



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

- RMHBDA 2016 Hemophilia Walk 1
- Message from the Executive Director 1
- RMHBDA 2016 Women's Retreat 1
- 2016 Family Camp was Great! 4
- RMHBDA 2016 Men's Retreat 4
- RMHBDA Education Weekend 2017 4
- 2016 Mile High Colorado Camp 5
- RMHBDA Family Camp 2017 8
- National Youth Leadership Institute 8
- RMHBDA's Fall Education Series 8
- First Annual Montana State Day 9
- Ride the Rockies 10
- RMHBDA Receives NHF Award! 10
- RMHBDA Montana License Plate! 10

Rocky Mountain Hemophilia & Bleeding Disorders Association

1627 West Main Street, #142
Bozeman, Montana 59715
406.586.4050

www.rmhbda.org

Brad Benne, Executive Director
brad@rmhbda.org



www.facebook.com/rmhbd



RMHBDA 2016 Hemophilia Walk

RMHBDA held its 5th Annual Montana and Wyoming Walk for Hemophilia at Zoo Montana in Billings on September 10 to benefit chapter activities supporting those suffering from bleeding disorders in Montana and Wyoming.



Team and Personal Fundraisers competed for Top Team and Personal Fundraiser Awards in each state. Using social media, online fundraising pages, and more, RMHBDA leveraged available media to promote the event and maximize fundraising efforts. We had over 195 walkers who, along with generous supporters, helped raise over \$45,000 and spread awareness of RMHBDA.

If you haven't already, visit our Facebook page at www.facebook.com/RMHBDA, and become a fan today. Read more below for team performance and see some of the pictures from the event. Make sure you plan on attending next year!

▶ Continued on page 2



RMHBDA 2016 Women's Retreat

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

Friday-Sunday, November 4-6, 2016
Chico Hot Springs, Pray, Montana

We need to organize, so please contact Brad if you are interested in not only attending, but also planning our program. Ladies, please leave the boys at home 😊

Our Women's Escape committee includes: 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.

RSVP: Brad Benne, brad@rmhbda.org, (406) 586-4050. 📞



Message from the Executive Director

Dear RMHBDA Supporters,

Thank you for joining us for our 5th Annual Walk to support our chapter and families dealing with bleeding disorders in Montana and Wyoming. We had over 195 walkers at Zoo Montana in Billings. Good-natured and generous supporters helped raise over \$45,000 and mission awareness. 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: Advanced Dental Professionals, St. Vincent's Healthcare, Barnard, Shire, Bayer, Biogen, Bozeman Deaconess, Avitus Group, Fifth Street Design, First Interstate Bank, Grifols, Aptevo, HF Healthcare, Accredo, Optioncare, Octapharma, CSL Behring, First Montana Title, Walmart, Billings Clinic, Cayton Excavation, Advanced Hydroseeding, Novo Nordisk, First State Bank of Malta, Pfizer, CVS Caremark, and Restore RX.

Sincerely,
Brad Benne,
Executive Director



THE ROCKY MOUNTAIN

From page 1: 2016 Hemophilia Walk

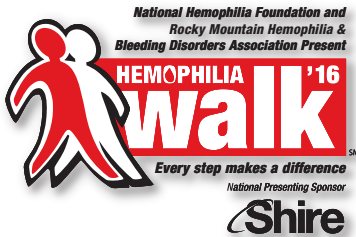
Participation was great for our 5th Annual Montana and Wyoming Walk for Hemophilia. Altogether, over \$45,000 was raised including these top fundraisers and teams — your work was awesome and deeply appreciated!

