SPRING/SUMMER 2018

Rocky Mountain Hemophilia & Bleeding Disorders Association

RMHBDA Newsletter

The Rocky Mountain

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

Education Weekend 2018

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, Shire, Bioverativ, CSL Behring, CVS Caremark, Grifols, HF Healthcare, Diplomat, Genentech, Octapharma, Restore RX, Aptevo, the National Hemophilia Foundation, the Hemophilia Federation of America, and Pfizer Hemophilia.

RMHBDA Education Weekend was held February 23–25 in Bozeman, Montana. We had 83 people in attendance from our community and an additional dozen sponsors and exhibitors. Educational sessions during Education Weekend included: infusion session, breakout sessions for our Blood Brotherhood and Sisterhood programs, a young adult panel, information on bullying, and a discussion on "Standards of Care" for individuals with bleeding disorders. 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 participated in some educational opportunities in the morning and enjoyed a field trip to Laser Dash on Saturday afternoon.

Raffle Winners

- Kristen Ressler
- Emily Dugan
- Andrew Borcher

RMHBDA in Washington

Lisa Maxwell & Jody Rudell

The 2018 Washington Days event was a little milder than in years past, which is directly related to the atmosphere of political instability. Politics on the hill are moving at a different pace. What could be an issue in the morning can evaporate by the evening. We still had some critical talking points and takeaways for our community.

- **Quality of Life took front stage.** They wanted us to drive home that people in our community have a huge need for a positive quality of life and without access to comprehensive insurance and access to our HTC's; patient care could be impacted negatively.
- **Ensuring access to the required drugs while on Medicaid was a large portion of our discussion.** Lisa was asked to sit on a panel to talk about why hewent before the pharmacy board in Wyoming to ask them to maintain the hemophilia agents on the preferred drug lists for Wyoming. We want to stress that there is no generic option for our folks, we cannot have restrictions.
- **Our community and budget cuts.** Simply put, our community cannot maintain a positive quality of life with drastic budget cuts. We asked them to maintain funding through the CDC and HRSA and within HRSA, there was much discussion on asking to maintain the support of the 340B Drug Discount Programs.

While walking down the hall at the Hart Senate building, we were amazed that Senator Tester recognized Lisa as he drew near. Of

course, the photo opportunity (shown) and some one-on-one time was appreciated, The personal stories we have shared throughout the years have made a lasting impression on our elected officials. Building on our past visits, our senators and their legislative aides in both Wyoming and Montana asked what they can do for us. Amazing! We met with five of our six elected officials personally.

Continued on page 2

Rocky Mountain Hemophilia & Bleeding Disorders Association

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www.facebook.com/rmhbda

From page 1: **RMHBDA in Washington**

Important Federal Issues Facing the Bleeding Disorder's Community

Support federal standards for public and private insurance so that patient protections and access to insurance is maintained:

- **For private plans.** Maintain current pre-existing conditions policies, the ban on lifetime and annual limits, and federal standards for Essential Health Benefits.
- **For Medicaid.** Maintain the Medicaid expansion and oppose state waivers that could threaten meaningful coverage.

Support federal hemophilia programs at CDC and HRSA that ensure access to care for people with bleeding disorders:

- **HRSA Maternal and Child Health Bureau Hemophilia Program.** This program provides funding to hemophilia treatment centers and allows participation in the 340B Program, which supports comprehensive care.
- **CDC Division of Blood Disorders.** This program supports critical surveillance and prevention activities.

Thank you to everyone that has written to our congressmen or visited D.C. to share their experiences with a bleeding disorder. Those visits made an impact on our elected officials and we're humbled and grateful to be able to represent all of us on a national level.

Bleeding Disorders Awareness Month

Three million people across the U.S. live with bleeding disorders that can cause extended bleeding after injury, surgery or trauma, and can be life-threatening if not treated effectively.

The National Hemophilia Foundation's Red Tie Campaign raises funds and awareness to find better treatments and cures for bleeding disorders.

