IDAHO CHAPTER
NATIONAL HEMOPHILIA FOUNDATION

NEWSLETTER

VISION STATEMENT

The Idaho Chapter of NHF envisions a united community that will make a positive difference in the lives of individuals affected by a bleeding disorder.

Education: within and outside the bleeding disorders community.

Advocation: at local, state, and national levels.

Inclusion: of family, friends, and all those impacted by the disorders.

Development: of a legacy for a future of hope.

INSIDE

FROM THE DIRECTOR

We had a great start to 2021 with education, advocacy efforts, and community connections. So far our events have been virtual, but we are hopeful to have events in person later this year. Please keep a look out for our emails (idaho@hemophilia.org), social media posts, and website for the most up-to-date information about our events!

As you prepare for your year, I invite you to save the dates/sign-up for the following large-scale programs:

- **Camp Red Sunrise**–Virtual: June 18-19 ***or*** In-Person: June 26-28. Our annual Family Camp will be in two sessions, one will be virtual and one will be in-person. As a family you can choose to attend one of the other (limited attendance allowed for in-person)
- **Family Education Weekend**–August 6-7
  Our annual conference/meeting is planned to be in-person at the Galaxy Event Center in Meridian, Idaho.
- **VWD Education and Appreciation Month**–September
  Our 2nd annual educational series focused on vonWillebrand disease is planned to be virtual and split up into 4 sessions.
- **Unite for Bleeding Disorders Walk**–October 2
  Our annual walk fundraiser will be in-person at a park in the Boise area. We invite you to create your team now!
- **Holiday Party**–December 11
  Our annual holiday party will be in-person at a venue in the Boise area.

As we plan for these events in person, we will have precautions in place to account for the concern of COVID-19. We will be communicating these restrictions and attendance expectations ahead of time for you to make the best decision for you and your family.

If you have any questions, concerns, thoughts, or just want to say hi do not hesitate to reach out to me. Talk with you soon.

Michael Krieger
Cell; 208-490-2596
Email: mkrieger@hemophilia.org

OUR CHAPTER

NHF Idaho is fortunate to be guided by an enthusiastic, talented, and hard working group of people.

Board of Directors

Walter Justus, *Acting President*
Joe Rex
Michelle Weickum

Office Staff

Executive Director
Michael Krieger
Cell; 208-490-2596
mkrieger@hemophilia.org

Development Manager
Marlyn Walker
Cell; 208-631-9729
mwalker@hemophilia.org

Address

4696 W. Overland Road
Suite 234
Boise, Idaho 83705
208-344-4476
idahoblood.org

Board Help Wanted

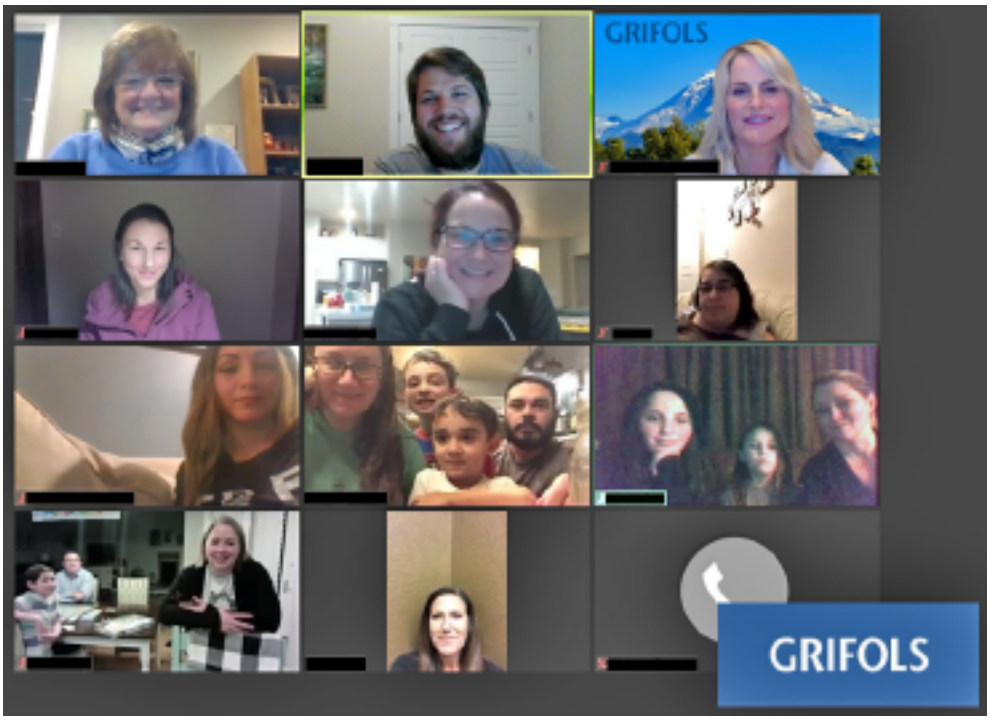
The NHF Idaho Chapter is looking for additional members to serve on our Board of Directors. If you, or someone you know, might like to serve our bleeding disorders community by being on our board, please let us know. To add balance to the board we would be especially interested in talking to folks outside of the bleeding disorders community.

