Summer/Fall 2019

KHF Hemosphere

Summer Camp

KHF's Camp Discovery for Children and Teens with Bleeding Disorders and their Siblings had another great season this year. Twenty-five children and teens participated in this year's KHF summer camp program. The five-day program combines fun and adventure as well as educational and empowerment activities. Each camper's primary goals at camp are to have fun, make friends, and learn to self-infuse. We make a concerted effort, plan, and tailor our activities for camp to meet this challenge put forth by our campers. As always, swimming and capturing the flag remain all-time favorite activities along with special treats such as the Game and Kona Ice Trucks, and the final night dance party.

For a third consecutive year, the canteen program operated by teen campers offered many sought-after goodies. Here campers could redeem their virtual dollars—which they earned for exemplary behavior, attitude, and achievements —for snacks, toys, and other must-have items. Again this year, all campers proudly donated a portion of their virtual earnings to help sponsor Genesis, a boy from India, who also has hemophilia, through the Save One Life Program. Older teen campers and junior counselors presented an update on Genesis as part of our Youth Leadership Program, which was developed and launched by our Camp Director, Justin Lindhorst, at this year's camp. We plan to have various community service, leadership development, and fun activities throughout the year for our Youth Leaders.

Our thanks and appreciation for a wonderfully engaging and empowering camp program go to our Camp Director, Justin Lindhorst; the Infirmary Director, Mary Jane (Missy) Frey, RN, and Rania Salem, RN, Sr. Infirmary Nurse; and all our outstanding counselors and camp committee members who planned, implemented, and ensured another superb and safe summer camp program. Our gratitude also extends to our sponsors who provided funding for camp. They are Bayer HealthCare, CSL Behring, CVS Caremark, Grifols, HEMA Biologics, Kosair Charities, Novo Nordisk, Pfizer, Takeda, and the WHAS Crusade for Children.

Mentoring for Hemophilia:
Benjamin Rush and John C. Otto

Richard J. Atwood

As we advance in our careers, some of us try to do it all on our own. In time, we realize that we could use a little help from our friends. A formal term for this encouraging advice is mentoring. A mentor has a certain skill set or professional qualifications, and offers guidance to someone else.

One of the key examples of hemophilia mentoring occurred in Philadelphia in 1803. Dr. Benjamin Rush (1746–1813) provided guidance for his young colleague, Dr. John Conrad Otto (1774–1844). Otto then published a groundbreaking medical journal article on "hemorrhagic disposition," now known as hemophilia. This article inspired other physicians worldwide to investigate bleeding disorders.

The medical careers of Rush and Otto overlapped for 20 years in Philadelphia. Beginning in 1793, Otto progressed from being Rush's student to becoming his colleague, and eventually his successor. Otto was also his mentor's friend. Before starting their medical careers, both men graduated from the College of New Jersey (now Princeton University), Rush in 1760 and Otto in 1792.

Otto moved to Philadelphia in 1793 to begin his medical studies under Rush as apprentice and student. The deadly yellow fever epidemic that summer—with its 10% mortality rate—compelled Rush to send Otto out of the city, most likely because he was a medical novice and also to protect his health. Returning in the fall, Otto attended medical lectures conducted by Rush, who was then a professor at the University of Pennsylvania. Otto was a favorite pupil, and he made hospital rounds and private calls with Rush. Otto earned his medical degree in 1796 with a thesis on epilepsy. He survived an attack of yellow fever in the 1798 epidemic during a visit to his hometown of Woodbury, New Jersey.

Settling in Philadelphia to practice medicine, Otto was elected to the Philadelphia Dispensary for the Medical Relief of the Poor, serving as physician there for five years. Rush had been instrumental in founding the dispensary in 1786 as the nation's first free clinic for the poor. In addition to his private practice, Otto was also a physician at the Orphan Asylum for 20 years, and at the Magdalen Asylum.

Otto visited New England in the summer of 1802. Rush gave Otto a letter of introduction, dated August 6, to Dr. John C. Warren (1753–1815), a professor at Harvard University in Cambridge, Massachusetts. Nothing is documented about Otto's trip, yet we can guess that Rush's letter was a catalyst for Otto to subsequently publish information he collected about a family with cases of hemophilia. Returning to Philadelphia, Otto married Eliza Tod (1790–1860) on December 18, 1802. Eliza, a merchant's daughter, was only 12 when she married. She would go on to deliver nine children, seven of whom survived.

