

Vital Link



...For Hoosiers Living with a Bleeding Disorder

September 2021

The Vital Link is published quarterly by Hemophilia of Indiana, Inc.

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2021 Hemophilia of Indiana Annual Meeting

On August 14th and 15th, members of the bleeding disorders community of Indiana and their families joined together for the 2021 Hemophilia of Indiana Annual Meeting! The Annual Meeting is Hemophilia of Indiana's largest community event and provides a weekend of education and support for Indiana's bleeding disorders community. The 2020 Annual Meeting was held on a virtual format, making it even more special for a live event in 2021. Even while wearing masks, there was lots of education and community involvement. The weekend started off on Saturday morning with a two-part key note general session presented by Dr. Anne Greist, Jennifer Maahs, and Shannon Tracey from the Indiana Hemophilia & Thrombosis Center followed by an afternoon of multiple education break out sessions. Saturday evening included an awards banquet to celebrate the 2021 Judy Moore Memorial Scholarship Winners. Sunday morning participants were treated to a fun educational and interactive key note presentation presented by Bob Loudon and Brenda McLean also from the Indiana Hemophilia & Thrombosis Center followed by breakout sessions for the Mom's in Action, Blood Brotherhood, and Latino community support groups. Planning is already underway for the 2022 Annual Meeting! Hemophilia of Indiana would like to say a special thank you to all of our sponsors for their support and dedication to the bleeding disorders community of Indiana!

Thank you to the Hemophilia of Indiana's
2021 Annual Meeting Title Sponsors!!

Genentech
A Member of the Roche Group



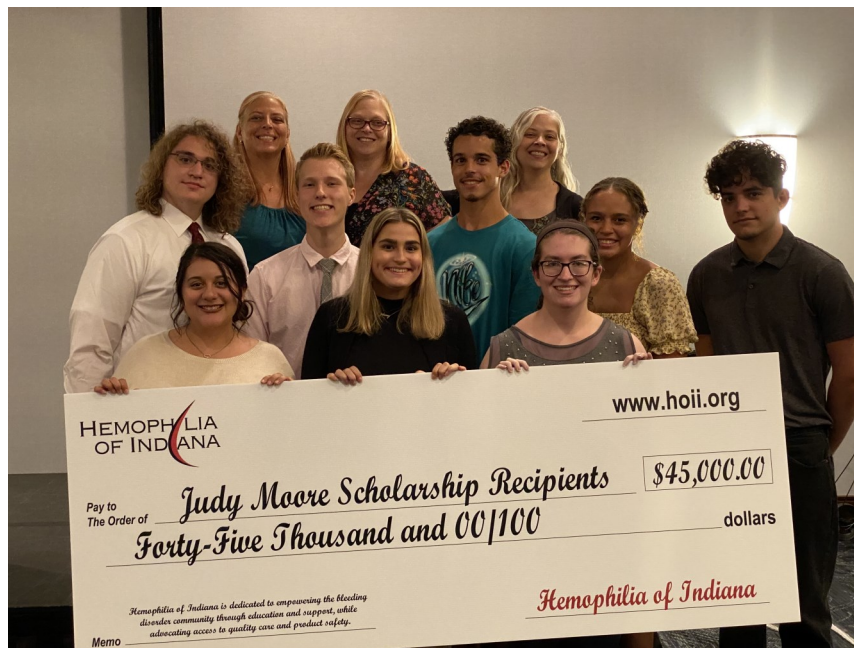
SANOFI GENZYME



CSL Behring
Biotherapies for Life™

Thank you !!!

Congratulations to all of our 2021 Judy Moore Scholarship Recipients!! **not all winners pictured



2021 Annual Meeting Teen Program

On Saturday, August 14th Hemophilia of Indiana participated in a GutMonkey Leading Edge program. Teens from the community participated in the four-hour workshop which focused on connection, resilience and fun.

GutMonkey has been delivering the Pfizer sponsored Leading Edge teen programs to the bleeding disorder community for 15 consecutive years and has delivered 245 programs with over 25,000 participants from all 50 states.

The teens and their Gut Monkey Leader, Tom, spent the morning at a local park they were able to experience an interactive experiential program where they played games, participated in a scavenger hunt, and shared in cooperative drawing among other unique experiences. Participants leaving the program have reported feelings of greater connectivity to their peers and Hemophilia of Indiana.





Indiana
Hemophilia
& Thrombosis
Center

Your medical home for hemophilia care

From our compassionate staff, robust resources, and commitment to tailored treatment, you and your family will find comfort in IHTC's leading approach to a lifetime of quality hemophilia care.

