Winter 2019/2020

KHF Hemosphere

6th Annual Unite for Bleeding Disorders Walk

We were very excited to debut a new venue for our Unite Walk, E. P. "Tom" Sawyer State Park on the eastern edge of Jefferson County. This is a popular and expansive park within city limits featuring multiple sports amenities, walking and fitness trails, easy access, large parking lot, picnic shelters, and flat terrain. However, the last Saturday in October, the day of our Walk, did not greet us with dry, sunny skies and balmy temperatures. Instead, we were confronted by a cold, wet, and stormy day. We appreciated all Walkers and volunteers who joined us nonetheless and helped us celebrate our Walk Day. The atmosphere and vibe at our picnic shelter was warm and joyful. We laughed, chatted, played games, and danced to DJ Axel's catchy tunes. We munched on popcorn, donuts, sipped coffee, and hot chocolate. We awarded medals and prizes to the top teams and top individual fundraisers.

We congratulate and thank all our teams and walkers for their commendable and much appreciated fundraising efforts. Of the eighteen teams, Walk Day results were as follows: Karen Lucky and Levi Hill, Team Captains of Team LEVI from Cynthiana, Kentucky, achieved top team status for a second consecutive year raising $3,754. Team XL from Louisville with Dianne Hardman as Team Captain achieved 2nd place raising $1,685. In 3rd place was Team Jack from Louisville led by Cory Meadows with $1,426; in 4th place Team Mac's Pack from Lawrenceburg, with Alane and Mac Foley as Team Captains with $1,194; and in 5th place, Team Roblynn, headed up by Team Captain Constance Wheat with $1,100. Top individual fundraising totals were achieved by Karen Lucky, 1st place with $3,554; Dianne Hardman, 2nd place with $1,160; and Cory Meadows in 3rd place with $950. Coveted Factor Club medals for individual fundraising amounts of $250 and more were awarded to Karen Lucky and Levi Hill, Dianne Hardman, Ursela Kamala, Cory Meadows, Laura Downs, Alane and Mac Foley, Tag Poynter, Venus Marcum, and Constance Wheat.

We thank our sponsors as well. They were Gold Level: CSL Behring; Silver Level: CVS Caremark, Genentech, Novo Nordisk, Octapharma; Bronze Level: HPC, Kosair Charities, PhRMA, Sanofi Genzyme, Takeda; Kilometer Level: Biomatrix, BMR Partners-St. Matthews Specialty Pharmacy, First Choice Home Infusion, and Republic Bank & Trust Company. The Walk raised $37,000 for KHF's programs and services.

This year's Unite Walk will be on Saturday, October 10 at E. P. "Tom" Sawyer State Park. ***See you all there!***

Unite Walk2 cure bleeding disorders KHF

Special News

How Adolescents Understand Hemophilia

Laurie Kelley

For a younger child, direct physical experience is most useful in understanding the outside world. For a teen, direct experience isn't always needed. In fact, your teen may prefer to learn by mentally exploring abstract ideas. He's an abstract thinker now, a logical thinker ready to tackle complex problems.

Because a teen is eager to find answers, connect the dots, and make sense of his increasingly complex world, he may reach wrong conclusions, even about hemophilia. So along with instructing our teens about sex, drugs, and career choices, we parents must continue the job we began when our children were preschoolers: providing age-appropriate information on hemophilia. In many ways, teaching teens is fun and easy. They're ready to absorb tons of information. The trick, of course, is catching them with the earbuds and cell phones off!

Before you begin teaching your teen, you'll need to know how he understands various concepts related to hemophilia, especially compared with his earlier stages of development.

How Adolescents Understand Blood

Teens know a lot about blood and the circulatory system. They're studying some biology in school, and they've probably watched TV and movie scenes dealing with blood—of course, not always in a medical way. Far from being just a "red liquid," blood is now classified in abstract, internal terms like cells. Because your teen can competently juggle the concept of a whole and its parts, he now sees blood as one part of an entire circulatory system. As one teen put it, blood "is the circulation system of your body. It's all the cells in your body, mostly red blood cells in your blood—that's why it's red."

Your teen believes that blood's main function is to bring oxygen to the body, specifically to the cells. He may tell you that blood "supplies the body with oxygen and takes carbon dioxide to the lungs."