In 1803, at age 29, Otto published "*An Account of an Hemorrhagic Disposition in Certain Families*" in Medical Repository, America's first medical journal, founded in 1798 in New York City. This article is considered the first clear description of hemophilia in the world, and was reprinted in England in 1808. Otto did not mention his visit to Boston, but he noted that Rush was familiar with similar cases of hemophilia in the town of York and in Northampton County, both in Pennsylvania, and also in Maryland.

In his article, Otto described the Smith family from Plymouth, New Hampshire. Otto probably gathered his information from secondary sources, rather than ever interviewing any Smith family members. We know that Otto learned of the Smith family from residents of nearby Holderness, New Hampshire, including Judge Samuel Livermore (1732–1803), Dr. John Porter, and Dr. John Rogers. These men, while personally knowing about some of the "bleeders"

Mentoring for Hemophilia:
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continued

in the Smith family, were secondary sources. Judge Livermore traveled to Philadelphia, the nation's capital, serving as a member of the Continental Congress, a US Representative, and a US Senator (1780–1801). He traveled with Captain Thomas Shepard, a relative of Captain John Shepard who also served with Robert Rogers' Rangers, a mercenary regiment of soldiers from New Hampshire. Otto recorded many secondary sources who knew members of the Smith-Shepard family. But his encouragement from Rush seems to have sparked this investigation.

Around 1752, Susannah Smith (1739–1818) of Durham, New Hampshire, married Captain John Shepard (1730–1779) of Barrington. Captain Shepard served in the British army and in Robert Rogers' Rangers. He and Susannah are usually credited with seven children, though some sources list more. Some of the Shepard sons (not specifically identified) are reported to have been "bleeders" and died young. After Captain Shepard died in 1779, and his property was confiscated because he was a Loyalist,[1] Susannah and several of her adult children moved to Holderness, to what is now called the Shepard Hill Historic District.

Otto supported Rush's contention that a cure-all for diseases, especially when blood vessels and nerves are in an "excitable state," is a purgative. Rush treated yellow fever with bloodletting,[2] usually about 10 ounces of blood taken three times a day, along with emetics and laxatives for purging. These medical procedures, though commonly practiced, were critically disputed by some physicians. Otto stated that sulphate of soda, a purging medicine, was the best treatment for hemorrhagic disposition. To be curative, he said, the purging dose needed to be administered two or three days in succession. Administering more often was sure to produce the "cure" even with its debilitating side effects.

When he learned more about a Maryland family of "bleeders," Otto published an update in his 1805 article "Singular Cases of Hemorrhagy" in the new journal Philadelphia Medical Museum. Otto wrote that all four sons of Benjamin Binny were victims of fatal hemorrhages, while the daughters were not affected.

In 1805, Rush became dean of the University of Pennsylvania Medical School. When Rush died in 1813, Otto replaced his former teacher as a physician and clinical lecturer at the Pennsylvania Hospital, a position he would hold for 22 years. Regrettably, Otto never published again on hemophilia.

We don't know why Rush didn't publish information on the cases of hemophilia known to him. We also don't know why Rush, as a mentor, seems to have prompted Otto to investigate the Smith family in New Hampshire. Perhaps Rush,[3] as a Founding Father and one of 56 signers of the Declaration of Independence, was busy with other matters. Fortunately, Otto wrote an influential article on hemophilia, clearly describing its bleeding pattern, the current treatment, and its genetics, and even introducing the term "bleeders" in the literature. We can be thankful that Otto's 1803 article was the consequence of successful mentoring for hemophilia.

1. Another twist to this story concerns the political spectrum extremes involved here: Rush and Otto were Revolutionaries for America, while Shepard was a Loyalist for England.
2. Bloodletting means to open up a vein. Rush's practice was controversial. But he published his results, so his methods were well known. Rush had some success, but some of his patients died. Other physicians who did not practice bloodletting had some success, and also had some patients die. A purging remedy for hemophilic bleeding may have been effective, or it may have distracted the patient enough to stop any bleeding. To us, this sounds barbaric, but it fit the medical theories at the time and remained popular for another half-century.
3. Recent biographies of Rush include Rush (2018) by Stephen Fried, and Dr. Benjamin Rush (2018) by Harlow Giles Unger. Unfortunately, a comprehensive biography of Otto is missing.

Event News

2019 Kentucky Unite for Bleeding Disorders Kick-Off Lunch

The Kick-Off Lunch for our 2019 Unite for Bleeding Disorders Walk resulted in ten new Walk sign-ups. Thank you Team Captains and Walkers! New teams are "Heart Strong-Team Captain: Travis Price," "Blood Brothers-Team Captain: April Smith," "Ike-A-Maniacs-Team Captain: Laura Webb," "Jackson's Globeclotters-Team Captain: Bradley Woods," "Sam's Slugs-Team Captain: Sam Johnson," "Team Jack-Team Captain: Cory Meadows," and "Team Mason-Team Captain: Mason Stout." New individual Walkers are Adja Ndiaye, Khadija Gueye, and Georgia Bryant. Thank you so much for accepting our challenge of raising $50,000 for this 6th Walk season. We came close last year thanks to twenty teams who worked so hard for our cause. We invite all our friends to join us for this year's Walk.

