Winter 2021-22

KHF Hemosphere

2021 KHF Year-End Event

The Year-End Event felt like a long awaited breath of fresh air. This celebration of the season occurred on the first Sunday in December and was by all measures a resounding success. We gathered in person at Holy Trinity's Clifton Campus in Louisville to catch up with our community members for fellowship and good cheer.

The silent auction, as always, was great fun, and we thank our guests who generously contributed the items to be auctioned off. We skipped the bake contest this year because of the pandemic and replaced it with a "Dress as your favorite Holiday character contest." This especially appealed to our younger guests who were able to win several gift cards. To everyone's surprise, a full-grown Grinch appeared out of nowhere and joined the merriment. Lo and behold, Santa Claus and Mrs. Claus paid us a visit, chatting with our guests, posing for photo ops, bearing wonderful gifts for the children, and even having fun with Mr. Grinch.

Connie Thacker created lovely reindeer crafts with the little ones, while the adults enjoyed winning some nice door prizes. Entertainment was provided by DJ Axel and hors d'oeuvres and refreshments by Chef John Taylor. Every family received a bag of Holiday cookies "for the road," which were special-ordered from "Baked by Em."

Our guest also enjoyed visiting with all the exhibitors, who participated in the event. We appreciated the support of Accredo, Biomatrix, BMR Partners, CSL Behring, HEMA Biologics, Novo Nordisk, Octapharma, Paragon Hemophilia Solutions, Pfizer, Sanofi Genzyme, and Takeda. We also thank all our volunteers who helped ensure a successful event!

MASAC Guidelines for Pregnancy and Perinatal Management of Women with Inherited Bleeding Disorders and Carriers of Hemophilia A or B

(Continuation of article from Fall 2021 "Hemosphere" Newsletter)

Umbilical Cord Blood Sampling

Umbilical cord blood should be obtained through proper technique at the time of delivery in order to avoid venipuncture of the infant and to ensure that the neonate is tested early for hemophilia. [4, 6, 7, 14] Instructions should be provided to the obstetrical team prior to delivery and plan should be confirmed in regards to exactly which test should be sent and which laboratory the test should be test to. Confirm that lab will run factor assays on cord blood.

(See Appendix A for the Indiana Hemophilia & Thrombosis Center Procedure for Collecting, processing & Shipping the Cord Blood Sample.)

Postpartum Management to Prevent Bleeding

Obstetricians and midwives routinely take precautions to prevent postpartum hemorrhage, and this is especially important in women with bleeding disorders. The third stage of labor should be actively managed to reduce blood loss and reduce the incidence of postpartum hemorrhage. [7, 15] Anti-fibrinolytics can be used to prevent or treat postpartum hemorrhage. [4, 7] Specifically, tranexamic acid is advised in women with type 1 VWD or low VWF levels (and this may also apply to types 2 and 3 VWD) during the postpartum period. [9] Tranexamic acid may be given systemically via the oral or IV route. The oral dose is 25 mg/kg (typically 1000-1300 mg) 3 times per day for 10 to 14 days or longer if blood loss remains heavy. [9]

Factor levels may drop precipitously postpartum and should be monitored. In women who require clotting factor replacement therapy, prophylaxis should be continued for at least five days postpartum or longer, since delayed postpartum hemorrhage is not uncommon and may occur more than two weeks after delivery. [3, 7, 12] Clotting factor replacement initially should be targeted closer to the physiological level of 150% then 50%. [9]

Recommendations

1. Multidisciplinary approach to pregnancy and delivery should be supported and women should only deliver at hospitals that have the essential resources.
2. NHF should work with NHLBI, the American Thrombosis and Hemostasis Network (ATHN), the Foundation for Women and Girls with Blood Disorders, the International Society of Hemostasis and Thrombosis and CDC to develop a national research agenda on pregnancy and perinatal management of women with inherited bleeding disorders and carriers of hemophilia A or B.