To learn more about this opportunity to serve, please call the Chapter office.

208-344-4476

Plasma Safety

Our January educational session was on Plasma Safety, hosted by Grifols. Nurse Educator, Virginia Kraus, led a great conversation and answered many questions from the community. This topic was very much appreciated and informative. It was a great way to start the year of our educational programs.



Women's Retreat

NHF Idaho's Victory for Women Retreat went virtual in 2021 with the Mad Hatter's Tea Party. We did not let going virtual stop Idaho's wonderful women from getting together for education and a few laughs. With over 20 ladies signed up for our two-day event, March 12 and 19, we had a beautiful presentation by Novo Nordisk on hemophilia. We had a great conversation and learned the basics in a new way. We followed that session up with an excellent presentation given by our very own Stephanie Shea on Essential Oils. We made bracelets, mixed our very own oil roller, and had a great time learning with new and old friends.

Takeda started off night two with a presentation on Mindfulness. We learned so much, but we still had one hour left to go of our great retreat. James Wallace taught us about herbal teas and how they can benefit women with a bleeding disorder and our families. He had terrific handouts that, if anyone would like, we could share with you.

Thank you to our great sponsors, Novo Nordisk and Takeda, for their outstanding support of this event. We also want to thank Stephanie and James for sharing their passions with us to grow and learn. Most of all, we want to thank each of you ladies that took your time to join us for this event.

See you next year at our Victory for Women Retreat.

HEMOPHILIA CAN BE DIFFICULT.

TRACKING IT SHOULDN'T BE.

HemMobile® App

TRACK BLEEDS

Photograph, map, and log each bleed

TRACK INFUSIONS

Record the date, time, and location of every infusion

SHARE REPORTS

Create consolidated reports to share with your treatment team

Download on the App Store® or on Google Play™

Pfizer will not have access to any personal information you enter into HemMobile®.

HemMobile® is not intended for curing, treating, seeking treatment for, managing, or diagnosing a specific disease, disorder, or any specific health condition.

HemMobile® is a registered trademark of Pfizer Inc.

App Store is a trademark of Apple Inc., registered in the U.S. and other countries. Google Play is a trademark of Google LLC.

Pfizer Hemophilia

Advocacy Education Series

During the months of February and March, we held a 5-part Advocacy Education Series. During our session we were able to learn more about the state legislature; gained tools to develop, refine, and tell our stories; practice our story telling, and learn more about each other. These topics prepared us for Washington Days and was a great kick start for planning our local advocacy efforts. Thank you to Takeda for supporting this advocacy series and also hosting one of the sessions.

WASHINGTON DAYS MARCH 1-5

This year, our Washington Days experience was a little bit different, but still a great success. Instead of packing our bags, traveling across the country, and spending a few days in Washington DC, we had a series of virtual trainings and video conference calls with the elected officials. Since it was virtual, we were able to take more families. We were well represented by four families, each with their own powerful story and experience; Shea, Walker, Justus, and Krieger. As Kyla Krieger, first-time attendee reflected, "I really enjoyed being a part of Washington Days this year. The representatives really listened to what we had to say, were very interactive, and seemed interested. I was not expecting them to be so attentive. I really enjoyed being an advocate for our community and I look forward to continuing throughout the year."

Overall, the Washington Days program had 388 community members, representing 46 states, participating in over 250 visits. Thank you to the families that participated this year and thank you to the offices of Russ Fulcher, Mike Simpson, Mike Crapo, and Jim Risch for listening to our stories and supporting the community.