Visit www.redtiecampaign.org to make a donation to our chapter!

The National Hemophilia Foundation will match funds up to $500 for RMHBDA.

THE 2018 NHF REDTIE CAMPAIGN
FOR ALL BLEEDING DISORDERS

Montana License Plates

RMHBDA Montana license plates are ready to have a place on your vehicle.

Please keep this in mind for your upcoming Montana license renewal and as an easy way of supporting your chapter. The more people who see it, the more people will want one!

Have a look on the Montana State website:
https://dojmt.gov/driving/plate-designs-and-fees/service-organizations-associations/

Big Sky Family Camp 2018

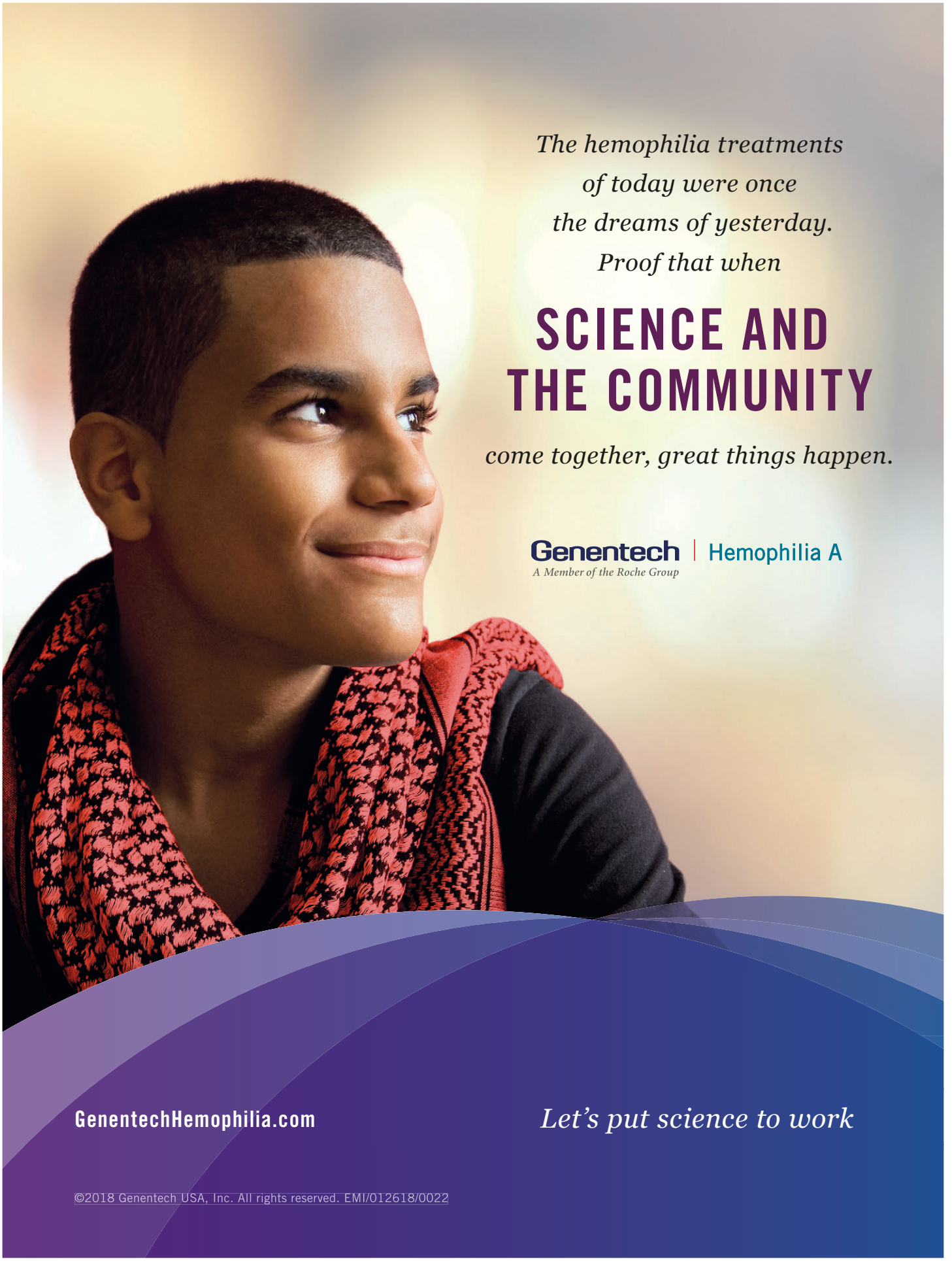
Each summer, RMHBDA invites affected families living in Montana and Wyoming to attend a weekend retreat. The weekend is packed full of education, bonding, and fun!