The 6th Annual Kentucky Unite for Bleeding Disorders Walk will be held on Saturday, October 26, at E. P. "Tom" Sawyer State Park here in Louisville. This is a new venue for our Walk in a very popular park on the eastern edge of Jefferson County, easily accessible from all interstates. With this end of October date, we will once again have a Halloween theme with prizes for best costumes, trick or treat candies, "ghoulish" music, "scary" games, pumpkin painting, door prizes, and more.

As before, we will present awards to the top 3 teams and top 3 fundraisers and prizes and medals to these winning teams. Incentive prizes will be awarded for amounts of $250 and more raised. Time is going by quickly, so please go to **www.uniteforbleedingdisorders.org/event/KY19** to register your Team and instruct your Team members to register as well. Then, everyone should start fund-raising. Moneys raised help support important services KHF provides to its Kentucky Bleeding Disorders Community, such as scholarships, summer camp, advocacy, and child safety items. Moreover, the Walk gives visibility to individuals affected by bleeding disorders and increases awareness in the larger community of what life with a bleeding disorder entails for affected men, women, and children.

Annual Meeting/Summer Family Event

This year's Annual Meeting/Summer Family Event's successful blend of activities were valuable education and information, Walk Kick-Off, and a harbor cruise on the Ohio River. At the newly enhanced and refurbished Hyatt Regency Louisville Hotel, our guests enjoyed visiting with our exhibitors and listening and engaging in productive discourse with our presenters, who did a phenomenal job and were praised profusely by our attendees. Speaker topics provided a cross-section of pertinent information and helpful tools: "The Science of Optimism," Judy Saltzberg, PhD; "Carrier Barrier-Women with Hemophilia," Mary Jane (Missy) Frey, RN-BC, BSN, CPN; "Factor Fingerprint," Angela Lambing, MSN, ANPc, GNPc. Interactive children's activities were once again facilitated by Connie Thacker of Christian Fellowship.

Event News

Our Camp Discovery outreach table staffed by Travis Price, Sr. Camp Counselor, and Samantha Johnson, Jr. Camp Counselor, sparked interest and excitement among parents and young children who were eager to learn more about our camp program. The Walk Kick-Off lunch stirred up considerable enthusiasm for the 2019 Unite for Bleeding Disorders Walk, and the steamboat cruise on the Ohio River provided much enjoyment on a warm and sunny Saturday afternoon. The following companies exhibited at the event: Accredo, Bayer HealthCare, Biomatrix, BMR Partners-St. Matthews Specialty Pharmacy, Cottrill's Pharmacy, CSL Behring, CVS Caremark, Genentech, Heritage Biologics, HPC, NORD, Novo Nordisk, Octapharma, Pfizer, PSI, Sanofi Genzyme, and Takeda. Speaker sponsors were Bayer HealthCare, CVS Caremark, and Genentech. We appreciate the participation and support of all exhibitors and sponsors.

Scholarships

We congratulate the recipients of two scholarship awards for the Fall 2019 semester! The Herb Schlaughenhoupt, Jr. Memorial Scholarship was awarded to Andrew Harmon. Andrew is the son of Keith and Sharen Harmon. He and his family reside in Bedford, KY. Andrew attends Midway University in Midway, KY and majors in Elementary Education. He plans to graduate next year. He has been on the Dean's list and is a member of Phi Theta Kappa. He enjoys soccer, basketball, video games, and reading.

For the first time this year, we awarded the Theodore (Ted) B. Forcht Memorial Scholarship. This scholarship was established to honor the memory of Ted Forcht who passed away this summer, for which we are greatly saddened and extend our heartfelt condolences to his wife, Jennifer Forcht, and his parents, Mr. & Mrs. Terry Forcht. The Theodore (Ted) B. Forcht Memorial Scholarship was awarded to Andrew (Drew) Marcum. Drew is the son of Eric and Venus Marcum of Louisville. Drew is a sophomore at Transylvania University in Lexington and majors in Computer Science. He enjoys art, video games, cooking, and camp. Drew is an outstanding Junior Counselor at KHF's summer camp, and we commend and thank him for being a wonderful mentor to our younger campers.