MASAC Guidelines for Pregnancy and Perinatal Management of Women with Inherited Bleeding Disorders and Carriers of Hemophilia A or B

Revisions: 251; 175; 252

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Source: National Hemophilia Foundation (NHF) Web Site www.hemophilia.org

Event News

2022 Spring Scholarship Awards

What better way to leap into spring than by announcing two post-secondary scholarship awards for the 2022 spring semester.

Lori Lyons Hall was awarded the Betty Meadors Mattingly Memorial Scholarship. Lori graduated summa cum laude from Eastern Kentucky University and is now pursuing a doctoral degree in Veterinary Science at Auburn University in Alabama. The Terry D. Turner Memorial Scholarship was awarded

to John Graham. John is a sophomore at Centre College in Danville. His major is finance and economics with an emphasis on politics. We extend our heartfelt congratulations and best wishes for their educational endeavors to these most deserving scholarship recipients!

The next deadline for submitting a scholarship application is July 15, 2022 for the 2022 fall semester. Remember, you may apply every semester even if you have received one or more scholarship awards from us. For an application form and guidelines, contact the KHF office at 502-456-3233 or 1-800-582-CURE (2873) or send an email to info@kyhemo.org.

Remember: KHF CARES

Kentucky Hemophilia Foundation continues to provide financial assistance to bleeding disorder families whose household income has decreased because of loss of job, lay off, furlough, reduced hours during the ongoing COVID-19 health crisis or due to another type of emergency such as the recent tornadoes in western and south-central Kentucky and as a result are unable to pay a specific household bill.

Requesting families must reside in Kentucky, and the person seeking assistance must either have a bleeding disorder or be the parent of a minor child with a bleeding disorder. Assistance is contingent on the availability of funds. Call 502-456-3233 or 800-582-CURE (2873) or send an email to info@kyhemo.org to make a request.

Event News

Poinsettias 2021

Many thanks to everyone who participated in our recent poinsettia fundraiser. Because of you purchasing one or more plants, we were able to raise $17,000 to support our programs and services, such as the Year-End Event, which offered information, support, and Holiday cheer to attending patient families.

We especially appreciate the dedication and tireless efforts of our volunteers, who are instrumental in the success of this fundraiser. They are Sharon McMahan from Owensboro, Sadalia Sturgill from Lebanon Junction, Mason Stout from Somerset, Eric Marcum from Louisville, Deborah Hitt from Shelbyville, Gail Yates and Myra Loser from Louisville. We are equally grateful for the many churches and businesses who placed poinsettia orders with us. A big shout out and thank you to Republic Bank & Trust Company who ordered for their area banking centers and to Forcht Group of Kentucky for their generous donation.

2022 KHF Activities Calendar

08 March	9th Annual KHF Advocacy Day (Virtual)
20-22 May	KHF Family Camp at Camp Discovery, Cedar Ridge Camp, Louisville, KY (in person)
13 June	Play a Round for a Cure Golf Scramble, Glen Oaks Country Club, Prospect, KY (in person)
25 June	KHF Family Day at the Louisville Zoo, Louisville, KY (in person)
24-28 July	Camp Discovery for Children and Teens, Cedar Ridge Camp, Louisville, KY (in person)
17 Sept.	Summer Family Event, Hyatt Regency Louisville, Louisville, KY (in person)
22 Oct.	9th Annual KHF Unite Walk, E. P. “Tom” Sawyer State Park, Louisville, KY (in person)
4 Dec.	Year-End Family Event, Holy Trinity Clifton Campus, Louisville, KY (in person)

More News

Clinical Study and New Website to Focus on von Willebrand Disease and Pregnancy

The onset of childbirth and the postpartum period are times when women with von Willebrand disease (VWD) are at an increased risk for excessive bleeding, exposing them to further, and in some instances, serious complications. While there exist therapies with VWD-specific indications, it is not uncommon for these patients to still experience excessive bleeding while receiving treatment. These scenarios are challenging as there is sparce clinical data and a subsequent lack of clear guidance on the optimal management of bleeding in these particular settings.