August 10-12, 2018
Flathead Lake Camp United Methodist
21339 Methodist Camp Road
Rollins, MT 59931
(406) 844-3483
www.flatheadcamp.org/

For the parents and teens, we will have teambuilding programming led by our guest, hemophilia leadership group, Gut Monkey (www.gutmonkey.com), 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 any questions at 406.586.4050



KOVALTRY®, Antihemophilic Factor (Recombinant): THE CONFIDENCE TO TAKE CONTROL

For children, adolescents, and adults with hemophilia A

For more information, visit YourKOVALTRY.com

INDICATIONS

- KOVALTRY® is a medicine used to replace clotting factor (Factor VIII or antihemophilic factor) that is missing in people with hemophilia A.
- KOVALTRY® is used to treat and control bleeding in adults and children with hemophilia A. KOVALTRY® can reduce the number of bleeding episodes in adults and children with hemophilia A when used regularly (prophylaxis). Your healthcare provider may give you KOVALTRY® when you have surgery.
- KOVALTRY® is not used to treat von Willebrand Disease.

IMPORTANT SAFETY INFORMATION

- You should not use KOVALTRY® if you are allergic to rodents (like mice and hamsters) or any ingredients in KOVALTRY®.
- Tell your healthcare provider if you have heart disease or are at risk for heart disease.
- The common side effects of KOVALTRY® are headache, fever, and itchy rash.
- Allergic reactions may occur with KOVALTRY®. Call your healthcare provider right away and stop treatment if you get tightness of the chest or throat, dizziness, decrease in blood pressure, and nausea.
- Your body can also make antibodies, called "inhibitors," against KOVALTRY®, which may stop KOVALTRY® 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.

KOVALTRY® Dosing: The recommended dose for routine prophylaxis in adults and adolescents is 20 to 40 IU of KOVALTRY® per kg of body weight 2x/week or 3x/week. The recommended dose for routine prophylaxis in children 12 years old and younger is 25 to 50 IU of KOVALTRY® per kg of body weight 2x/week, 3x/week, or every other day according to individual requirements.

IMPORTANT SAFETY INFORMATION (CONT'D)

- Tell your healthcare provider about any side effect that bothers you or that does not go away.
- Call your healthcare provider right away if bleeding is not controlled after using KOVALTRY®.

For additional important risk and use information, please see Brief Summary on following page.

You are encouraged to report negative side effects or quality complaints of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

Talk to your doctor to see if KOVALTRY® is right for you.

Kovaltry®

Antihemophilic Factor (Recombinant)

HIGHLIGHTS OF FDA-Approved Patient Labeling
Patient Information
KOVALTRY (KOH-vahl-tree)
Antihemophilic Factor (Recombinant)

This leaflet summarizes important information about KOVALTRY with vial adapter. 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 KOVALTRY. If you have any questions after reading this, ask your healthcare provider.

Do not attempt to self-infuse unless you have been taught how by your healthcare provider or hemophilia center.

What is KOVALTRY?

KOVALTRY is a 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.

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

KOVALTRY is not used to treat von Willebrand Disease.

Who should not use KOVALTRY?

