WINTER 2013

RMHBDA Newsletter

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.

In This Issue

Rocky Mountain Hemophilia & Bleeding Disorders Association

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Family Camp 2014

June 20- 22, 2014 | Camp on the Boulder | McLeod, 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 at Camp on the Boulder, in McLeod, Montana. For more information, visit www.campontheboulder.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. 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

Blood Brotherhood

Hemophilia Federation of America – Rocky Mountain & Snake River Hemophilia Association's Men's Retreat

February 21-23, 2014 at Chico Hot Springs, Pray, Montana

Our men's retreat will include education, a dogsled trip in the Absaroka Mountains, relaxing in the hot springs, amazing food, and a quality bonding experience. All of your expenses at Chico Hot Springs will be covered, and we can also offer travel assistance.

We need help organizing. Please contact Brad at 406.586.4050 to serve on the Blood Brotherhood planning committee or to RSVP for this event. This is YOUR organization!

10th Annual Education Weekend 2014

April 4-6, 2014
Best Western Grand Northern Hotel, Helena, MT

Registration deadline is March 14, 2014!

Hosted by Rocky Mountain Hemophilia & Bleeding Disorders Association & the University of Colorado Hemophilia & Thrombosis Center

It's time for the 10th Annual Education Weekend for people affected by bleeding disorders in Montana and Wyoming! You and your family are invited for a weekend of informative sessions, youth programming for all ages, and an opportunity to connect with others dealing with similar challenges. This education weekend and annual meeting of RMHBDA is designed to bring you education, up-to-date information about life with a bleeding disorder, and connect you with other families in our two-state area. Check-in for the event will be Friday, April 4, 4–6 pm, followed by a chapter welcome and Pizza Party.

Continued on page 6

It's Not Too Late to Make a Donation to RMHBDA

As I embark on my third year as Executive Director of RMHBDA, I am filled with a sense of hope and excitement for the future of our chapter. I want to express my sincerest thanks to you and all of our family, friends, our generous pharmaceutical and home health sponsors, and corporate sponsors that make our programs and mission possible. Rocky Mountain Hemophilia & Bleeding Disorders Association is looking forward to 2014 and continuing to support the families in our community. RMHBDA is the only nonprofit organization in Montana and Wyoming that comprehensively supports both children and adults with genetic bleeding disorders. We have empowered numerous of individuals and families to live a healthy lifestyle, better manage their medical care, advocate for access to healthcare and to financially and emotionally plan for their future.

Your generosity and support of our work is greatly appreciated and we thank you for caring!

Sincerely,
Brad Benne, Executive Director

MT & WY Hemophilia Walk

Through pouring rain and bright skies, in the early mornings and early afternoons, 12,000 people all across the country walked to support the bleeding disorders community this year! Thank YOU for making another Hemophilia Walk season a wonderful success. Walkers, donors, volunteers, and national and local sponsors made it possible to raise more than $2.7 million to support NHF's mission and to raise awareness about bleeding disorders.

For more information or to find out how you can support the 2014 Walks, please visit the Hemophilia Walk's comprehensive website: www.hemophilia.org/walk.

NHF is pleased to have Baxter as the National Presenting Sponsor, leading our group of national sponsors, which includes: Pacesetter Sponsor Bayer HealthCare; and Official Sponsors Grifols, Pfizer Hemophilia and Biogen Idec Hemophilia. Thank you to all of our national and local sponsors for your generous support and commitment.

RMHBDA Education Scholarship

For Undergraduate Students & Families Affected by Bleeding Disorders

The Rocky Mountain Hemophilia and Bleeding Disorder Association is a chapter located in Bozeman that is dedicated to representing, educating, supporting and helping those patients with bleeding disorders and their families in Montana and Wyoming. Having an association with the National Hemophilia Foundation, we gain support from the NHF, national and local corporate partners and local individuals. Our mission is to provide ongoing support through education, family camp and financial means as well as other specific programs to meet the needs of the individuals we serve.