Top Fundraisers

1. Chris Graham	\$5,300
2. John & Will Benne	\$2,390
3. Campbell Hunter	\$2,335
4. Dylan Hunter	\$1,955
5. Brad Benne	\$1,500
6. Travis Bruyere	\$1,450
7. Lisa Maxwell	\$895
8. Andrea Stafford	\$821
9. Kevin Amende	\$800
10. Kristal Graham	\$787
11. Jodi Rudell	\$550
12. Connor Ferriter	\$500
13. Christy & Forrest Berg	\$415
14. Patricia & Ken Benne	\$300
15. Nicohl Fowler	\$210
16. Silent Donor	\$200
17. Katie Schneider	\$200
18. Ulises Y Cynthia Anzures	\$200
19. Silent Donor	\$200
20. Jason Dugan	\$150

Top Teams

1. Ty's Crew	\$9,380
2. Blood Brothers V	\$6,065
3. The Warriors	\$4,855
4. Best of the Bleed	\$4,787
5. Creative Clotters	\$1,775
6. RMHBDAvitus	\$1,500
7. Maxout	\$895
8. Silent Donor	\$821
9. Clot Like an Amende	\$800
10. Connor's Ferriter	\$750
11. VW Ladybugs	\$700
12. Yellowstone VW Bugs	\$360
13. Trot to Clot	\$200
14. HemTeam	\$1





BAYER **access solutions**



Don't let insurance or financial challenges get between you and your treatment

Free Trial Program*

- Enroll today for up to 6 free doses†
- Delivered to your home free of charge

Access to Therapy

We might be able to provide treatment at no cost if you‡:

- Experience challenges getting insurance coverage for a Bayer product
- Are uninsured or underinsured
- Are between jobs and are experiencing a gap in insurance coverage

\$0 Co-pay Program§

If you have private insurance, you may be eligible for the \$0 Co-pay Program.

- You may be able to receive up to **\$12,000 in assistance** per year, regardless of income
- **Assistance is awarded per patient.** Multiple members of the same household can apply
- Enrollment can be completed in **one short phone call**

Live Helpline Support

- Consult with an expert in insurance
- Spanish-speaking Case Specialists are also available

CALL

1-800-288-8374

8:00 AM-8:00 PM (ET) Monday-Friday. Spanish-speaking Case Specialists are also available.

*The Free Trial Program is available to newly diagnosed patients and patients who are currently using other therapy. Participation in the Free Trial Program is limited to 1 time only. This program is complimentary and is not an obligation to purchase or use a Bayer product in the future. Reselling or billing any third party for the free product is prohibited by law.

†The Free Trial Program includes up to 6 free doses to a maximum of 5,000 IU for new patients and 40,000 IU for previously treated patients.

‡The program does not guarantee that patients will be successful in obtaining reimbursement. Support medication provided through Bayer's assistance programs is complimentary and is not contingent on future product purchases. Reselling or billing any third party for free product provided by Bayer's patient assistance programs is prohibited by law. Bayer reserves the right to determine eligibility, monitor participation, determine equitable distribution of product, and modify or discontinue the program at any time.

§People with private, commercial health insurance may receive co-pay or co-insurance assistance based on eligibility requirements. The program is on a first-come, first-served basis. Financial support is available for up to 12 months. Eligible patients can re-enroll for additional 12-month courses. The program is not for patients receiving prescription reimbursement under any federal-, state-, or government-funded insurance programs, or where prohibited by law. All people who meet these criteria are encouraged to apply. Bayer reserves the right to discontinue the program at any time.

2016 Family Camp was Great!



Our annual Family Camp would not be possible without our generous program funders: CVS Caremark, Bayer, Shire, Aptevio, Biogen, CSL Behring, Grifols, Octapharma, Novo Nordisk, Pfi er Hemophilia, Optioncare, and the University of Colorado Hemophilia Treatment Center.

 University of Colorado
Anschutz Medical Campus
Hemophilia and Thrombosis Center

RMHBDA Family camp was held July 29-31, 2016, at Flathead Lake Methodist Camp near Kalispell, Montana. Eleven families attended that included 25 youth and 25 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 Pfi er Hemophilia.

Children ages 2–10 enjoyed numerous activities and games.

Thank you to the camp committee and our chapter volunteers! Your good work and valuable time made family camp a wonderful experience for everyone! 



RMHBDA 2016 Men's Retreat

December 2–4, 2016

Chico Hot Springs, Pray, Montana

We need to organize, so please contact Brad if you are interested in not only attending, but also planning our program.

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.

RSVP: Brad Benne, brad@rmhbda.org, (406) 586-4050. 



RMHBDA Education Weekend 2017

February 17–19, 2017

Hilton Garden 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! 