You should not use KOVALTRY if you

- are allergic to rodents (like mice and hamsters).
- are allergic to any ingredients in KOVALTRY.

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

- Tell your healthcare provider about all of your medical conditions.
- Tell your healthcare provider and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies.
- Tell your healthcare provider if you have been told you have heart disease or are at risk for heart disease.
- Tell your healthcare provider if you have been told that you have inhibitors to Factor VIII (because KOVALTRY may not work for you).

What are the possible side effects of KOVALTRY?

The common side effects of KOVALTRY are headache, fever and itchy rash.

Allergic reactions may occur with KOVALTRY. Call your healthcare provider right away and stop treatment if you get tightness of the chest or throat, dizziness, decrease in blood pressure, and nausea.

Your body can also make antibodies, called "inhibitors," against KOVALTRY, which may stop KOVALTRY 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.

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

Tell your healthcare provider about any side effect that bothers you or that does not go away.

Reference: KOVALTRY® [prescribing information]. Whippany, NJ: Bayer HealthCare Pharmaceuticals, Inc; 2016.

How do I store KOVALTRY?

Do not freeze KOVALTRY.

Store KOVALTRY at +2°C to +8°C (36°F to 46°F) for up to 30 months from the date of manufacture. Within this period, KOVALTRY may be stored for a period of up to 12 months at temperatures up to +25°C or 77°F.

Record the starting date of room temperature storage clearly on the unopened product carton. Once stored at room temperature, do not return the product to the refrigerator. The product then expires after storage at room temperature for 12 months, or after the expiration date on the product vial, whichever is earlier. Store vials in their original carton and protect them from extreme exposure to light.

Administer reconstituted KOVALTRY as soon as possible. If not, store at room temperature for no longer than 3 hours.

Throw away any unused KOVALTRY after the expiration date.

Do not use reconstituted KOVALTRY if it is not clear.

What else should I know about KOVALTRY and hemophilia A?

Finding veins for injections may be difficult in young children. When frequent injections are required, your healthcare provider may propose to have a device surgically placed under the skin to facilitate access to the bloodstream. These devices may result in infections.

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

This leaflet summarizes the most important information about KOVALTRY. If you would like more information, talk to your healthcare provider. You can ask your healthcare provider or pharmacist for information about KOVALTRY that was written for healthcare professionals.

Resources at Bayer available to the patient:

For Adverse Reaction Reporting, contact Bayer Medical Communications 1-888-84-BAYER (1-888-842-2937)

To receive more product information, contact KOVALTRY Customer Service 1-888-606-3780

Bayer Reimbursement HELPline 1-800-288-8374

For more information, visit www.KOVALTRY-us.com

Bayer HealthCare LLC
Whippany, NJ 07981 USA
U.S. License No. 8

Kovaltry®
Antihemophilic Factor (Recombinant)

Wyoming Governor Declares Bleeding Disorders Awareness Month

Governor's Proclamation

WHEREAS, March is Bleeding Disorders Awareness Month; and

WHEREAS, Bleeding Disorders Awareness Month expands upon the designation by President Ronald Reagan 30 years ago of March 1986 as "Hemophilia Awareness Month"; and

WHEREAS, all bleeding disorders share the inability to form a proper blood clot and are characterized by extended bleeding after injury, surgery, trauma or any bleeding incident. They can lead to medical complications or be fatal if not treated effectively; and

WHEREAS, many individuals with hemophilia became infected with HIV and Hepatitis C in the 1980s due to contaminated blood supplies and products; and

WHEREAS, Bleeding Disorders Awareness Month can generate greater awareness and understanding of, not only hemophilia, but all inheritable bleeding disorders, including Von Willebrand disease – which alone impacts an estimated one percent of the U.S. population or more than 3.2 million individuals; and

WHEREAS, Bleeding Disorders Awareness Month can foster a greater sense of community and shared purpose among individuals with all inheritable bleeding disorders and engage the general public.