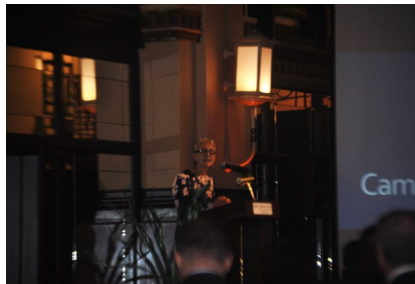
Indiana's only Center of Excellence for bleeding and clotting disorders

The Indiana Hemophilia & Thrombosis Center (IHTC) is the state's only federally-designated Hemophilia Treatment Center and the first HTC in the U.S. to receive national medical home certification. We offer comprehensive bleeding disorder care, all at one center. All members of IHTC's clinical care team have extensive experience and deep expertise in bleeding disorders. This offers our patients the comfort and convenience of having every aspect of their bleeding disorder care all in one location. Visit ihtc.org

2021 Hearts For Hemophilia “A Midsummer Nights Dream” Gala

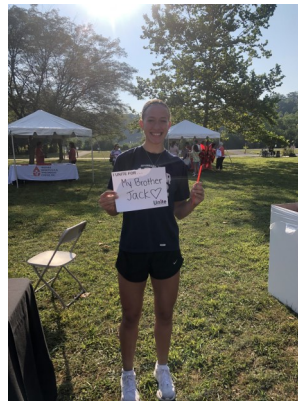
The 2021 Hearts for Hemophilia “A Midsummer Nights Dream” Gala was held on Friday, July 30th at the beautiful Grand Hall at Union Station. Normally held at the end of January, this year’s Gala had to be moved to July as a result of pandemic. The Gala included a raffle, silent auction, live auction, and fund a need. This year’s keynote speaker was Dr. Anne Greist from the Indiana Hemophilia and Thrombosis Center and gave an incredible presentation about the current state of bleeding disorders and the pandemic while supporting the programs and services provided by Hemophilia of Indiana to the bleeding disorders community. Following the conclusion of the program, guests danced the night away to the music of Greta Speaks and had fun “gambling” in the onsite casino! Hemophilia of Indiana would like to thank all of our incredible sponsors, donors, supporters, and volunteers that made the 2021 Hearts for Hemophilia Gala a huge success! The 2022 Hearts for Hemophilia Gala has been moved back to its normal time of the year and will be held on Friday, January 28th! More information can be found on our website (www.hoii.org) and check out all of the pictures from this year’s event!!





2021 Unite for Bleeding Disorders Walk

The 2021 Unite for Bleeding Disorders Walk was held on Saturday, August 21st at Fort Harrison State Park. Over 80 members of the bleeding disorders community united together to celebrate the bleeding disorders community of Indiana and fundraise for Hemophilia of Indiana! The Top Team Captain award went to Carolyn Salazar with Emiliano's Advocates! Emiliano's Advocates are on a hot streak as being the Top Fundraising Team for two years in a row! Bill Davis, also a team member of Emiliano's Advocates was this year's Top Individual Fundraiser! Congratulations to all the incredible Team Captains and their team members for all of your hard work and effort in supporting Hemophilia of Indiana and the Bleeding Disorders Community of Indiana!!!



Community Member Corner

Welcome to Community Member Corner! This new feature is from the community members perspective! Have you been interested in attending the Annual Meeting but haven't been able to attend? Here is your opportunity to hear about it from community member and Judy Moore Memorial Scholarship Recipient Hery Acosta Acosta's perspective:

When I was younger, at the annual meeting I would go to eat food and then join in to do all the activities that the kids were supposed to do. Those included the zoo, escape rooms and fun little activities. Me and my friends would always have the time of our lives and enjoy every second of it.

Things change though as an adult, you no longer get to go to those activities, but you do get some freedom into what you want to attend and learn about. I have always loved the annual meeting, a nice weekend where you get to spend time with some of your favorite people and catch up with them. It is also a great time to learn more about your bleeding disorder and how to deal with it.

The HOII staff do a wonderful job each year of putting this event together and getting all the sponsors to go. They also award the Judy Moore scholarship every year to deserving individuals with bleeding disorders.

The Annual Meeting has many differences from child to adult, but there is never a dull moment and there are many opportunities for all.

JIVI®
ADYNOVATE®


antihemophilic factor
(recombinant) PEGylated-augl
LET'S GO

PK (Pharmacokinetics) Study Data



Talk to your doctor
about the study.