Your teen has moved through two previous thinking stages: preschool (ages 3–7) and school age (ages 7–11). What's the biggest mental step up from school age thinking? An adolescent can now understand the body's workings by considering the whole system and its parts—all at once. This wasn't possible in the previous two thinking stages. Your teen can now discuss the circulatory system and the veins and arteries, their distinct jobs, and how they work together. He may be able to explain a technical distinction between veins and arteries: "Blood starts in your heart, and goes through arteries and capillaries. The veins bring blood back to the heart. The blood gets more nutrients and vitamins, and gets pumped out again." The body has become a complex, interrelated, functioning collection of systems.

How Adolescents Understand Hemophilia

Like the school age child he once was, your teen will still categorize hemophilia as a "blood disorder" or "blood disease." But he usually can carry the definition one step

further, to describe it as a blood-clotting disorder caused by a "malfunctioning" of the blood. This definition is a long way from the preschooler's definition of hemophilia as "when I get a boo-boo," or the school age child's general description of "something missing" in the blood. Your teen will try to connect everything: "It's a blood-clotting disorder in which it takes longer for the blood to clot, resulting in bruises and internal injuries."

How Adolescents Understand Hemophilia

Laurie Kelley *continued*

But he may not mention clotting factors as the cause of his disorder. Don't worry. With a little probing, you can help him complete the picture. He'll learn to say, "It's when you bleed internally because you don't have factor VIII to stop it, and you need factor infusions to stop it."

How Adolescents Understand Bleeds and Blood Clotting

Although your teen knows that hemophilia is a blood-clotting disorder, the process of blood clotting may still be a mystery, despite living with it daily. When asked what happens when someone gets cut, many teens say, "You bleed," "you clot," and "your skin grows back." But can they offer explanations of things unseen—inside the body, more scientific and abstract? Yes, often with a little questioning. If your teen doesn't volunteer information, you can help him figure it out logically.

If your teen's explanations seem too simple, ask, "And then what?" "How does that happen?" "Can you explain more?" Because teens are able to think in the abstract, they're aware of unseen blood components. They may mention platelets, white blood cells, or cell regeneration. They may outline a limited step-by-step sequence of what happens internally:

"Plasma would stop it from bleeding. The cells regenerate and make it heal."

"Blood is clotting so no blood can get out and no bacteria can get in."

"The scab and skin regenerate."

"When the blood clots, it heals itself. It repairs the veins."

But how does blood clot? What's the complete, step-by-step, logical explanation? Teens may mention one or two steps, but there are three basic steps in blood clotting:

1. Vasoconstriction
2. Platelet plug
3. Fibrin net

Are teens able to understand the three steps? Yes. A teen who has been taught how blood clots, by parents or HTC staff, will probably remember it:

"Platelets gather together and make a wall, and blood can't get out. Factor VIII helps make a clot."

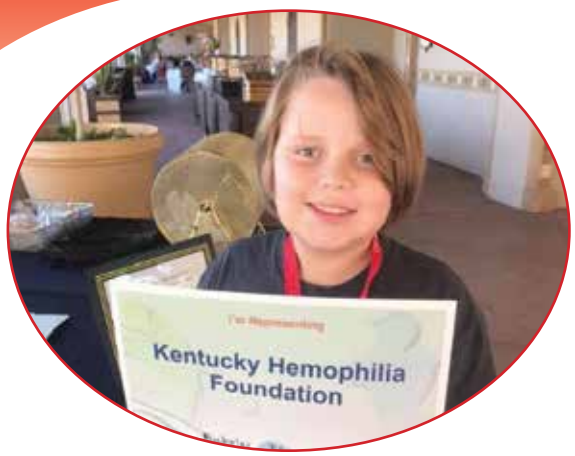
"Fibrinogen makes a net and red blood cells start sticking to it. Factor VIII deficient means the net doesn't get made."

"The genes in the blood put a protective cover over the hole, and it gets better."

Each explanation is advanced, giving a limited step-by-step account, but each misses one step. Most teens with hemophilia are eager to give a full explanation. But although they can produce a detailed description of how blood works in the circulatory system (thanks to high school science classes), they're less able to explain how blood clotting works. This process may not be taught in high school, but we should consider teaching it at home.

This is the first installment of this article. Look for subsequent Hemosphere Newsletter episodes for the next part.

Event News



Gettin' in the Game

Nicholas Thompson of Morehead, KY, was selected from a sizable number of candidates to represent the Kentucky Hemophilia Foundation in CSL Behring's Gettin' in the Game Junior Championships in Phoenix, Arizona.