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.

Women's Retreat

We hosted a Women's retreat November 8–10, 2013 at Chico Hot Springs in Pray, Montana. The event was a wonderful success with 20 women attending from Kalispell, Montana to Cheyenne, Wyoming. Thank you to all of those that attended our program, your feedback on your surveys will be very beneficial in planning future programs. We are truly grateful to Sue Geraghty, Sharon Funk, and Josh Meyer for their insightful and beneficial expertise they shared with the group. Remember, just "breathe". A special thank you to the Robertson clan for putting together gift bags for everyone and roughing it in sharing a small space for lodging. Lastly, this retreat was made possible by the National Hemophilia Foundation's "Victory for Women" program supported by CSL Behring and Grifols.

Having issues with co-pays or gaps in coverage for your **hemophilia A** treatment??

We may be able to help.

Bayer offers a range of programs that can help you **navigate insurance questions about your hemophilia A** treatment. If you're having issues with co-pays or gaps in coverage, we may be able to offer assistance. Speak with one of our case specialists to find out more.

Call **1-800-288-8374** and press 1 to speak to a trained **insurance specialist!**

The only FDA-approved recombinant factor IX indicated for routine prophylaxis to treat adults with hemophilia B[1]

For more information, contact your Baxter representative today:

Steve McKell
Phone: (801) 395-4670
E-mail: steven_mckell@baxter.com

To learn more, visit www.RIXUBIS.com.

RIXUBIS
[COAGULATION FACTOR IX (RECOMBINANT)]

Indications for RIXUBIS [Coagulation Factor IX (Recombinant)]

RIXUBIS is an injectable medicine used to replace clotting factor IX that is missing in people with hemophilia B (also called congenital factor IX deficiency or Christmas disease).

RIXUBIS is used to prevent and control bleeding in adults with hemophilia B. Your healthcare provider may give you RIXUBIS when you have surgery. RIXUBIS can reduce the number of bleeding episodes in adults when used regularly (prophylaxis).

Detailed Important Risk Information for RIXUBIS [Coagulation Factor IX (Recombinant)]

You should not use RIXUBIS if you are allergic to hamsters or any ingredients in RIXUBIS.

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 hamsters, are nursing, are pregnant or planning to become pregnant, or have been told that you have inhibitors to factor IX.

You can have an allergic reaction to RIXUBIS. Call your healthcare provider or get emergency treatment right away if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea, or fainting.

Your body may form inhibitors to factor IX. An inhibitor is part of the body's defense system. If you form inhibitors, it may stop RIXUBIS 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 IX.

If you have risk factors for developing blood clots, the use of factor IX products may increase the risk of abnormal blood clots.

Some common side effects that have been reported with RIXUBIS include: unusual taste in the mouth, limb pain, and atypical blood test results.

Call your healthcare provider right away about any side effects that bother you or if your bleeding does not stop after taking RIXUBIS.

Please see Brief Summary of RIXUBIS Prescribing Information on following page.

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.

Reference: 1. RIXUBIS [Prescribing Information]. Westlake Village, CA: Baxter Healthcare Corporation; June 2013.

Baxter

RIXUBIS [Coagulation Factor IX (Recombinant)]
For Intravenous Injection
Brief Summary of Prescribing Information: Please see package insert for full Prescribing Information.

INDICATIONS AND USAGE

Control and Prevention of Bleeding Episodes

RIXUBIS [Coagulation Factor IX (Recombinant)] is an antihemophilic factor indicated for control and prevention of bleeding episodes in adults with hemophilia B.

Perioperative Management

RIXUBIS is indicated for perioperative management in adults with hemophilia B.

Routine Prophylaxis

RIXUBIS is indicated for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults with hemophilia B.