BAYER
Explore
HEAD-TO-HEAD
Pharmacokinetic (PK)
Study Data
See half-life, clearance and other PK data from the crossover study comparing Jivi® and Eloctate®.
Visit PKStudies.com to find out more.
Pharmacokinetics is the study of the activity of drugs in the body over a period of time.
Jivi
antihemophilic factor
(recombinant) PEGylated-aucl
LET'S GO

At Pfizer Hemophilia, we have always been deeply committed to you and to listening to what you have to say. Over the years, what you've shared with us has proven invaluable. The events we sponsor, the technology we develop, and the educational materials we create are all designed in response to the requests, needs, and desires of the hemophilia community.

We are grateful for having the chance to partner with you.

—Your Pfizer Hemophilia Team

Covid-19 Webinar

We collaborated with the West Virginia and Central Ohio chapters to bring a virtual COVID-19 webinar to our community. We were lucky to have the Medical Director from the West Virginia University Hemophilia Treatment Center, Dr. Samuel Merrill provide the latest information about the vaccines. In addition, we had Krista Capehart, Director of Professional and Regulatory Affairs for the West Virginia Board of Pharmacy discuss the implementation and distribution plan for the vaccine. Many questions asked by the audience were answered during the call! If you missed the session and interested in watching the session, go to: www.idahoblood.org/COVID19 to see the recording.

Constructive Conversations

Our March Educational Dinner was hosted by Pfizer. We had a great group of caregivers on the call learn more about Constructive Conversations. During the session, we were able to learn the dos and don'ts as a parent bringing up hard conversations with their child. The examples were related to bleeds and activities, but transferable into other experiences. We appreciated learning the 6 steps for applying motivational interviewing in our conversations.

Men's Group

Our first Men's Group of the year was a success!! Thank you to Octapharma for sponsoring our event full of education and fun. Our virtual call had community members from across the state, plus a few from neighboring states. During our time together we successfully navigated through a virtual Escape Room. We have planned a Men's Group event every quarter this year! Check out our calendar to join our next event!

YOUR HTC

The Idaho **Hemophilia Treatment Center** (HTC) is part of the St. Luke's Health System, located in Boise. A dedicated staff of skilled caregivers provide treatment and extensive support including: annual checkups, counseling, disease specialists, lab tests, and education for patients with hemophilia, von Willebrand disease, and other blood disorders.

Staff

Hematologists/Oncologists
Nicolas Camilo, MD
Eugenia Chang, MD
Matthew Hansen, MD
Nathan Meeker, MD

Infectious Disease
Sky Blue, MD,

Nurse Practitioner
Stephanie Ciesla, FNP

Social Worker
Diane Bartlett, LCSW

Physical Therapist
Kay Craig, DPT

Education/Career Counselor
Colin Car, MSEd

Dietician
Valerie Robenstein, RD

Genetic Counselor
Christina Ikard, MS, CGC

Address

100 E. Idaho St.
Boise, ID 83712

For information and appointments
208.381.2782
or Toll Free
1-800-845-4624

TAKE CONTROL TO A HIGH LEVEL

WITH REBINYN®
IN HEMOPHILIA B

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

Rebinyn® elevates factor levels above your normal levels[a]

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

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

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

Achieve higher factor levels for longer

Compared with Alprolix®[c], Rebinyn® provides

4x greater factor coverage

6x higher factor levels at 7 days

Image of hemophilia patient shown is for illustrative purposes only.

[a]In a phase 3 study of adults, single dose pharmacokinetics were tested during the first Rebinyn® 40 IU/kg dose in 6 adults.

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

[c]Based upon a phase 1 study comparing a single 50 IU/kg dose of Rebinyn® 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 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 and connect with your local HCL

novo nordisk®

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

 Printed in the U.S.A. US19REB00028 July 2019

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

USA17BI003951 12/2017

novo nordisk®

LLEVE EL CONTROL A UN NIVEL ALTO

CON REBINYN®
EN LA HEMOFILIA B

Clayton, de 34 años, es un piloto que disfruta el excursionismo y acampar en su tiempo libre. Clayton tiene hemofilia B.