Gettin' in the Game is an annual sporting event for boys and girls with bleeding disorders. Youths from across the country have a chance to be nominated by their respective chapters for participation. Each chapter may nominate two youths. KHF holds a random drawing of those boys and girls who express an interest. Nicholas chose baseball as his sports discipline and according to his mom, Veronica, had a great time honing his baseball skills under Arizona's sunny skies. Our second nominee unfortunately had to withdraw at the last moment.

Teen Impact Award

We congratulate Lilly Omerso of New Albany, Indiana, who was presented with a Teen Impact Award at the National Hemophilia Foundation's Bleeding Disorders Conference in Anaheim, California. Lilly was recognized for her excellence in volunteerism, and she participated previously in Hemophilia: The Musical.

We also congratulate Sam Charas of Lexington, Kentucky who received a Teen Impact Award for a second consecutive year for his excellence in leadership as a Boy Scout youth leader and his achievements as an avid and accomplished young outdoorsman who likes to hike and scuba dive.

Year-End Event Celebrating the Holiday Season

The Year-End Event is a family-focused community event that provides an opportunity for families to interact in a relaxed and casual setting enjoying the friendship that is fostered by this event. Food, fellowship, and fun are the cornerstones of this event. We look forward to this festive gathering all year, especially to seeing all the smiling faces of the many boys and girls who attend in hopes of catching a glimpse of the Man in the Red Suit. To their excitement, Santa Claus paid us a visit accompanied by Mrs. Claus and brought a gift for each child.

Event News

Chef John Taylor once again served up delicious hors d'oeuvres, and our annual Bake Contest provided a scrumptious array of desserts once the judging had concluded. Winners were Roger Harrell in 1st place with an Italian Cream Cake, Jennifer Dunegan in 2nd place with a Snowman Cake, and in 3rd place Isaac Webb with an Orange Zest Dark Chocolate Cheese Cake. The kids enjoyed making reindeer headbands with Connie Thacker's guidance, and the silent auction featured many sought after items that were kindly donated by our guests.

DJ Axel offered uplifting and seasonal musical entertainment culminating in "Here Comes Santa Clause" signaling Santa's and Mrs. Claus's eagerly-awaited arrival. A drawing for door prizes and gifts of appreciation for our dedicated volunteers concluded this wonderful Sunday afternoon.

Many thanks to our exhibitors and sponsors who joined us and supported our event. They were Accredo, Biomatrix, BMR Partners-St. Matthews Specialty Pharmacy, CSL Behring, CVS Caremark, Genentech, Grifols, HPC, Novo Nordisk, Octapharma, Pfizer, and Takeda.

Door Prizes

Raising Awareness at 21st Amendment Tavern

Many thanks to Eddie Schmidt of SOS Talent Promotions for recently organizing a benefit comedy show at 21st Amendment Tavern in Louisville. The show featured a number of talented stand-up comics from the area, who generously donated their time and talents to KHF as well as raised awareness for men, women, and children affected by inheritable bleeding disorders. The show was great fun, and we appreciated the performers' generosity and interest in our cause.

More News

2020 Calendar of Events

Easter Lily and Spring Flowers Fundraiser
March/April 2020

Family Day at the Louisville Zoo
Information, Picnic, Games for Kids & Walk Call to Action
Saturday, May 16, 2020
The Louisville Zoo
Louisville, KY

Play A Round for a Cure Golf Scramble Fundraiser
Monday, June 8, 2020
Glen Oaks Country Club
Prospect, KY

Post-Secondary Education Scholarship
Submission Deadline for Fall 2020 Semester
July 15, 2020
Call or email KHF office for application and guidelines

Camp Discovery
Summer Camp for Kentucky Children and Youths with Bleeding Disorders
Sunday, July 26 - Thursday, July 30, 2020
Cedar Ridge Camp
Louisville, KY

Summer Family Event
Annual Education Meeting, Post-Meeting Social Activity, & Walk Kick-Off Lunch
Saturday, September 12, 2020
Hyatt Regency
Louisville, KY

Kentucky Unite for Bleeding Disorders Walk
Saturday, October 10, 2020
E. P. “Tom” Sawyer State Park
Louisville, KY

Poinsettia Fundraiser
November/December 2020

Year-End Family Event
Sunday, November 29, 2020
Holy Trinity Clifton Campus
Louisville, KY

Note: Additional activities or events may be scheduled throughout the year. Therefore, it is important that you ask to be added to our email and mailing lists and communicate any changes in your contact information to us.