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

CONTRAINDICATIONS

RIXUBIS is contraindicated in patients with:

- Known hypersensitivity to RIXUBIS or its excipients including hamster protein
- Disseminated intravascular coagulation (DIC) [see *Warnings and Precautions*]
- Signs of fibrinolysis [see *Warnings and Precautions*]

WARNINGS AND PRECAUTIONS

Hypersensitivity Reactions

Hypersensitivity reactions, including anaphylaxis, have been reported with factor IX-containing products. The risk is highest during the early phases of initial exposure to factor IX concentrates in previously untreated patients (PUPs), in particular in patients with high-risk gene mutations. Early signs of allergic reactions, which can progress to anaphylaxis, include angioedema, chest tightness, hypotension, lethargy, nausea, vomiting, paresthesia, restlessness, wheezing, and dyspnea. Immediately discontinue administration and initiate appropriate treatment if allergic- or anaphylactic-type reactions occur. In case of severe allergic reactions, alternative hemostatic measures should be considered.

There have been reports in the literature showing an association between the occurrence of a factor IX inhibitor and allergic reactions. Evaluate patients experiencing allergic reactions for the presence of an inhibitor.

RIXUBIS contains trace amounts of Chinese hamster ovary (CHO) proteins. Patients treated with this product may develop hypersensitivity to these non-human mammalian proteins.

Inhibitors

Evaluate patients regularly for the development of factor IX inhibitors by appropriate clinical observations and laboratory tests. Perform an assay that measures factor IX inhibitor concentration if expected factor IX activity plasma levels are not attained, or if bleeding is not controlled with an expected dose. Contact a specialized hemophilia treatment center if a patient develops an inhibitor.

Patients with factor IX inhibitors are at an increased risk of severe hypersensitivity reactions or anaphylaxis if re-exposed to RIXUBIS. RIXUBIS may not be effective in patients with high titer factor IX inhibitors and other therapeutic options should be considered.

Nephrotic Syndrome

Nephrotic syndrome has been reported following attempted immune tolerance induction in hemophilia B patients with factor IX inhibitors. The safety and efficacy of using RIXUBIS for immune tolerance induction have not been established.

Thromboembolic Complications

The use of factor IX containing products has been associated with the development of thromboembolic complications (e.g., pulmonary embolism, venous thrombosis, and arterial thrombosis). Due to the potential risk for thromboembolic complications, monitor patients for early signs of thrombotic and consumptive coagulopathy, when administering RIXUBIS to patients with liver disease, with signs of fibrinolysis, peri- and post-operatively, or at risk for thrombotic events or DIC. The benefit of treatment with RIXUBIS should be weighed against the risk of these complications in patients with DIC or those at risk for DIC or thromboembolic events.

Monitoring Laboratory Tests

- Monitor factor IX activity plasma levels by the one-stage clotting assay to confirm that adequate factor IX levels have been achieved and maintained [see *Dosage and Administration in full Prescribing Information*].
- Monitor for the development of inhibitors if expected factor IX activity plasma levels are not attained, or if bleeding is not controlled with the recommended dose of RIXUBIS. Assays used to determine if factor IX inhibitor is present should be titered in Bethesda Units (BUs).

ADVERSE REACTIONS

The most common adverse reactions observed in >1% of subjects in clinical studies were dysgeusia, pain in extremity, and positive furin antibody test.

Clinical Trials Experience

Because clinical trials are conducted under widely varying conditions, adverse reaction rates observed in the clinical trials of a drug cannot be directly compared to rates in the clinical trials of another drug and may not reflect the rates observed in clinical practice.

During clinical development, in a combined study, 91 male previously treated patients (PTPs; exposed to a factor IX-containing product for ≥150 days) received at least one infusion of RIXUBIS as part of either on-demand treatment of bleeding episodes, perioperative management of major and minor surgical, dental, or other invasive procedures, routine prophylaxis, or pharmacokinetic evaluation of RIXUBIS. Six subjects (6.6%) were <6 years of age, 10 (11%) were 6 to <12 years of age, 3 (3.3%) were adolescents (12 to <16 years of age), and 72 (79%) were adults (16 years of age and older). The subjects received a total of 7,353 infusions with a median of 85 infusions of RIXUBIS (range 3 to 212 infusions), for a median of 83 exposure days (range 83 to 209 days).