Rebinyn® eleva los niveles de factor sobre sus niveles normales[a]

+94% Niveles del factor IX (FIX) alcanzados después de una infusión[b]

83-hrs (3,5 días) semivida promedio en adultos[a]

Con una dosis única de Rebinyn® de 40 IU/kg en adultos con niveles de FIX de ≤2%[a]

Logre niveles superiores de factor por más tiempo

Comparado con Alprolix®[c], Rebinyn® proporciona

4x más cobertura del factor

6x niveles de factor más altos en 7 días

La imagen del paciente con hemofilia se utiliza solamente con fines ilustrativos.

[a]En un estudio de fase 3 de adultos, la farmacocinética de la dosis única se evaluó durante la primera dosis de Rebinyn® de 40 IU/kg en 6 adultos.

[b]Basado en un aumento del 2,34 % en los niveles de factor por IU/kg infundidos en adultos.

[c]Basado en un estudio de fase 1 en el que se comparó una dosis única de Rebinyn® de 50 IU/kg con una dosis de 50 IU/kg de rFIXFc de semivida extendida en 15 adultos. Para realizar la comparación directa entre los productos, todos los pacientes recibieron la dosis estándar de Alprolix de 50 IU/kg.

INDICACIONES Y USO

¿Qué es Rebinyn® Factor IX de Coagulación (Recombinante), Glicopegilado?

Rebinyn® es un medicamento inyectable que se utiliza para reponer el factor IX de coagulación que les falta a los pacientes con hemofilia B. Rebinyn® se usa para tratar y controlar las hemorragias de las personas que tienen hemofilia B. Su proveedor de atención médica podría administrarle Rebinyn® si se somete a una cirugía. Rebinyn® no se usa para la profilaxis habitual ni para la terapia de tolerancia inmunológica.

INFORMACIÓN IMPORTANTE DE SEGURIDAD

¿Cuál es la información más importante que debo saber sobre Rebinyn®?

- **No intente administrarse usted mismo la infusión a menos que su proveedor de atención médica o el personal del centro para el tratamiento de la hemofilia le hayan enseñado cómo hacerlo.** Siga cuidadosamente las indicaciones de su proveedor de atención médica en lo que respecta a la dosis y el esquema de administración de las infusiones de Rebinyn®.

¿Quiénes no deben usar Rebinyn®?

No use Rebinyn® si usted:

- es alérgico al factor IX o cualquiera de los otros ingredientes de Rebinyn®.
- es alérgico a las proteínas de hámster.

¿Qué debo informar a mi proveedor de atención médica antes de usar Rebinyn®?

Comuníquele a su proveedor de atención médica si:

- tiene o ha tenido alguna afección médica.
- toma algún medicamento, incluso medicamentos de venta sin receta y suplementos alimenticios.
- está amamantando, embarazada o planea quedar embarazada.
- le han dicho que tiene inhibidores del factor IX.

¿Cómo se usa Rebinyn®?

- Rebinyn® se administra mediante infusión en una vena.
- **Llame a su proveedor de atención médica de inmediato si la hemorragia no se detiene después de usar Rebinyn®.**
- No deje de usar Rebinyn® sin consultar con su proveedor de atención médica.

¿Cuáles son los posibles efectos secundarios de Rebinyn®?

- **Algunos de los efectos secundarios frecuentes son** hinchazón, dolor, sarpullido o enrojecimiento en el lugar de la infusión, y comezón.
- **Llame a su proveedor de atención médica u obtenga tratamiento de inmediato si presenta alguno de los siguientes signos de reacción alérgica:** urticaria, opresión en el pecho, respiración sibilante, dificultad para respirar y/o hinchazón de la cara.
- **Informe a su proveedor de atención médica sobre cualquier efecto secundario que le moleste o que no desaparezca.**
- Los animales a los que se les administraron dosis repetidas de Rebinyn® presentaron polietilenglicol (PEG) dentro de las células que revisten los vasos sanguíneos del plexo coroideo, que es lo que produce el líquido que acolcha el cerebro. Se desconocen las posibles implicaciones para los seres humanos de estas pruebas en animales.

Consulte el Resumen Breve de la Ficha Técnica en la siguiente página.

Rebinyn® es un medicamento de venta con receta.

Se recomienda que informe a la Administración de Alimentos y Medicamentos (Food and Drug Administration, FDA) sobre los efectos secundarios adversos de cualquier fármaco de venta con receta. Visite www.fda.gov/medwatch, o llame al 1-800-FDA-1088.