More News

2019 – 2020 Kentucky Hemophilia Foundation Membership

We thank all of the members of the Kentucky Hemophilia Foundation for their support of the current program year.

Individual/Family Memberships, 20+
Sara Ceresa
Curtis & Winnie Jacobs
James M. Meade
David & Terry Moore

Supporting Memberships, $35+
Barry Lynn Hatfield
Judy Hayes
in memory of Jason Hayes
Donald L. Mattingly
Sadalia Sturgill

Patron Memberships, $50+
Danny & Maritza Adams
John & Carol Nord
Stacey & Troy Powell

Sustaining Memberships, $100+
Barbara W. Grayson
D. Spalding Grayson
Glen E., Sr. & Deborah Hitt
Dr. David & Leslie Houvenagle
Vivian Marcum
Keith Peterson

Benefactor Memberships, $250+
Charles & Ruth Hall

Champion/Corporate Members, $500
Rosemary Johnson-Dean
for her father, Robert B. Johnson
LTC (R) John & Pat Tharp

In Memory

September 1, 2019 – January 31, 2020

Gone from our sight but never our memories; gone from our touch but never our hearts…

Cathi Bonkowski
Buell & Judy Snyder

Neda "Vonnie" Buckman
Mary & John Clark
Ken, Cathy, Craig & Aimee Johnson
Sandra McWilliams
Lana & Dorland Moore
The Entire Sharp Family
Larry & Cathy Weishaar
William & Joann Williamson

Alan Taylor Hall
Charles & Ruth Hall
Terry & Liz Watts

William Walter Hall, Sr.
Terry & Liz Watts

Kevin McLaughlin
Gail Yates
for Herb Schlaughenhoupt, Jr.
Memorial Scholarship Fund

Anita Hardesty Meadors
Mark & Mary Ann Beck
John & Kelly Cason
Commonwealth Bank & Trust
Mortgage Department
Kelli Ann Corney
John & Debra Ray Gunning

Marv & Mary Lou Habicht
Janet & Lloyd Markland
Shana Meredith
Pattie & Ed Moore
Rick & Kim Rasche
Deanna & James Ray
Christina M. Smith
Ken & Lorraine Smith

Preston "Tom" Moberly
Sheila & Brian Burns
First Christian Church, Elizabethtown
Teachers and Staff of T. K. Stone Middle School

Do The Five

Follow these steps to prevent or reduce complications of bleeding disorders

1. Get an annual comprehensive checkup at a hemophilia treatment center.
2. Get vaccinated – Hepatitis A and B are preventable.
3. Treat bleeds early and adequately.
4. Exercise to protect your joints.
5. Get tested regularly for blood-borne infections.

To find out more about the National Prevention Program developed by the National Hemophilia Foundation in collaboration with the Centers for Disease Control and Prevention (CDC), click on www.hemophilia.org or call toll-free 800-42-HANDI.

KHF does not give medical advice or engage in the practice of medicine. KHF under no circumstances recommends particular treatments for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.

KOSAIR CHARITIES

WHAS CRUSADE FOR CHILDREN

We are celebrating 60 Years of Service!

Please remember KHF when doing your estate planning! This will help us continue our service to Kentuckiana's Bleeding Disorders Community.

KENTUCKY HEMOPHILIA FOUNDATION
1850 Taylor Avenue #2
Louisville, KY 40213-1594

Non Profit Org.
U.S. Postage
PAID
Louisville, KY
Permit No. 883

Hemdifferently

Exploring the science behind gene therapy research

Gene therapy research has the potential to bring an entirely new option to people with specific genetic conditions. Many gene therapies are in clinical trials to evaluate the possible risks and benefits for a range of conditions, including hemophilia. HemDifferently is here with gene therapy education, providing accurate information in a way you can understand.

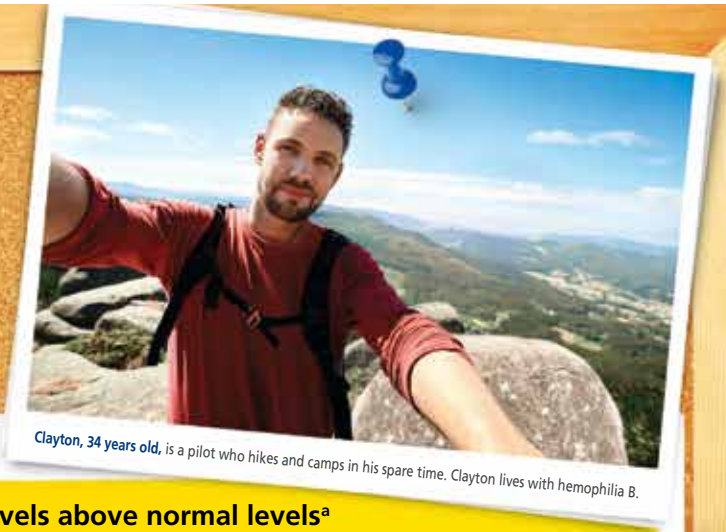
Let's explore gene therapy together at **HemDifferently.com**