NOW THEREFORE, I, MATTHEW H. MEAD, Governor of the State of Wyoming, do hereby proclaim March, 2018 as

BLEEDING DISORDERS AWARENESS MONTH

in Wyoming.

IN WITNESS WHEREOF, I have hereunto set my hand and caused the Executive Seal of the Governor of Wyoming to be affixed this 27 day of February, 2018.

SEAL OF THE GOVERNOR OF WYOMING

Matthew H. Mead
Governor

Mile High Colorado Camp 2018

SAVE THE DATE! July 15–20,2018

Leadership Pre-Camp Retreat July 13-15

University of Colorado Anschutz Medical Campus
Hemophilia and Thrombosis Center

Camp forms are available now: www.cohemo.org

The Hemophilia and Thrombosis Center (HTC) is proud to once again sponsor the summer camp program at **Rocky Mountain Village**.

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 non-refundable $75.00 deposit. The remainder of the camp cost, approximately $1000.00 per camper, is underwritten by other sources. If you have questions 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!

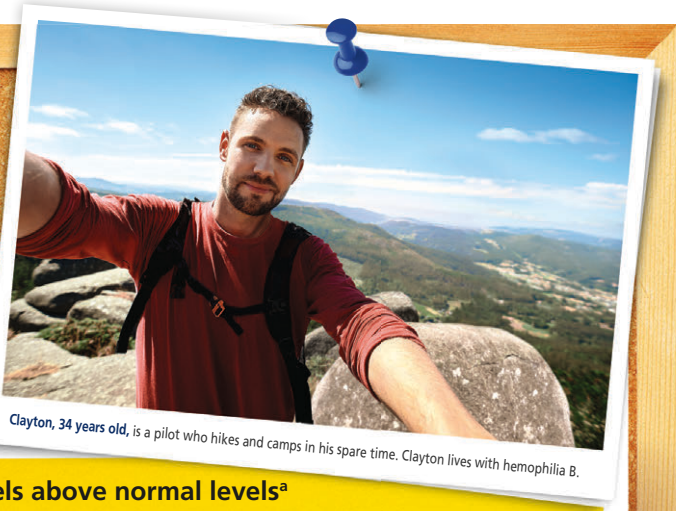
This summer make a dream come true. Your contribution will send a youth to Hemophilia summer camp at Mile High Camp in Colorado. Your support makes a lasting difference in the lives of children with a bleeding disorder.

Picture from 2015 Camp!

In hemophilia B

TAKE CONTROL TO A HIGH LEVEL WITH REBINYN®

NOW AVAILABLE



Clayton, 34 years old, is a pilot who hikes and camps in his spare time. Clayton lives with hemophilia B.

Rebinyn® elevates factor levels above normal levels[a]

+94% Factor IX (FIX) levels achieved immediately after an infusion[b]

17% FIX levels sustained after 7 days[a]

With a single dose of Rebinyn® 40 IU/kg in adults with ≤2% FIX levels[a]

[a]In two phase 3 studies, factor levels were evaluated for 1 week after the first dose of Rebinyn® 40 IU/kg. The average levels after 7 days were 16.8% in 6 adults, 14.6% in 3 adolescents, 10.9% in 13 children ages 7 to 12 years, and 8.4% in 12 children up to age 6 years.

[b]Based upon a 2.34% increase in factor levels per IU/kg infused in adults.

Image of hemophilia B patient shown is for illustrative purposes only.

INDICATIONS AND USAGE

What is Rebinyn® Coagulation Factor IX (Recombinant), GlycoPEGylated?

Rebinyn® is an injectable medicine used to replace clotting Factor IX that is missing in patients with hemophilia B. Rebinyn® is used to treat and control bleeding in people with hemophilia B. Your healthcare provider may give you Rebinyn® when you have surgery. Rebinyn® is not used for routine prophylaxis or for immune tolerance therapy.

IMPORTANT SAFETY INFORMATION

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

- **Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center.** Carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing Rebinyn®.

Who should not use Rebinyn®?