The von Willebrand factor in pregnancy (VIP) study (https://vipstudy.com/) was therefore developed to enhance understanding of how best to manage bleeding during delivery and the postpartum period in women with VWD. Investigators for this prospective, multicenter trial will focus on maintaining von Willebrand factor (VWF) levels at a specific target level using VWF replacement therapy, and assessing the impact on bleeding rates during and after childbirth.

The VIP study is being stewarded by a trio of experienced principal investigators including Drs. Jill Johnsen (Bloodworks and University of Washington), Barbara Konkle (University of Washington), and Dr. Peter Kouides (Mary M. Gooley Hemophilia Center and University of Rochester). The VIP Study is currently recruiting pregnant women in the U.S. above 18 years of age with VWD of any type.

An exciting component of the VIP is a new companion website, created to keep patients and healthcare professionals informed about the study. It will provide information on VIP's design, patient eligibility, and locations of participating centers. The site was officially launched on December 10th during an educational webinar that preceded the American Society of Hematology Annual Meeting.

Source: PR Newswire/The VIP Study, November 28, 2021

In Memory

Gone from our sight but never our memories; gone from our touch but never our hearts…
May their memory be a blessing!

February 2022

Tina Jo Tucker Pelly
Mr. & Mrs. Amel Baker
Angie, Phillip, & Laura Freeman
Ellen Goff
Gregory & Michele Hoskins
Barry & Carol Myers
Greg & Susan Wise

More News

Kentucky Hemophilia Foundation Membership

07/01/21 – 06/30/22

We thank all of the members of KHF who are supporting the current program year!

Individual/Family Memberships, $20
Michael & Cathy Johnson

Supporting Memberships, $35
Judy Hayes
in memory of Jason Hayes
John L. Silletto

Patron Membership, $60
Mary E. Marasa

Sustaining Memberships, $100
Arthur Hackman
John & Leah Graham
Barbara W. Grayson
D. Spalding Grayson
Dr. David & Leslie Houvenagle

Benefactor Memberships, $250
Glen & Deborah Hitt
Ruth Ann LeVay
Eric & Venus Marcum
Laura & Glenn Webb

Champion/Corporate Membership, $500
LTC (R) John & Pat Tharp

21–22 Winter Donations

We thank the following individuals and companies for their generous support!

Donor, $3,000+
Forcht Group of KY
for Poinsettia Fundraiser

Donors, $2,500
Lone Star Chapter of NHF
Zoeller Company
via Louisville Community Foundation

Donor, $1,000
Marion Forcht
Kristen Forcht Urbahn

Donor, $500
Sneely @ nclworldwide.com

Donor, $300
Bill Stopher

Donors, $100+
Godby Realty & Auction
Kroger Community Rewards
Carol Nord
Keith Peterson

Donors, $50 - $99
Stan Hankins
for Poinsettia Fundraiser
Dianne Hardman
for KHF Unite Walk
Glen & Deborah Hitt
for Poinsettia Fundraiser
Justin Lindhorst
David & Terry Moore
Cheri & Charles Music
Gary Rawlings
Mr. & Mrs. James A. Ray

Donors, Up to $49
Amazon Smiles
Curtis & Winfred Jacobs
Mary E. Marasa
for Poinsettia Fundraiser
Darlene “Memaw” Schultz
in honor of Michael Schultz
Mason Stout
for Poinsettia Fundraiser
Sadalia Sturgill
for Poinsettia Fundraiser

Thank You

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.

Like us on Facebook and keep up-to-date on all **KHF** activities and events.

KOSAIR CHARITIES

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LET'S GO

JIVI®
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PK (Pharmacokinetics) Study Data

Talk to your doctor about the study.

Scan the QR code to learn more about PK at **UnderstandingPK.com**

COVID-19 and Hemophilia

Preparedness and Self-Care in a Pandemic

This information is provided for educational purposes only and is not intended to replace discussions with a health care provider. Speak to your treatment team if you have any questions about your/your child's care.

This content is brought to you by Pfizer.

The COVID-19 pandemic brought with it many lessons that can be carried into the future, including ones on preparedness, health care provider (HCP) communication, and self-care.

HCP Communication

Good communication with your hemophilia treatment center or care team can be an important part of living with hemophilia. During a pandemic, your team can help you understand possible risks based on your condition, as well as advise on treatment and vaccination.

