE in its original package.
- · Protect it from light.
- Do not freeze.
- Store refrigerated (2°C to 8°C or 36°F to 46°F) or at room temperature [not to exceed 30°C (86°F)], for up to six months.
- When storing at room temperature:
- Note on the carton the date on which the product is 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 ELOCTATE after the expiration date printed on the vial or, if you removed it from the refrigerator, after the date that was noted on the carton, whichever is earlier.

After reconstitution (mixing with the diluent):

- Do not use ELOCTATE if the reconstituted solution is not clear to slightly opalescent and colorless.
- Use reconstituted product as soon as possible.
- You may store reconstituted solution at room temperature, not to exceed 30°C (86°F), for up to three hours. Protect the reconstituted product from direct sunlight. Discard any product not used within three hours.

What else should I know about ELOCTATE?

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

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RMHBDA Education Scholarships

For Undergraduate Students and Families Affected by Bleeding Disorders

★ Scholarship applications for academic year 2016-17 are due by June 1, 2016.



We, at RMHBDA, 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 RMHBDA 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. Download RMHBDA's application and instructions from www.rmhbda.org.

Education Scholarships for Those Affected with Blood Disorders



University of Colorado Anschutz Medical Campus

Hemophilia and Thrombosis Center

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 a 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. 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.

\$1,000

Eric Dostie Memorial College Scholarship

\$1000

For persons with bleeding disorders, or a family member.
Deadline March 1, 2016
Beth Carew Memorial Scholarship Program

\$4000

For persons with hemophilia, von Willebrand disease or other inherited bleeding disorders. Deadline April 15, 2016 Biogen Idec Hemophilia Scholarship

\$2500-\$7000

For persons with hemophilia A or B. Deadline April 16, 2016 Baxalta Education Advantage Scholarships

\$150-\$7000

For persons with hemophilia A or B, or von Willebrand disease. \$7000 University Scholarship \$1000 Community College and Technical Scholarship \$150 GED Assistance Deadline April 29, 2016 HFA Educational Scholarship

\$2000

For persons with bleeding disorders seeking post-secondary education from a college, university or trade school. Deadline April 30, 2016 HFA Medical/Health Services Educational Scholarship

\$4000

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. Deadline April 30, 2016
HFA Parent/Sibling/Child Educational Scholarship

\$2000

For parents/siblings/children of a person with a bleeding disorder seeking post-secondary education from a college, university or trade school.

Deadline April 30, 2016

Professor Ulla Hedner Scholarship

\$7000

For persons with bleeding disorders, no age limit.

Deadline April 30, 2016

Novosecure Scholarship

\$2000-\$5000

For persons with hemophilia or their caregivers seeking college or vocational education. Deadline May 1, 2016 NHF Colorado Chapter Academic Scholarship

\$2500

For persons with a bleeding disorder or family members, living in Colorado. Deadline TBA Emergent B More Scholarship

\$2000

For persons with hemophilia B. (Scroll down the page to find the link for the scholarship application) Deadline May 5, 2016 Pfizer Soozie Courter Hemophilia Scholarship

\$2500 & \$4000

For persons with hemophilia A or B; graduate or college & vocational school applicants. Deadline May 6, 2016 HF Healthcare Nate Slack Scholarship

\$1000

For persons with hemophilia or related bleeding disorder, or persons in the immediate family of a person with hemophilia or related bleeding disorder. Deadline May 20, 2016 NHF Kevin Child Scholarship

\$1000

For persons with hemophilia A or B. Deadline June 2016 Education is Power Scholarship

\$500-\$2000

For persons with hemophilia or von Willebrand disease. Deadline June 1, 2016 Eric Delson Memorial Scholarship Program

\$2500

For persons with hemophilia or von Willebrand disease to attend college, vocational or technical school. Deadline July 1, 2016 Eric Delson Memorial Scholarship Program 2

\$1500

For persons with hemophilia or von Willebrand disease who are attending private school, grades 7-12. Deadline July 1, 2016 Joshua Gomes Memorial Scholarship Fund

\$1000

For persons living with HIV/AIDS accepted or enrolled in a college in the United States. Deadline July 15, 2016 Matrix Health Group: Memorial Scholarship Program

\$1000

Several scholarships available with varying criteria, but most with either hemophilia, von Willebrand Disease or other bleeding disorders.