Scan the QR code to learn more
about PK at [UnderstandingPK.com](https://www.understandingpk.com)

PK; Pharmacokinetics

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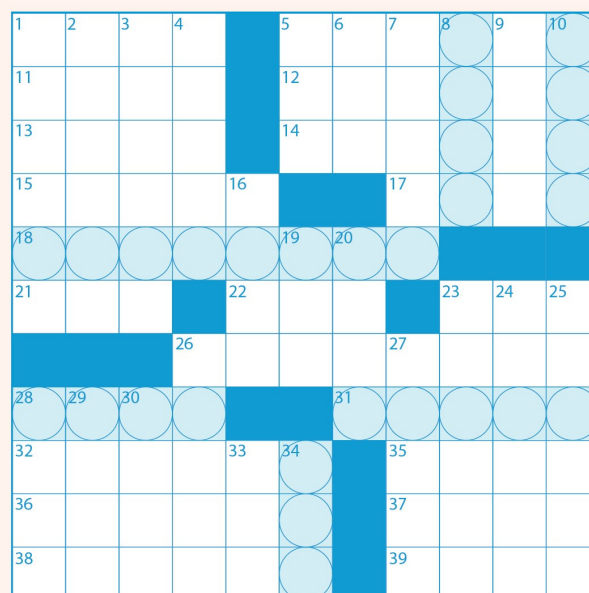


CAN YOU SOLVE

FOR A DIFFERENT HEMOPHILIA A

TREATMENT?

Test your HEMLIBRA knowledge



ACROSS

1. Wine barrel
5. Deep fissures
11. Mideast gulf port
12. District
13. Ripped
14. Familiar with
15. Mean
17. Roost
18. The #1 prescribed prophylaxis for hemophilia A*

*According to IQVIA claims data from various insurance plan types from October 2019 to November 2020 and accounts for usage in prophylaxis settings in the US.

21. Calendar divs.
22. Regret
23. Banquet hosts (abbr.)
26. International travel necessity
28. Check out the _____ treated bleeds data with HEMLIBRA
31. Number of dosing options HEMLIBRA offers

* Number of people with hemophilia A treated as of February 2021.

32. Small hole in lace cloth
35. Central Plains tribe
36. Melodic
37. Towering
38. Reduce
39. Spanish cheers

DOWN

1. Memorable, as an earworm
2. Devotee
3. Medical fluids
4. Prepare to propose, perhaps
5. PC's "brain"
6. Owns
7. Concert venue
8. See Medication Guide or talk to your doctor about potential _____ effects
9. Winter hrs. in Denver and El Paso
10. HEMLIBRA is the only prophylactic treatment offered this way under the skin

16. Pre-Euro currency in Italy
19. Subway alternative
20. Relax
23. Human
24. New Orleans cuisine
25. Mentally prepares
26. Collared shirts
27. Instagram post
28. Ardent enthusiasm
29. Brontë heroine Jane
30. Old Portuguese coins
33. Opposite of WNW
34. _____ thousand patients have been treated with HEMLIBRA worldwide†

SOLUTIONS

Across: 1. cask, 5. chasms, 11. Aden, 12. parish, 13. tone, 14. used to, 15. cruel, 17. nest, 18. HEMLIBRA, 21. yrs, 22. rue, 23. MCS, 26. passport, 28. zero, 31. three, 32. eyelid, 35. Oreo, 36. arose, 37. tall, 38. lessen, 39. cles, 40. Reiss, 33. ESE, 34. ten

Down: 1. catchy, 2. adore, 3. serums, 4. kneel, 5. CPU, 6. has, 7. arena, 8. side, 9. MSTs, 10. shot, 11. lira, 19. bus, 20. rest, 23. mortal, 24. Creole, 25. steels, 26. polos, 27. photo, 28. zeal, 29. Eyre, 30. Reiss, 33. ESE, 34. ten

Discover more at HEMLIBRA.com/answers

INDICATION & IMPORTANT SAFETY INFORMATION

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. People who use activated prothrombin complex concentrate (aPCC; Feiba®) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots.

These serious side effects include:

- **Thrombotic microangiopathy (TMA)**, a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs
- **Blood clots (thrombotic events)**, which may form in blood vessels in your arm, leg, lung, or head

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



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

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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



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3 Simple Ways to Be Savvier and Safer Online

Seniors can use these tips to enjoy the internet safely.

Author: Stephanie Conner

Adults & Aging

Technology can be overwhelming. After all, you didn't grow up with computers, and now they're everywhere. Whether you want to see your children's Facebook updates, have video chats with your grandkids or send emails to friends, you'll need some tech savvy.

1. Start simply.

Get a simple device with an internet connection, says Michael Miller, author of *My iPad for Seniors* and *My Video Chat for Seniors*. A computer can be hard to figure out, he says, and a phone's small screen can be challenging to read. He recommends a tablet, such as an iPad.

Then, focus on learning a few simple applications that help you accomplish your goals. This may include emailing, video chatting, streaming TV or movies, and checking social media.

2. Be very cautious online.

Older adults are common targets of scams, unfortunately, "because they are more trusting in general," says Scott Schober, author of *Senior Cyber: Best Security Practices for Your Golden Years*. They also tend to have financial savings that online scammers are after.