More News

Outgoing Board Members

At our recent Annual Meeting, we expressed our appreciation to three board members who rotated off the board of directors after serving six years. They were: Paula Bias, who was our camp director for many years and served on the camp and golf committees and skillfully decorated the auction tables at our golf scramble and Vegasville gala; Deborah L. Hitt, who served as president, vice-president, secretary, and member of Vegasville, golf, and walk committees and volunteered to take all of KHF's event photos; Venus M. Marcum, who served as president, vice-president, secretary, and as our enthusiastic walk committee chair for six walk seasons. We bestow much gratitude and appreciation on these wonderful ladies for their exemplary volunteer spirit and dedication to serving Kentucky's bleeding disorders community.

New Board Members

We extended a warm welcome to two new board members who were elected at this year's Annual Meeting. Andrew Hartmans, who holds a MDiv degree from the Louisville Presbyterian Seminary and a BA degree from the University of Western Ontario and has been the Director at Cedar Ridge Camp since 2001. He has been a pleasure to work with in that capacity for seventeen years. Andrew has longstanding experience in non-profit management and programming for youth. He serves as a minister for Presbyterian Church USA, clerk and recording clerk for Presbytery of Mid-Kentucky, and is a member of the American Camping Association. He enjoys gardening, working around the house, and bee keeping. Eric Marcum, who holds a BSN degree from Sullivan University and an AN degree from Jefferson Community College, is Director of Outpatient Services at The Brook Hospital Dupont, where he has been employed since 1997. Eric previously completed two three-year terms on the KHF Board. He served as president two years, vice-president one year, and secretary two years. Eric has served on the golf committee and Vegasville committee and has been a long-term advocate for bleeding disorders. He enjoys, music, drums, golf, fishing, and food.

KHF Officers

Officers elected by the membership present at the Annual Meeting for fiscal year 2019/2020 are Cory Meadows, President; Laura Webb, Vice-President; Brad Comer, Treasurer; and Bradley Woods, Secretary. The officers' term is one year, and we congratulate them for their willingness to serve in this important volunteer capacity. We also thank the officers who served this past year for their dedication and expertise. They were Venus Marcum, President; Cory Meadows, Vice-President; Kristin Traylor, Treasurer; and Laura Webb, Secretary.

Advocacy Training & Appreciation

KHF's Consumer Advocate Training and Appreciation Dinner was a success! Jim Romano, Director of Government Relations at Patient Services Inc. (PSI), discussed many helpful strategies and examples of how to be an effective advocate year-round. Jim's presentation was laced with personal anecdotes and humor to the delight of our attendees complemented by Patrick and Jennifer Dunegan's and Mason Stout's advocate testimonials. All of our attendees had either participated in KHF's Advocacy Days in Frankfort or in Washington Days or both. We thank our speakers and our attendees for moving KHF's Advocacy Program forward in this manner and for ensuring that we keep the needs and concerns of our bleeding disorders community front and center.

More News

13th Annual Fund Drive

We thank the following individuals and companies for their generous support of the 2018 – 2019 Fund Drive

Challenge Gift, $25,000
Forcht Bancorp, Mr. & Mrs. Terry Forcht

Fundraisers Toward Meeting the Challenge, $19,000+
Various Corporate Solicitations & Miscellaneous Fundraising

Forcht Challenge Donors
Chevron Matching Employee Funds
The Community Foundation of Louisville for the Zoeller Company
David L. Hasch
Don L. Mattingly
Network for Good
Patricia P. Thomas Estate
Woodmen of the World, Chapter 14

Donors, $500 – 800+
Joseph H. Cieslak, Louisville Oral Surgery & Dental Implants
Jennifer Hitt, GE Appliances Giving Campaign
Kroger Community Rewards

Donors, $250 +
Community Health Charities
Greg Fiscus, GE Appliances Giving Campaign
Charles & Ruth Hall
Bill Stopher
LTC (R) John & Mrs. Patricia Tharp

Donors, $100 +
Clark County REMC
Ricky James
Kenny's Department Store
Sally K. Newcomb
Keith Peterson
Mr. & Mrs. James Ray in memory of Betty Meadors Mattingly

Donors, Up to $99
Amazon Smiles
Mary R. Burnette
Dolores Davis
Mrs. William L. Farmer, Sr.
Father William Fichteman
Stan Hankins
Glen E. & Deborah L. Hitt, Sr.
Louisville Web Group
Ruth Ann Moffett
Charles & Cheri Music
Olive Branch UMC Mission Fund
Dr. Don Stokes
Woman of Immanuel, Immanuel UCC
Gail F. Yates

2018 – 2019 KHF Membership

Thanks to all of our members for their support

Individual/Family Memberships, 20+
Patricia Ashby
Arthur Hackman
Christi & Chad Hille
James P. Huff
Patricia Swearingen