A total of 161 adverse events were reported in 48 (52.7%) of the 91 subjects. Adverse reactions that occurred in >1% of subjects are shown in Table 3.

Table 3: Summary of Adverse Reactions

System Organ Class	Adverse Reactions (AR)	Number of ARs (N)	Number of Subjects (N=91) n (%)	Percent per Infusion (N=7353)
Nervous System Disorders	Dysgeusia	2	1 (1.1%)	0.03%
Musculoskeletal and Connective Tissue Disorders	Pain in extremity	1	1 (1.1%)	0.01%
Investigations	Positive furin antibody test[a]	1	1 (1.1%)	0.01%
	Factor IX or furin antibodies of indeterminate specificity[a]	9	7 (7.7%)	0.12%

[a]See Immunogenicity.

Immunogenicity

All 91 subjects were monitored for inhibitory and binding antibodies to factor IX, and binding antibodies to CHO protein and furin, at the following time points: at screening, at 72 hours following the first infusion of RIXUBIS and the commercial recombinant factor IX product in the cross-over portion of the pharmacokinetic study, after 5 and 13 weeks following first exposure to RIXUBIS, and thereafter every 3 months. Antibodies against furin were tested by an in-house enzyme-linked immunosorbent assay (ELISA). A titer of 1:20 or 1:40 was considered to be indeterminate for the above validated assay, as these titers were too low to be verified by the confirmatory assay.

No subjects developed neutralizing antibodies to factor IX. Thirteen subjects (14.3%) developed low-titer, non-neutralizing antibodies against factor IX at one or more time points. Two of these 13 subjects were found to have these antibodies at screening, prior to receiving RIXUBIS. No clinical adverse findings were observed in any of these 13 patients.

Thirteen subjects (14.3%) had signals for antibodies against furin (indeterminate specificity). Four of these 13 subjects expressed signals for antibodies at screening, prior to RIXUBIS treatment. An additional subject had an antibody signal after treatment with the comparator product and prior to RIXUBIS treatment. Another additional subject had a positive titer of 1:80 that was not present when checked at a later time point and therefore considered transient. A second subject had a positive antibody signal after the data cutoff date that was also transient. No clinical adverse findings were observed in any of these 15 patients.

In a study of 500 normal volunteers, using the same assay as in the clinical trial, 7% had titers of 1:20 or 1:40 and 1.2% had higher titers ranging from 1:80 to 1:320. These antibodies are thought to be part of a natural immune system response. To date, these antibodies have not been associated with any clinical adverse findings.

The detection of antibody formation is highly dependent on the sensitivity and specificity of the assay. Additionally, the observed incidence of antibody (including neutralizing antibody) positivity in an assay may be influenced by several factors, including assay methodology, sample handling, timing of sample collection, concomitant medications, and underlying disease.

Thrombogenicity

There was no clinical evidence of thromboembolic complications in any of the subjects. Out-of-range values for thrombogenicity markers (thrombin-antithrombin III, prothrombin fragment 1.2, and D-dimer), determined during the pharmacokinetic portion of the combined study, did not reveal any pattern indicative of clinically relevant thrombogenicity with either RIXUBIS or a comparator factor IX-containing product.

Post-marketing Experience

Because the following reactions are reported voluntarily from a population of uncertain size, it is not always possible to reliably estimate their frequency or establish a causal relationship to drug exposure.

No post-marketing adverse reactions have been reported with RIXUBIS.

The following class adverse reactions have been seen with another recombinant factor IX: inadequate factor IX recovery, inhibitor development, anaphylaxis, angioedema, dyspnea, hypotension, and thrombosis.

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From page 1: **10th Annual Education Weekend 2014**

On Saturday morning, we will cover a range of topics, some include: healthcare reform, genetic testing, men's and women's breakout sessions, and Pat Torrey.