Obtenga más información en rebinyn.com y conéctese con su HCL local.

novo nordisk®

Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 EE. UU.

 Impreso en EE. UU. US19REB00052 Agosto de 2019

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

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

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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®?

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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.

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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

USA17BI003951 12/2017

novo nordisk®

Executive Department
State of Idaho

The Office of the Governor
Proclamation

State Capital
Boise

WHEREAS, this designation will formalize and expand upon the designation 35 years ago of March 1986 as "Hemophilia Awareness Month" by President Ronald Reagan; and

WHEREAS, the U.S. Department of Health and Human Services designated March 2016 as National Bleeding Disorders Month; and

WHEREAS, multiple states and local governments since 2016 have passed a proclamation or resolution declaring March as Bleeding Disorders Awareness Month; and

WHEREAS, bleeding disorder advocates, during this month, wear a red material around their neck (e.g. leis, scarves, ties); and

WHEREAS, these bleeding disorders, which share the inability to form a proper blood clot, are characterized by extended bleeding after injury, surgery, trauma or menstruation and can lead to significant morbidity and can be fatal if not treated effectively; and

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

WHEREAS, this awareness month in Idaho will 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, this awareness month will foster a greater sense of community and shared purpose among individuals with all inheritable bleeding disorders; and

WHEREAS, this awareness month will elevate awareness of and engagement in the inheritable bleeding disorders journey beyond our community to the general public, enabling the prevention of illness, unnecessary procedures, and disability;

NOW, THEREFORE, I, BRAD LITTLE, Governor of the State of Idaho, do hereby proclaim March 2021 to be

BLEEDING DISORDERS AWARENESS MONTH

in Idaho.

IN WITNESS WHEREOF, I have hereunto set my hand and caused to be affixed the Great Seal of the State of Idaho at the Capitol in Boise on this 1st day of March in the year of our Lord two thousand and twenty-one.

BRAD LITTLE
GOVERNOR

LAWERENCE DENNEY
SECRETARY OF STATE

Governor Brad Little recognizes March 2021 as Bleeding Disorders Awareness Month in Idaho.

TEEN PROGRAM
Calling all Teens

We want to hear from you. We are working to get a regular schedule of activities. What do you like to do? What activities would you like to try? What outdoor skills do you want to learn? We are looking for ideas and suggestions.

We also need teens to help plan and develop the program. Involvement looks great on a scholarship or college application, or a resume.

Please contact the chapter office with your ideas or your desire to help.

208-344-4476

COMMUNITY ASSISTANCE FUNDS AVAILABLE

We are aware of the huge cost of factor and the care of those with bleeding disorders.

We want to remind you that the Chapter can help with the expense of utilities, doctors' bills, travel and other household bills up to $500 per year. If you need help with immediate expenses, please call or email Michael at the Chapter office and ask for a Community Assistance Project form.

208-344-4476
mkrieger@hemophilia.org

WE ARE LOOKING FOR INDIVIDUALS TO MAKE A DIFFERENCE
in our community and who would like to be on a committee.
Help is needed on the following:

CAMP
SOCIAL MEDIA
TEEN PROGRAM
VICTORY FOR WOMEN
MEN'S GROUP
UNITE WALK

If you can help, please contact the Chapter office, today!
208-344-4476
or idaho@hemophilia.org

OWN A SMALL BUSINESS?

Members of the NHF Idaho Chapter community are invited to submit advertisements for their business to appear in our Newsletter,

FREE

Ads will be subject to space availability and approval by the staff. Ads should be submitted in a ready to print digital format. Acceptable files are JPG (150dpi, minimum) or PDF. Size of ad must be 3¾″w x 3⅜″h. For additional information call the Chapter office,
208-344-4476

The NHF Idaho Chapter NEWSLETTER is published quarterly in Boise, ID. For information, questions, to submit articles or advertising for the Newsletter please contact,

Michael Krieger 208-490-2596 or mkrieger@hemophilia.org.

GO SEEK. GO EXPLORE.
GO AHEAD.

PEOPLE LIKE YOU. STORIES LIKE YOURS.
Explore more at HEMLIBRAjourney.com

Discover your sense of go. Discover HEMLIBRA.

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**.

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

4696 W. Overland Road
Suite 234
Boise, Idaho 83705-2864