One popular tactic is phishing. A phishing email looks like a real email from a legitimate source, such as your bank. Scammers want you to click links or provide personal information so they can access your financial or other accounts. If you are not sure about the source of a request, do not respond—and you can always ask someone you know to help you check something out.

3. Build your tech skills.

Turn to trusted sources to learn more about technology, such as classes on how to use specific applications (Zoom or Facebook, for example) or how to set up a tablet or computer. Classes directed to seniors move at a pace for people who did not grow up with technology all around them. Of course, tech-savvy family members and trusted friends can be helpful as well.

By starting with easy technology, taking steps to be safe online and building on your tech knowledge, you can enjoy the benefits of a more connected world.



WE'RE IN THIS TOGETHER.

Friday 6:26 pm

Sharing stories by the campfire with friends

Isaac, living with hemophilia B

Not an actual patient

Let's make today brilliant.

Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world is stronger than ever.

 bleedingdisorders.com | 

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Upcoming Educational Dinners:

Contact Angel DiRuzza at adiruzza@hoii.org to register.
Check out our Facebook (@HEMOINDY) page and website
calendar for more details on upcoming in person
educational dinners!

Topic: Common Factors with Perry Parker

Sponsored by CSL Behring

When: Sunday, October 17th

Where: Top Golf

9200 E 116th St

Fishers, IN 46037

Topic: Emerging Skills

Sponsored by Sanofi Genzyme

When: Tuesday, November 2nd

Where: Restaurant TBD - Fort Wayne, IN

Topic: Navigating Your Insurance

Sponsored by Novo Nordisk

When: Thursday, November 4th

Where: Parisi's Ristorante Italiano

1412 S Bend Ave

South Bend, IN 46617

Topic: Your Time To Thrive

Sponsored by Sanofi Genzyme

When: Tuesday, November 16th

Where: Restaurant TBD - Indianapolis, IN

A **ONCE-WEEKLY** TREATMENT OPTION FOR HEMOPHILIA B.



HOW DOES
THIS FACTOR IN?

To find out about a prescription
option, talk to your doctor or visit
[OnceWeeklyForHemophiliaB.com](https://www.OnceWeeklyForHemophiliaB.com)

TAKE CONTROL TO A HIGH LEVEL

WITH REBINYN®
IN HEMOPHILIA B

Rebiny® elevates factor levels above your normal levels^a

+94% Factor IX (FIX) levels achieved after an infusion^b

83-hr average half-life (3.5 day) in adults^a

With a single dose of Rebiny® 40 IU/kg in adults with ≤2% FIX levels^a



Clayton, 34 years old, is a pilot and enjoys hiking and camping in his spare time. Clayton lives with hemophilia B.

Achieve higher factor levels for longer

Compared with Alprolix®, Rebiny® provides

4x

greater factor coverage

6x

higher factor levels at 7 days

Image of hemophilia patient shown is for illustrative purposes only.

^aIn a phase 3 study of adults, single dose pharmacokinetics were tested during the first Rebiny® 40 IU/kg dose in 6 adults.

^bBased upon a 2.34% increase in factor levels per IU/kg infused in adults.

^cBased upon a phase 1 study comparing a single 50 IU/kg dose of Rebiny® to a single 50 IU/kg dose of extended half-life rFIXFc in 15 adults. To allow for direct comparison between products, all patients received the Alprolix standard 50 IU/kg dose.

INDICATIONS AND USAGE

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

Rebiny® is an injectable medicine used to replace clotting Factor IX that is missing in patients with hemophilia B. Rebiny® is used to treat and control bleeding in people with hemophilia B. Your healthcare provider may give you Rebiny® when you have surgery. Rebiny® 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 Rebiny®?

- 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 Rebiny®.

Who should not use Rebiny®?

Do not use Rebiny® if you:

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

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

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 Rebiny®?

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

What are the possible side effects of Rebiny®?

- 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 Rebiny® 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.

Rebiny® 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 rebiny.com and connect with your local HCL



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

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rebiny®

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.

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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:

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For information about REBINYN® contact:

Novo Nordisk Inc.

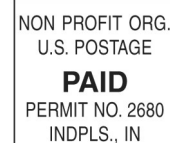
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*The material provided in Vital Link is only for general information purposes. HoII does not give medical advice or engage in the practice of medicine. HoII recommends in all cases that you consult your physician or HTC before pursuing any course of treatment.

Mark your Calendars!

- FitLivin THXRUN Day Run - November 25th
- Year End Educational Event - December 11th
- 2022 Hearts for Hemophilia Gala - January 28th

Call our office @ (317) 570-0039 or email Kristy McConnell @ kmccconnell@hoii.org if you would like to get involved in any of our events!

- Check out our social media pages for updates!!!