No gene therapies for hemophilia have been approved for use or determined to be safe or effective.

BIOMARIN®

In hemophilia B

TAKE CONTROL TO A HIGH LEVEL WITH REBINYN®



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®

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. HEMLIBRA may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

Please see Brief Summary of Medication Guide on following page for Important Safety Information, including **Serious Side Effects**.

HEMLIBRA®
emicizumab-kxwh
injection for subcutaneous use | 150 mg/mL

Medication Guide
HEMLIBRA® (hem-lee-bruh) (emicizumab-kxwh) injection, for subcutaneous use

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
  - confusion
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - stomach (abdomen) or back pain
  - nausea or vomiting
  - feeling sick
  - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - swelling in arms or legs
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - trouble seeing

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

See "**What are the possible side effects of HEMLIBRA?**" for more information about side effects.

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I use HEMLIBRA?

See the detailed "Instructions for Use" that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.
- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. **Do not** give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

What are the possible side effects of HEMLIBRA?

- See "**What is the most important information I should know about HEMLIBRA?**"

The most common side effects of HEMLIBRA include:

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 86°F (30°C).
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

Keep HEMLIBRA and all medicines out of the reach of children.

General information about the safe and effective use of HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048

For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised: 10/2018

Genentech
A Member of the Roche Group

DEDICATION and PERSONAL SUPPORT

Your Pfizer Patient Affairs Liaison is a professional dedicated to serving you and the hemophilia community by connecting patients and caregivers with Pfizer Hemophilia tools and resources. We are committed to continuing Pfizer's more than 20 years of listening to the hemophilia community and working to meet its needs.

Chris Liddell

Southern OH, MI, KY, IN

"I've worked in rare disease for 15 years, and I have experience collaborating with and advocating for different members of this community."

PATIENT AFFAIRS LIAISONS

Pfizer Hemophilia

248-660-7384 chris.liddell@pfizer.com

MY WORK IS GUIDED BY:

Compassion

Listening to your needs and addressing questions and concerns that you may have

Commitment

Educating you about Pfizer's tools and resources, including the Pfizer Community Connections Program, the HemMobile® app for logging bleeds and infusions, B2B materials, and more

Connection

Connecting you with hemophilia advocacy groups and programs like Leading Edge, the National Hemophilia Foundation, the Coalition for Hemophilia B, and others

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Pfizer

Dana Clemmans

Patient supporter

About Dana

Dana is a Hemophilia Community Liaison who is driven by her passion to help patients. Her greatest contribution comes from letting those in the Greater Midwest area know she is there for them as a resource when they need it.

Connect with Dana

DLRC@novonordisk.com
(630) 291-3714

Hemophilia Community Liaison

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novo nordisk®

KHF Event Calendar

Celebrating 60 Years of Service in 2020

Easter Lily and Spring Flowers Fundraiser
March/April 2020

Family Day at the Louisville Zoo
Information, Picnic, Games for Kids & Walk Call to Action
Saturday, May 16, 2020
The Louisville Zoo
Louisville, KY

Play A Round for a Cure Golf Scramble Fundraiser
Monday, June 8, 2020
Glen Oaks Country Club
Prospect, KY

Post-Secondary Education Scholarship
Submission Deadline for Fall 2020 Semester
July 15, 2020
Call or email KHF office for application and guidelines

Camp Discovery
Summer Camp for Kentucky Children and Youths with Bleeding Disorders
Sunday, July 26 - Thursday, July 30, 2020
Cedar Ridge Camp
Louisville, KY

Summer Family Event
Annual Education Meeting, Post-Meeting Social Activity, & Walk Kick-Off Lunch
Saturday, September 12, 2020
Hyatt Regency
Louisville, KY

Kentucky Unite for Bleeding Disorders Walk
Saturday, October 10, 2020
E. P. “Tom” Sawyer State Park
Louisville, KY