Do not use Rebinyn® if you:

- are allergic to Factor IX or any of the other ingredients of Rebinyn®.
- are allergic to hamster proteins.

What should I tell my health care provider before using Rebinyn®?

Tell your health care provider if you:

- have or have had any medical conditions.
- take any medicines, including non-prescription medicines and dietary supplements.
- are nursing, pregnant, or plan to become pregnant.
- have been told you have inhibitors to Factor IX.

How should I use Rebinyn®?

- Rebinyn® is given as an infusion into the vein.
- **Call your healthcare provider right away if your bleeding does not stop after taking Rebinyn®.**
- Do not stop using Rebinyn® without consulting your healthcare provider.

What are the possible side effects of Rebinyn®?

- **Common side effects include** swelling, pain, rash or redness at the location of the infusion, and itching.
- **Call your healthcare provider right away or get emergency treatment right away if you get any of the following signs of an allergic reaction:** hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.
- **Tell your healthcare provider about any side effect that bothers you or that does not go away.**
- Animals given repeat doses of Rebinyn® showed Polyethylene Glycol (PEG) inside cells lining blood vessels in the choroid plexus, which makes the fluid that cushions the brain. The potential human implications of these animal tests are unknown.

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

Rebinyn® is a prescription medication.

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.

Learn more at rebinyn.com

novo nordisk®

Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.

rebinyn®
Coagulation Factor IX (Recombinant), GlycoPEGylated

rebinyn®

Coagulation Factor IX (Recombinant), GlycoPEGylated

Brief Summary Information about:
REBINYN® Coagulation Factor IX (Recombinant), GlycoPEGylated

Rx Only

This information is not comprehensive.

- Talk to your healthcare provider or pharmacist
- Visit www.novo-pi.com/REBINYN.pdf to obtain FDA-approved product labeling
- Call 1-844-REB-INYN

Read the Patient Product Information and the Instructions For Use that come with REBINYN® before you start taking this medicine and each time you get a refill. There may be new information.

This Patient Product Information does not take the place of talking with your healthcare provider about your medical condition or treatment. If you have questions about REBINYN® after reading this information, ask your healthcare provider.

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

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

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

What is REBINYN®?

REBINYN® is an injectable medicine used to replace clotting Factor IX that is missing in patients with hemophilia B. Hemophilia B is an inherited bleeding disorder in all age groups that prevents blood from clotting normally.

REBINYN® is used to treat and control bleeding in people with hemophilia B.

Your healthcare provider may give you REBINYN® when you have surgery.

REBINYN® is not used for routine prophylaxis or for immune tolerance therapy.

Who should not use REBINYN®?

You should not use REBINYN® if you

- are allergic to Factor IX or any of the other ingredients of REBINYN®
- if you are allergic to hamster proteins

If you are not sure, talk to your healthcare provider before using this medicine.

Tell your healthcare provider if you are pregnant or nursing because REBINYN® might not be right for you.

What should I tell my healthcare provider before I use REBINYN®?

You should tell your healthcare provider if you

- Have or have had any medical conditions.
- Take any medicines, including non-prescription medicines and dietary supplements.
- Are nursing.
- Are pregnant or planning to become pregnant.
- Have been told that you have inhibitors to Factor IX.

How should I use REBINYN®?

Treatment with REBINYN® should be started by a healthcare provider who is experienced in the care of patients with hemophilia B.

REBINYN® is given as an infusion into the vein.

You may infuse REBINYN® 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 hemophilia treatment center or healthcare provider. Many people with hemophilia B learn to infuse the medicine by themselves or with the help of a family member.

Your healthcare provider will tell you how much REBINYN® to use based on your weight, the severity of your hemophilia B, and where you are bleeding. Your dose will be calculated in international units, IU.

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

If your bleeding is not adequately controlled, it could be due to the development of Factor IX inhibitors. This should be checked by your healthcare provider. You might need a higher dose of REBINYN® or even a different product to control bleeding. Do not increase the total dose of REBINYN® to control your bleeding without consulting your healthcare provider.