For our youth, we will have a variety of programming available. Please pack your life-jackets for pool time in the afternoon.

Don't miss your chapter's annual meeting on Saturday for all members; important decisions will be made at this meeting and your input is needed! Lodging and meals will be provided to attending members, so don't hesitate to send your registration off today! Don't miss this opportunity with your Chapter, Industries, HTC Staff, Accredited Speakers, and your family. It will be a special and rewarding weekend for all.

Need assistance to attend Education Weekend? RMHBDA will provide Patient Assistance applications in all registration packets, please save all gas, food, and travel expense receipts! If you have any questions, please direct them to Brad Benne at 406-586-4050.

Safe Travels! Thank you for coming!

RMHBDA Education Weekend Tentative Schedule

Friday, April 4

4:00-6:00 pm	**Registration & exhibits**
6:00-6:15 pm	**Welcome**
6:15-7:30 pm	**Dinner and Program Sponsored**

Saturday, April 5

7:00-8:00 am	**Breakfast**
8:00-10:30 am	**Sessions**
10:30-12:00 am	**Exhibits/Break**
12:00-1:00 pm	**Lunch**
1:00-3:00 pm	**Annual Meeting/BOD Development**
3:00-7:00 pm	**Bowling/Free Time**
6:00 pm	**Dinner and Program Sponsored**

Sunday, April 6

7:00-8:00 am	**Breakfast**
8:00-11:30 am	**Sessions**
11:30 am	**Check out/Good Byes**

Safe Travels! Thank you for coming!

RIXUBIS Available for Adults with Hemophilia B

Baxter Healthcare Corporation has announced that RIXUBIS [Coagulation Factor IX (Recombinant)] is now available for adults with hemophilia B. RIXUBIS is the only FDA-approved recombinant factor IX indicated to treat adults age 16 years and older with hemophilia B for:

- Routine prophylaxis to prevent or reduce the frequency of bleeding episodes
- Control and prevention of bleeding episodes
- Use with surgery

You should not use RIXUBIS if you are allergic to hamsters or any ingredients in RIXUBIS. In clinical studies, RIXUBIS demonstrated efficacy with routine prophylaxis. Forty-three percent of patients experienced zero bleeds during six months of prophylactic treatment. Prophylaxis efficacy of RIXUBIS was studied in 56 previously treated patients between 12 and 65 years of age with severe or moderately severe hemophilia B for a mean treatment duration of six months. Some common side effects that have been reported with RIXUBIS include: unusual taste in the mouth, limb pain, and atypical blood test results.

Bayer Updates on Kogenate® FS, Factor Matters, and Factor Solutions

An update on Kogenate® FS antihemophilic factor (recombinant) with Vial Adapter, an additional reconstitution system that we launched at the meeting, and our Factor Solutions program, which offers personalized information about insurance, as well as co-pay assistance for those who qualify.

Factor Matters, our unique patient-support program designed to connect people with resources and information related to hemophilia A. For each participant who signed up for Factor Matters, Bayer donated $5 to the organization of their choosing, whether it was NHF, HFA or LA Kelley Communications, Inc.

Given the "buzz" around insurance, our Factor Solutions is very popular. Factor Solutions offers a helpline with personalized support and financial assistance (in both English and Spanish). Factor Solutions includes our copay prescription assistance and insurance gap assistance programs for qualified applicants, in addition to information about how to ensure access and coverage as healthcare reform changes start to take effect. In fact, at NHF, we brought two of our Factor Solutions case managers to help community members better understand the changing insurance landscape and what it means to them.

FDA Approves BLA for Novo Nordisk's New Recombinant Factor VIII Product

Last month, Novo Nordisk announced approval by the US Food and Drug Administration (FDA) of its Biologics License Application (BLA) for Novoeight®, the company's recombinant factor VIII therapy.

The approved indications for Novoeight® include use in adults and children with hemophilia A for the control and prevention of bleeding, perioperative management and routine prophylaxis to prevent or reduce the frequency of bleeding episodes.