Deadline August 1, 2016

The HTC maintains the scholarship information listed above, each of which has their own requirements and deadlines. Please read each carefully when considering application for scholarships. Visit www.ucdenver.edu/academics/colleges/medicalschool/centers/HemophiliaThrombosis/Pages/home.aspx or use this equivalent http://goo.gl/nEcd6u. 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 the HTC. Please also check with these resources directly when searching for scholarships since there may be others you qualify for that are not listed on our website.



NOW AVAILABLE KOVALTRY®

Antihemophilic Factor (Recombinant)



Explore this new treatment at www.KOVALTRY.com







ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated] Important Information Indication

ADYNOVATE is used on-demand to control bleeding in patients 12 years of age and older with hemophilia A. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

You should not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE [Antihemophilic Factor (Recombinant)]

Tell your healthcare provider if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Have been told that you have inhibitors to factor VIII

(because ADYNOVATE may not work for you).

Your body may form inhibitors to Factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may

stop ADYNOVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.

You can have an allergic reaction to ADYNOVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

The common side effects of ADYNOVATE are headache and nausea. Tell your healthcare provider about any side effects that bother you or do 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 following page for ADYNOVATE Important Facts.

For full Prescribing Information visit www.ADYNOVATE.com.

Reference: 1. ADYNOVATE Prescribing Information. Westlake Village, CA: Baxalta US Inc.





Important facts about

ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated]

This leaflet summarizes important information about ADYNOVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADYNOVATE. If you have any questions after reading this, ask your healthcare provider.

What is the most important information I need to know about ADYNOVATE?

Do not attempt to do an infusion to yourself unless you have been taught how by your healthcare provider or hemophilia center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing ADYNOVATE so that your treatment will work best for you.

What is ADYNOVATE?

ADYNOVATE is an injectable medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia). Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

ADYNOVATE is used on-demand to control bleeding in patients 12 years of age and older with hemophilia A. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

Who should not use ADYNOVATE?

You should not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE

Tell your healthcare provider if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

How should I use ADYNOVATE?

ADYNOVATE is given directly into the bloodstream.

You may infuse ADYNOVATE at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADYNOVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADYNOVATE to use based on your individual weight, level of physical activity, the severity of your hemophilia A, and where you are bleeding.

Reconstituted product (after mixing dry product with wet diluent) must be used within 3 hours and cannot be stored or refrigerated. Discard any ADYNOVATE left in the vial at the end of your infusion as directed by your healthcare professional.

How should I use ADYNOVATE? (cont'd)

You may have to have blood tests done after getting ADYNOVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

Call your healthcare provider right away if your bleeding does not stop after taking ADYNOVATE.

What should I tell my healthcare provider before I use ADYNOVATE?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADYNOVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

What are the possible side effects of ADYNOVATE?

You can have an allergic reaction to ADYNOVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

The common side effects of ADYNOVATE are headache and nausea. Tell your healthcare provider about any side effects that bother you or do not go away.

These are not all the possible side effects with ADYNOVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADYNOVATE and Hemophilia A?

Your body may form inhibitors to Factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.

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

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADYNOVATE. The FDA approved product labeling can be found at www.ADYNOVATE.com or 855-4-ADYNOVATE.

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.

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Save the Date! Mile High Colorado Camp

Mile High Colorado Camp **Leadership Pre-Camp Retreat**

July 10-15, 2016 **July 8-10**

Camp forms available now: http://goo.gl/Ppb9Ct

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



University of Colorado Anschutz Medical Campus Hemophilia and Thrombosis Center



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 nonrefundable \$75 deposit. The remainder of the camp cost, approximately \$1000 per camper,



is underwritten by other sources. If you have guestions 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.



Want to Learn More?

Octapharma Representative:

KEN WAGG

505-414-7173

Kenneth.Wagg@octapharma.com

octapharma®

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World Hemophilia Day — April 17, 2016 **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.

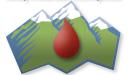
Families come in many forms but they all share the ability to support and advocate. World Hemophilia Day provides an opportunity to talk to your extended family and friends, colleagues, and caregivers to raise awareness and increase support for those living with an inherited bleeding disorder.

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.



Rocky Mountain Hemophilia



& Bleeding Disorders Association

1627 West Main Street, #142 Bozeman, Montana 59715

SPRING 2016