Use in children

REBINYN® can be used in children. Your healthcare provider will decide the dose of REBINYN® you will receive.

If you forget to use REBINYN®

If you forget a dose, infuse the missed dose when you discover the mistake. Do not infuse a double dose to make up for a forgotten dose. Proceed with the next infusions as scheduled and continue as advised by your healthcare provider.

If you stop using REBINYN®

Do not stop using REBINYN® without consulting your healthcare provider.

If you have any further questions on the use of this product, ask your healthcare provider.

What if I take too much REBINYN®?

Always take REBINYN® exactly as your healthcare provider has told you. You should check with your healthcare provider if you are not sure. If you infuse more REBINYN® than recommended, tell your healthcare provider as soon as possible.

What are the possible side effects of REBINYN®?

Common Side Effects Include:

- swelling, pain, rash or redness at the location of infusion
- itching

Other Possible Side Effects:

You could have an allergic reaction to coagulation Factor IX products. **Call your healthcare provider right away or get emergency treatment right away if you get any of the following signs of an allergic reaction:** hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.

Your body can also make antibodies called "inhibitors" against REBINYN®, which may stop REBINYN® from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

You may be at an increased risk of forming blood clots in your body, especially if you have risk factors for developing blood clots. Call your healthcare provider if you have chest pain, difficulty breathing, leg tenderness or swelling.

Animals given repeat doses of REBINYN® showed Polyethylene Glycol (PEG) inside cells lining blood vessels in the choroid plexus, which makes the fluid that cushions the brain. The potential human implications of these animal tests are unknown.

These are not all of the possible side effects from REBINYN®. Ask your healthcare provider for more information. You are encouraged to report side effects to FDA at 1-800-FDA-1088.

Tell your healthcare provider about any side effect that bothers you or that does not go away.

What are the REBINYN® dosage strengths?

REBINYN® comes in three different dosage strengths. The actual number of international units (IU) of Factor IX in the vial will be imprinted on the label and on the box. The three different strengths are as follows:

Cap Color Indicator	Nominal Strength
Red	500 IU per vial
Green	1000 IU per vial
Yellow	2000 IU per vial

Always check the actual dosage strength printed on the label to make sure you are using the strength prescribed by your healthcare provider.

How should I store REBINYN®?

Prior to Reconstitution (mixing the dry powder in the vial with the diluent):

Store in original package in order to protect from light. Do not freeze REBINYN®.

REBINYN® vials can be stored in the refrigerator (36-46°F [2°C-8°C]) for up to 24 months until the expiration date, or at room temperature (up to 86°F [30°C]) for a single period not more than 6 months.

If you choose to store REBINYN® at room temperature:

- Note the date that the product is removed from refrigeration on the box.
- The total time of storage at room temperature should not be more than 6 months. Do not return the product to the refrigerator.
- Do not use after 6 months from this date or the expiration date listed on the vial, whichever is earlier.

Do not use this medicine after the expiration date which is on the outer carton and the vial. The expiration date refers to the last day of that month.

After Reconstitution:

The reconstituted (the final product once the powder is mixed with the diluent) REBINYN® should appear clear without visible particles.

The reconstituted REBINYN® should be used immediately.

If you cannot use the reconstituted REBINYN® immediately, it should be used within 4 hours when stored at or below 86°F (30°C). Store the reconstituted product in the vial.

Keep this medicine out of the sight and out of reach of children.

What else should I know about REBINYN® and hemophilia B?

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

More detailed information is available upon request.

Available by prescription only.

For more information about REBINYN®, please call Novo Nordisk at 1-844-REB-INYN.

Revised: 11/2017

REBINYN® is a trademark of Novo Nordisk A/S.