According to a Novo Nordisk press release, Novoeight® has been evaluated via the guardian™ clinical program, which included more than 210 patients with severe hemophilia A. In the completed trials, Novoeight® demonstrated good efficacy in preventing and treating bleeds. No patients developed inhibitors (antibodies to infused factor protein), and all patients in the surgery trial were treated effectively. Novoeight® will be launched with the newly introduced prefilled device, MixPro®.

"The approval of Novoeight® marks an important step in offering a new alternative for people with hemophilia A, and demonstrates our commitment to hemophilia," said Mads Krogsgaard Thomsen, executive vice president and chief science officer at Novo Nordisk. The company plans to launch Novoeight® in the US soon after April 2015, upon the expiration of existing patents.

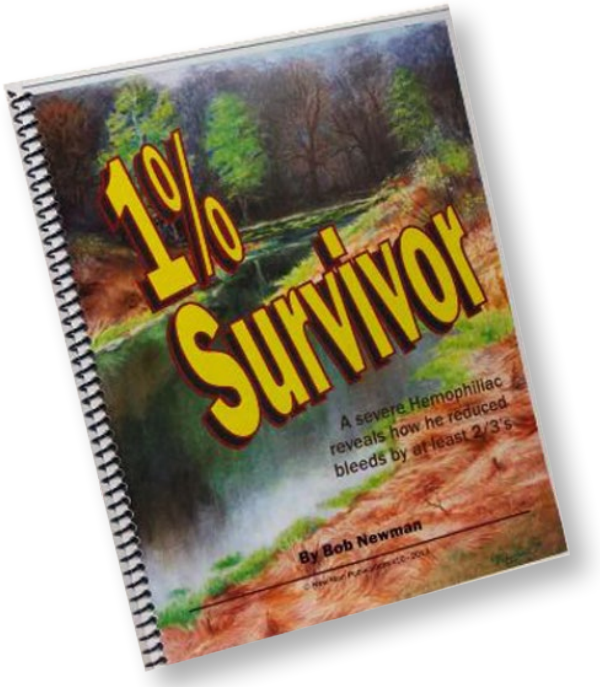
New HERO Initiative Video

I am pleased to announce the next video in a series showcasing outcomes from the US Hemophilia Experiences, Results, and Opportunities (HERO) Summit for Solutions, which was held in Philadelphia last spring. The video, titled "The HERO Initiative: Working to Address Gaps in Care & Improving Outcomes," focuses on ensuring access to comprehensive care, improving understanding of the burden of hemophilia, and pain management.

1% Survivor

My name is Bob and I have had severe hemophilia type A for 84 years. For the past eight years, I have developed a method of reducing bleeding episodes by at least two-thirds and also have greatly improved my general health.

I recently have written a book about it that I would like to share it with you. To find out more, visit www.1percentSurvivor.com.



Save One Life

Imagine, for a moment, living with hemophilia. Consider the uncertainties — how an ordinary day can turn into a life-or-death emergency. Imagine the resources needed to improve the quality of your life or to save it. And imagine the cost — the price of life-saving factor, refrigeration, electricity, clean water — all things we take for granted.

Now, imagine living that life in a poor country. No money for medications. No refrigeration to keep it viable. No clean water. And, no local treatment center.

Those are the life-and-death challenges patients with hemophilia face every day in countries like Zimbabwe, India, and Honduras. They're the life-and-death challenges Laurie Kelley, founder of Save One Life, has seen during her many trips to educate patients about hemophilia in developing countries. As the mother of a child with hemophilia, she knew first-hand the daily struggles. But in poor countries, where most hemophilia patients live in households earning about $1 a day, those challenges become staggering.

Laurie's vision was to build a humanitarian bridge by raising awareness and encouraging people in developed countries to give back to the rest of the world in a personal way. "I believed that families with hemophilia in wealthier countries, with vast resources and adequate healthcare, would be willing to help once they understood the suffering of people with hemophilia in developing countries," she says.