AT CSL BEHRING, WE'RE WORKING TO UNVEIL INNOVATIVE SOLUTIONS IN HEMOPHILIA A & B

**A century of experience...
a future of discovery**

Continuing the legacy of Emil von Behring, recipient of the first Nobel Prize in medicine, CSL Behring specializes in developing biotherapeutics for serious and rare conditions, including hemophilia A and B.



Biotherapies for Life® is a registered trademark of CSL Behring LLC.
©2016 CSL Behring LLC 1020 First Avenue, PO Box 61501, King of Prussia, PA 19406-0901 USA
www.CSLBehring-us.com COA15-11-0087f 1/2016

CSL Behring
Biotherapies for Life®

2016 Mile High Colorado Camp

Mile High Colorado Camp was a huge success again this year, nearly a 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 2017** 🍷



THE FIRST FACTOR VIII WITH A PROLONGED HALF-LIFE

Learn how a prolonged half-life
may affect your infusion schedule



Meet your CoRe Manager Becky Ybarra
E: becky.ybarra@biogen.com T: 801-913-8204

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.

44279-02

Manufactured by:
Biogen Inc.
Cambridge, MA 02142 USA
U.S. License # 1697

ELOCTATE® is a registered trademark of Biogen.

RMHBDA Family Camp 2017

June 16–18, 2017

**Camp on the Boulder,
McLeod, Montana**

3916 Boulder Road, P.O. Box 47
McLeod, MT 59052
406.932.6314
www.campontheboulder.org



For 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 and 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. ♦

National Youth Leadership Institute

The National Youth Leadership Institute (NYLI) is a three-year program within the National Hemophilia Foundation (NHF) designed to assist young adults ages 18–22 from the bleeding disorders community to become well-trained, recognized leaders. NYLI also provides an amazing opportunity for youth to learn and share experiences of living with a bleeding disorder around the country.

NHF achieves these outcomes by providing young adults with training, support, and opportunities to provide education to the bleeding disorders community. ♦



NATIONAL HEMOPHILIA FOUNDATION

www.hemophilia.org

RMHBDA's Fall Education Series



October 24, Cody, WY @ The Erma, 6:30 pm

October 25 Bozeman, MT, (location & time TBD)



November 15 Bozeman, MT, (location & time TBD)

November 16 Great Falls, MT, (location & time TBD)

November 17 Kalispell/Whitefish, MT, (location & time TBD) ♦

We Love Donations!

**Donations 2016
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.

Welcome to **amazon smile**

You shop. Amazon gives.

AmazonSmile (smile.amazon.com) Amazon's way of letting Amazon customers enjoy their convenient online shopping plus the benefit of the AmazonSmile Foundation donating 0.5% of the price of eligible purchases to the charitable organizations selected by customers.