For Patent Information, refer to: http://novonordisk-us.com/patients/products/product-patents.html

Manufactured by:
Novo Nordisk A/S
Novo Allé, DK-2880 Bagsværd, Denmark

For information about REBINYN® contact:
Novo Nordisk Inc.
800 Scudders Mill Road
Plainsboro, NJ 08536, USA

USA17BIO03951 12/2017

novo nordisk®

World Hemophilia Day 2018

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.

Scholarships

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. The scholarships listed below each have their own requirements and deadlines. Please read each carefully when considering applying for scholarships. The listing is in order by deadline.

Name	*Amount(s)*	*Number Awarded*	2018 Deadline
Education Advantage™ Scholarship Program	$150 – $7,000		
Diplomat/Hemophilia of North Carolina Scholarship	$500 – $3,000		05/01
Lawrence Madeiros Scholarship	$1,000	1	05/01
Aptevo Therapeutics B More Scholarship Program	$2,000	1 – 20	05/03
Hemophilia Federation of America	$2,000 – $4,000	1 – 4	05/15
HF Healthcare Scholarship	$1,000		05/16
Novosecure Scholarship Program	$2,500 – $5,000	14	05/31
RMHBDA	$1,000		06/01
Kevin Child Scholarship	$1,000	1	06/15
FOSRx Scholarship Program	$1,000 – $5,000	1 – 3	06/30
Eric Delson Memorial Scholarship Program 1	$2,500	3	07/01
Eric Delson Memorial Scholarship Program 2	$1,500	1	07/01
Joshua Gomes Memorial Scholarship Fund	$1,000	1	07/15
Millie Gonzalez Memorial Scholarship	$1,500	1	08/01

RMHBDA Loves 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.

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Biotherapies for Life®

CSL Behring

For adults and children with hemophilia A

REACH HIGHER

With the Long-lasting Protection of AFSTYLA

2x WEEKLY — FDA approved for dosing 2 to 3 times a week

ZERO BLEEDS (median AsBR*) — Regardless of age and dosing schedule

ZERO INHIBITORS — In previously treated people

AFSTYLA was studied in 258 adults, adolescents, and children—the largest hemophilia A pivotal trial program to date

*AsBR=Annualized spontaneous bleeding rate.

Ask your doctor if twice-weekly dosing is right for you

Important Safety Information

AFSTYLA is used to treat and control bleeding episodes in people with hemophilia A. Used regularly (prophylaxis), AFSTYLA can reduce the number of bleeding episodes and the risk of joint damage due to bleeding. Your doctor might also give you AFSTYLA before surgical procedures.

AFSTYLA is administered by intravenous injection into the bloodstream, and can be self-administered or administered by a caregiver. Your healthcare provider or hemophilia treatment center will instruct you on how to do an infusion. Carefully follow prescriber instructions regarding dose and infusion schedule, which are based on your weight and the severity of your condition.

Do not use AFSTYLA if you know you are allergic to any of its ingredients, or to hamster proteins. Tell your healthcare provider if you previously had an allergic reaction to any product containing Factor VIII (FVIII), or have been told you have inhibitors to FVIII, as AFSTYLA might not work for you. Inform your healthcare provider of all medical conditions and problems you have, as well as all medications you are taking.

Immediately stop treatment and contact your healthcare provider if you see signs of an allergic reaction, including a rash or hives, itching, tightness of chest or throat, difficulty breathing, lightheadedness, dizziness, nausea, or a decrease in blood pressure.

Your body can make antibodies, called inhibitors, against FVIII, which could stop AFSTYLA from working properly. You might need to be tested for inhibitors from time to time. Contact your healthcare provider if bleeding does not stop after taking AFSTYLA.

In clinical trials, dizziness and allergic reactions were the most common side effects. However, these are not the only side effects possible. Tell your healthcare provider about any side effect that bothers you or does not go away.

Please see full prescribing information at AFSTYLA.com.

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.

AFSTYLA®
Antihemophilic Factor (Recombinant), Single Chain

Rocky Mountain Hemophilia
& Bleeding Disorders Association
1627 West Main Street, #142
Bozeman, Montana 59715

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