Save One Life provides sponsorships for individual hemophilia patients. People in developed countries can choose a child or young adult from a poor country to support for only $22 a month, less than a dollar a day. These funds provide vitamins to anemic children with hemophilia, pain medication, school fees, clothing and other daily living needs. But most of all, these funds provide transportation to the clinic when a child has a bleed. Since these families live in urban slums or distant, rural villages far from medical care, this is crucial. "We've found that most of the sponsorship money, regardless of the country, goes to school fees to help the child get a good education and lift the family out of poverty, and transportation to a hospital when the child has a bleed," Kelley notes.

Today, Save One Life provides sponsorships to more than 1100 individuals with bleeding disorders in 12 developing countries. In addition, about 40 students received scholarships through Save One Life's scholarship fund and hemophilia camps in the Dominican Republic, Romania and Nigeria received support through Save One Life's camp fund.

We invite you to learn more about Save One Life and its programs at www.saveonelife.net.

Save the Date! Mile High Colorado Camp

Mile High Colorado Camp **July 20-25, 2014**

Leadership Pre-Camp Retreat **July 18-20, 2014**

The Hemophilia and Thrombosis Center (HTC) is proud to once again sponsor the summer camp program at **Rocky Mountain Village**. Camp forms will be available in mid-March! Stay Tuned!

Who Should Attend?

- Children with hemophilia or other bleeding disorders
- Siblings of the above groups

Mile High Colorado Camp is for ages 7–18. We accept 6-year-olds on a case by case basis. 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 want 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 non-refundable $75 deposit. The remainder of the camp cost, approximately $1,000 per camper, is underwritten by other sources. Scholarships will be granted on an individual basis. Scholarship forms are available. If you have questions or need scholarship forms or additional information, please call Brad Benne at 406.600.2554.

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.

States Divided on Whether to Extend Health Plans that Do Not Comply with the ACA

At least 21 of 30 states with Republican governors (including Florida, New Jersey, Ohio, and Texas) have indicated that they will let health insurers extend policies through 2014 that otherwise would be canceled because they do not comply with the higher standards in the Affordable Care Act (ACA), and many will allow renewals well into 2015.

President Obama proposed the administrative "fix" last month in an effort to alleviate the political fallout from over five million plan cancellations in the individual market. It allowed state insurance commissioner to choose whether to let subscribers of plans that have been or will be cancelled to remain or re-enroll in those plans without complying with the ACA (see Update for Week of November 11th).

However, Democratic-led states have been reluctant to go along, citing concerns from the insurance industry that allowing substandard plans would undermine the risk pool for the new health insurance marketplaces. Participating insurers based their 2014 premiums on the assumption that large numbers of younger and healthier consumers would be transitioned from "junk" plans into the marketplaces.

The Obama Administration acknowledged that insurers may lose money as a result of extending these plans and issued proposed rules last week that would adjust the ACA reinsurance program to compensate for these losses (see above).

Despite this concession, only nine Democratic-led states (including Illinois, Kentucky, Missouri, and Oregon) have agreed to extend the plans. California's insurance commissioner has sought to do so, even though the Covered California board unanimously voted last week not to allow plan extensions for marketplace insurers.

At least ten other Democratic-led states, all of which created their own ACA marketplace, have decided not to allow insurers to extend deficient plans into 2014. This includes Connecticut, Massachusetts, Minnesota, New York, and Washington.

The District of Columbia's insurance commissioner was fired on November 15th for issuing an unapproved news release denouncing the President's plan for siphoning away marketplace consumers. However, his interim successor supported his decision not to allow deficient plans to be extended (without directly criticizing the Administration).

Less than five states remain undecided, including Republican-led Nevada whose insurance commissioner stated that state law prevents him from extending the plans. (The Office of Legislative Counsel in Oregon issued a similar finding even though the state agreed to extend deficient plans.)