Supporting Memberships, $35+
Judy Hayes in memory of Jason Hayes
Mary Marasa
Donald L. Mattingly
Charles H. Music

Patron Memberships, $50+
Dr. David & Leslie Houvenagle
Cory W. Meadows
Travis Price
Ian & Elaine Thomas
Gail Yates

Sustaining Memberships, $100+
Barbara W. Grayson
D. Spalding Grayson
Thomas & Alice Hendrix
Glen & Deborah Hitt
Venus & Eric Marcum
Vivian Marcum
Kathleen Nichols
Glenn & Laura Webb
Nita Wayne-Zehnder

Benefactor Memberships, $250+
John & Lea Graham
LTC (R) John & Patricia Tharp

Champion/Corporate Member, $500
Ted & Jennifer Forcht
Terry & Marion Forcht
Rosemary Johnson-Dean
Keith & Kristin Forcht Urbahn, Benjamin and William Urbahn

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.

Upcoming Events

Poinsettia Fundraiser
November/December 2019

Year-End Family Event
Sunday, December 1, 2019

Vegasville Fundraiser
February 22, 2020

KOSAIR CHARITIES

COMMUNITY HEALTH CHARITIES KENTUCKY

WHAS CRUSADE FOR CHILDREN

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

Non Profit Org.
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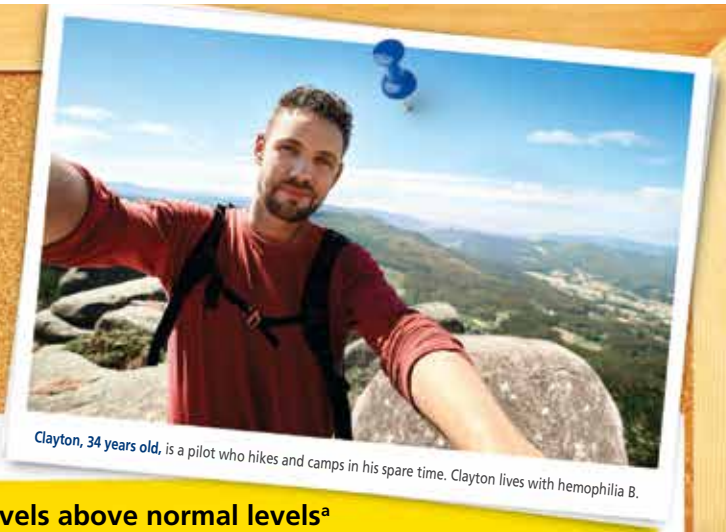
PAID
Louisville, KY
Permit No. 883

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®

A ONCE-WEEKLY SUBCUTANEOUS (GIVEN UNDER THE SKIN) INJECTION FOR PEOPLE WITH HEMOPHILIA A WITH FACTOR VIII INHIBITORS

We extend our appreciation to the individuals, families, and healthcare providers who participated in the clinical trials that led to the approval of HEMLIBRA®. We thank you and celebrate with the community who made it a reality.

Discover **HEMLIBRA.com**

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 with hemophilia A with factor VIII inhibitors.

WHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use. HEMLIBRA may cause the following serious side effects when used with 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 signs and symptoms of TMA during or after treatment with HEMLIBRA.
- **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 the signs or symptoms of blood clots during or after treatment with HEMLIBRA.

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

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

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.

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 OTHER POSSIBLE SIDE EFFECTS OF HEMLIBRA?

The most common side effects of HEMLIBRA include: redness, tenderness, warmth, or itching at the site of injection; headache; and joint pain. These are not all of the possible side effects of HEMLIBRA.

You may report side effects to the FDA at (800) FDA-1088 or www.fda.gov/medwatch. You may also report side effects to Genentech at (888) 835-2555.

Please see Brief Summary of Medication Guide on the following page for more important safety information, including **Serious Side Effects**.

Medication Guide Brief Summary
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. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use. HEMLIBRA may cause the following serious side effects when used with 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 with hemophilia A with 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.
- 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.
- 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 before the next scheduled dosing day and then continue with your normal weekly dosing schedule. Do not double your dose 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 7 days at 86°F (30°C) or below.
- 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

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 1-855-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Issued: 11/2017

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

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

KHF Event Calendar

Nov. Dec.

Poinsettia Fundraiser
November/December 2019

Dec. 1

Year-End Family Event
Sunday, December 1, 2019
Holy Trinity Clifton Campus • Louisville, KY

Feb. 22

Vegasville Fundraiser
February 22, 2020
The Olmstead • Louisville, KY