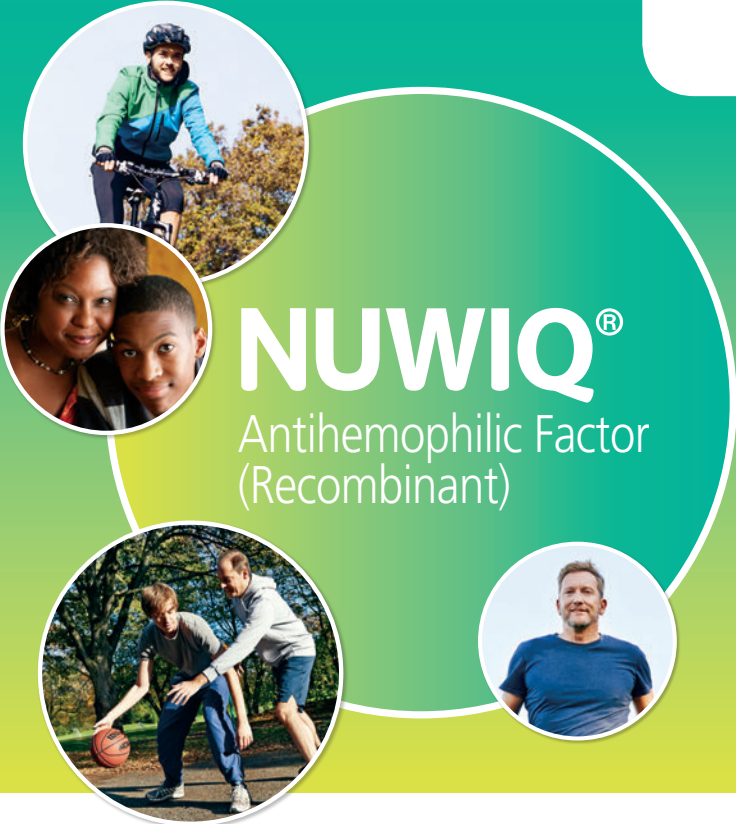


Safe and secure donation at no cost to RMHBDA or the donor — just visit www.rmhbda.org on the Donate/Join page.



Search the internet with the patent-protected, Yahoo!-powered search engine (just like you'd search on any other search engine), and we'll donate about a penny for nearly all searches to your selected cause. www.goodsearch.com

Now Available!



NUWIQ[®]

Antihemophilic Factor
(Recombinant)

Want to Learn More?

Contact your
Octapharma Representative:

KEN WAGG

PHONE:
505-414-7173

EMAIL:
Kenneth.Wagg@octapharma.com

©2016. Octapharma USA Inc. All rights reserved.
Date of preparation: 1/2016. NUW-017-CAD-e

octapharma[®]
For the safe and optimal use of human proteins

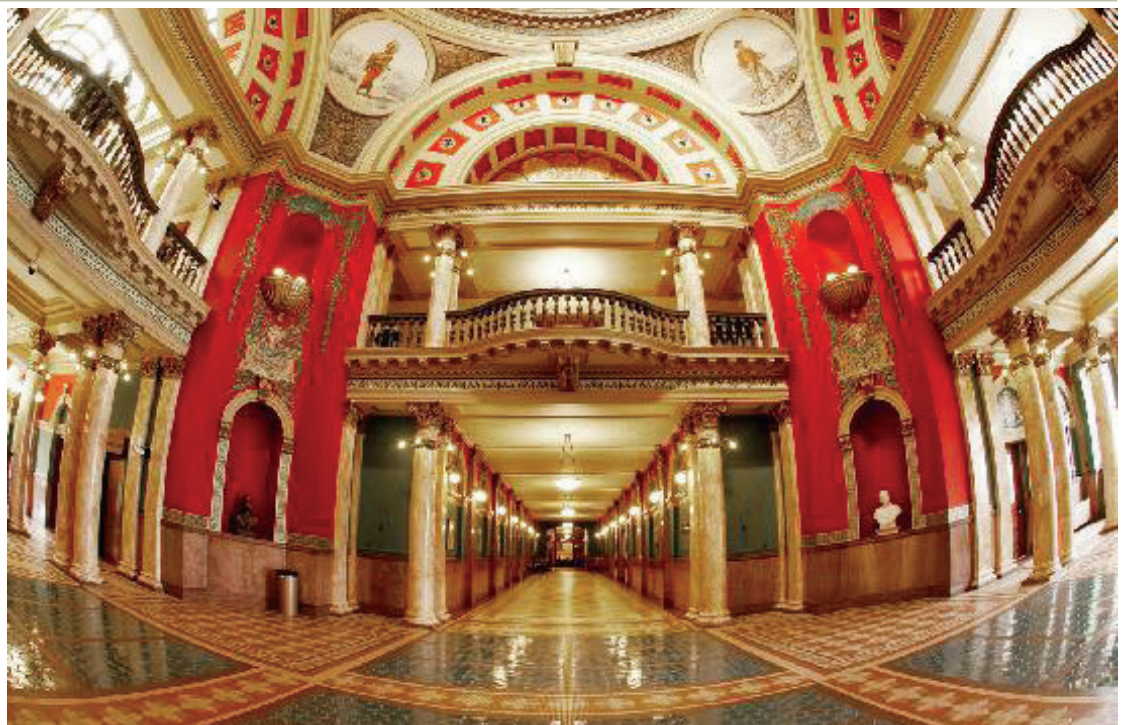
First Annual Montana State Day

Friday, March 3, 2017
10a– 1p, Helena, Montana

**Please —
Your Voice Matters;
You Will Be Heard!**

Lodging at the Holiday Inn in Helena, Montana on March 2nd will be provided by the chapter.