Courtesy of Patient Services, Inc., P.O. Box 1602, Midlothian, VA 23113, 800.366.7741, www.uneedpsi.org

RMHBDA Receives Award

Rocky Mountain Hemophilia & Bleeding Disorders Association has been selected to receive a PACT State Advocacy award for 2014. The PACT grant continues to be funded by Baxter Biosciences. Since 2005, nearly $1.6 has been awarded for this important purpose.

With the PACT State Advocacy funds, our chapter will have the resources to work toward becoming an accepted, knowledgeable, and critical voice in defining our state's service in providing "affordable" and "accessible" health care to families with bleeding disorders in Montana.

Tentative 2014 Program & Event Calendar

As of December 20, 2013. The chapter is still determining exact dates for several programs and events for the community.

January
NACCHO Camp Conference: **January 23–26**

NHF National Walk Training: **January 27–29**

February
Men's Retreat/Blood Brotherhood, Chico Hot Springs: **February 20–22**

NHF Washington Days: **February 26–28**

March
Hemophilia Awareness Month!

HFA Annual Symposium: **March 27–29**

April
RMHBDA Education Weekend, Helena: **April 4–6**

World Hemophilia Day: **April 17**

May
Facts First/Walk "Call to Action": **TBD**

June
RMHBDA Family Camp, Camp on the Boulder, McLeod, MT: **June 20–22**

July
Mile High Summer Camp Leadership Pre–camp Retreat: **July 11–13**

Mile High Summer Camp, Rocky Mountain Village, Empire, CO: **July 13 – 18**

August
Facts First/Walk Kickoff Event: **TBD**

September
RMHBDA Walk for Hemophilia, Billings: **September 6**

NHF Annual Meeting, Washington, D.C.: **September 18–21**

CSL Behring "Getting In the Game": **TBD**

December 2014
Facts First: **TBD**

Rocky Mountain Hemophilia
& Bleeding Disorders Association
a 501(c)(3) nonprofit Montana corporation

November 12, 2013

RE: Magellan National Medicaid Pooling Initiative (NMPI)

To Whom It May Concern,

Rocky Mountain Hemophilia & Bleeding Disorders Association is a non-profit patient advocacy organization representing more than 200 families and individuals affected by bleeding disorders in the states of Montana and Wyoming. Our mission is to ensure that individuals affected by hemophilia and other inherited bleeding disorders have timely access to quality medical care, therapies and services, regardless of financial circumstances or place of residence.

We recently learned of a request for proposal (RFP) notification received by several blood clotting factor manufacturers from Magellan Medicaid Administration Inc. The RFP seeks supplemental rebates for factor products and by-passing agents. We appreciate that the complexities involved in treating hemophilia and other inherited bleeding disorders can result in high medical expenses for patients and payers such as the state and we support the state's need to identify cost containment strategies. However, it is critical that such strategies not compromise continuity of care for those with complex medical conditions.

Hemophilia and related bleeding disorders are rare, complex genetic conditions for which there are no known cures. Individuals often experience spontaneous and prolonged internal bleeding into the joints and soft tissues. To effectively manage these disorders, patients often require life-long infusions of clotting factor therapies that replace the missing or deficient blood proteins, thus preventing debilitating and life-threatening internal bleeding. While today's therapies are more costly than other types of medication, they are also safer and more effective, allowing those affected to become an active and engaged member of society.

Attached please find a letter from the National Hemophilia Foundation and Hemophilia Federation of America requesting you to continue the practice of allowing patient access to all FDA-approved therapies available to treat hemophilia and other inherited bleeding disorders. On behalf of individuals in the state of Montana affected by bleeding disorders, we urge you to grant this request. If you would like additional information or have questions, please feel free to contact (insert chapter representative's name, title and contact information). Thank you for your consideration of our request.

Sincerely,

Brad R. Benne
Executive Director

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WINTER 2013

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Now donate at www.rockymountainhemophilia.org with PayPal.

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