Please contact Brad (406.586.4050, brad@rmhbda.org) if you are interested in advocating and educating our legislators about dealing with bleeding disorders in Montana. 🍷



Ride the Rockies

If you've ever wondered what our doctors get up to in their free time, you just may be exhausted when you find out. Our director, Dr. Marilyn Manco-Johnson, is well known for being full of energy but this month she brought that vigor to a new level. She joined one of her patients, Kyle Haas, with Team Project ReCycle and rode Ride the Rockies.

Ride the Rockies is a bicycle ride that for the past 31 years has brought cyclists over the high roads of Colorado, traversing about 400 miles through various towns and cities. The routes change every year and test the endurance of cyclists as they rise over multiple mountain passes and ride on roads where even lifelong residents of the state might be nervous about driving a car. This year the course began in Carbondale, wound from Aspen to Copper Mountain, past Grand Lake, through Rocky Mountain National Park, and ended in Fort Collins. They climbed Independence Pass, Fremont Pass, Tennessee Pass, Ute Pass and even Trail Ridge Road for a total elevation gain of 29,311 feet—that's higher than Mt. Everest!

Though Marilyn has been biking for many years, this is the first year she has been a part of Ride the Rockies. During the week of Ride the Rockies, she and Kyle checked in with the HTC a few times and let us know they were well and enjoying the beautiful route across the state. While it was tough, both Marilyn and Kyle were able to complete each day. Kyle even reported he didn't have a single flat tire.

The cyclists had mornings with ice on their tents and rides with temperatures in the 90s but both Marilyn and Kyle reported one of the most intense challenges was facing 50 mph headwinds as they ascended Trail Ridge Road. These were followed by powerful crosswinds at the top, requiring riders to cluster together to keep from being blown off the road. A bear crossed their path one of the days but overall cyclists were thrilled to be enjoying the incredible views and energy that comes from such an adventure.

Kyle, who has hemophilia, was able to keep all his medications and supplies safely stowed with the Ride the Rockies medical staff. He and Marilyn both expressed appreciation to all in the Ride the Rockies support and medical staff that were so vigilant in keeping all the participants healthy during such a challenging ride.

~~~

*We at the HTC are both impressed and relieved that Marilyn and Kyle made it through without any problems and congratulate them on completing Ride the Rockies 2016!* ♦



## RMHBDA Receives NHF Award!

RMHBDA is a proud recipient of the Partnership Chapter of Excellence Award in recognition of our participation in shared initiatives, trainings, and programs of NHF. We are committed to the relevance and vitality of our national chapter network as we work together to improve the lives of the bleeding disorders community nationwide. ♦



**NATIONAL HEMOPHILIA FOUNDATION**  
www.hemophilia.org

## RMHBDA Montana License Plate!

As a result of research into the fund-raising benefits of organization license plates in Montana, RMHBDA has begun the process of having license plates available for purchase for Montana vehicles. **These will be available January 2017.** The design, derived from research into the most popular plates, and executed by RMHBDA's design firm, is being reviewed by Montana DOT and should be available for purchase first quarter of 2017. The plates will also be available just for decoration for those in Wyoming who wish to support RMHBDA. We'll keep you posted! ♦







is now brought to you by

## **Aptevo Therapeutics—** a company that's anything but ordinary



### **At Aptevo, we pride ourselves on:**

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

Connecting with people to learn about their needs

Developing empowering programs that enrich peoples' lives

---

**Learn more at [IXINITY.com](http://IXINITY.com)**

---

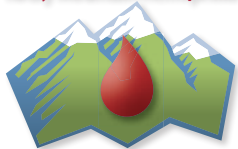


Aptevo BioTherapeutics LLC, Berwyn, PA 19312

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

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

Rocky Mountain Hemophilia



& Bleeding Disorders Association

1627 West Main Street, #142  
Bozeman, Montana 59715



Address Correction Requested

Non Profit Org.  
US Postage  
**Paid**  
Bozeman, MT  
Permit No. 94

**FALL 2016**

Rocky Mountain Hemophilia



& Bleeding Disorders Association