Being prepared and proactive in hemophilia care[1]

One of the lessons of the COVID-19 pandemic is that it is important to be prepared, and that also applies to the hemophilia community. National Hemophilia Foundation's (NHF's) Medical and Scientific Advisory Council recommends:

- Having a 14-day supply of factor products available during crisis for those who treat at home
- If an ER visit is required, call in advance so staff knows you are coming and why; this will help them prepare
- Staying in contact with your doctor's office or hemophilia treatment center (HTC). They can explain what to do if you need to visit in person or can help get you connected with telehealth appointments, if available

Caring for yourself[2]

Events such as the COVID-19 pandemic can create uncertainty for many, which can stir up emotions such as anxiety, fear, anger, sadness, discouragement, or a sense of being out of control. Self-care is important to help you address these feelings. Here are a few tips you can use to take care of your mental health:

- Set and maintain a routine
- Focus on things you can control
- Use technology to maintain social connections with your loved ones
- Focus on reasons to be grateful
- Read books or listen to music
- Take a break from news and social media if it makes you anxious
- Look for ways to help your community
- Acknowledge and appreciate what others are doing to help

Further information

Many of the larger advocacy groups have sites to keep you in the know, see below:

- **The Coalition for Hemophilia B**
  hemob.org
- **Hemophilia Federation of America**
  hemophiliafed.org
- **Hope for Hemophilia**
  hopeforhemophilia.org
- **National Hemophilia Foundation**
  hemophilia.org
- **World Federation of Hemophilia**
  wfh.org

These websites are neither owned nor controlled by Pfizer. Pfizer does not endorse and is not responsible for the content or services of these sites.

Be sure to also inquire of your local chapter/advocacy organization and speak to your HTC's social worker for more information about available assistance programs.

References: 1. Supplemental MASAC statement regarding home delivery and refill under state of emergency declaration. National Hemophilia Foundation website. Published March 30, 2020. Accessed July 27, 2021. https://www.hemophilia.org/news/supplemental-masac-statement-regarding-home-delivery-and-refill-under-state-of-emergency-declaration **2.** Reichert S. Self-care tips during the COVID-19 pandemic. Mayo Clinic Health System website. Published April 7, 2020. Accessed March 30, 2021. https://www.mayoclinichealthsystem.org/hometown-health/speaking-of-health/self-care-tips-during-the-covid-19-pandemic

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

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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

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

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WE'RE IN THIS TOGETHER.

Let's make today brilliant.

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

bleedingdisorders.com

Takeda

Natalie Kukla

Patient advocate

About Natalie

Natalie is a Novo Nordisk Hemophilia Community Liaison who has three family members living with bleeding disorders. She wants to make a difference and is excited to support people in the hemophilia community.

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Emotional Wellness as a Mature Adult:

Discussing the Unique Challenges of Living With Hemophilia

For more information, visit b2byourvoice.com to download *Learn from Experience: A Guide for Mature Adults.*

This content is brought to you by Pfizer.

How Hemophilia Affects Mature Adults

Mature adults may look back and recognize how living with hemophilia has influenced who they are today. Persevering through the challenges of being a child diagnosed with hemophilia when less was known about the condition, and navigating the issues of being a young adult with a bleeding condition can shape one's perspective. Knowledge and wisdom are some of the benefits that accrue with age, but along with these can also come additional health concerns such as high blood pressure, diabetes, and arthritis; depression and stress; and financial planning and retirement concerns. For those who have lived with hemophilia for many decades, the task of managing these concerns of older age may seem to be less important. However, there are some key points to keep in mind when addressing the effect hemophilia can have on mental health.

The Risk of Clinical Depression

Mature adults living with hemophilia typically have experienced substantial challenges related to their disease throughout their lives. In some instances, hardships may contribute to the development of clinical depression, which is more common among people living with hemophilia than the general population. The results from one study conducted at a hemophilia treatment center showed that 37% of a sample of patients met the criteria for depression. Of that 37%, 20% had moderate to severe symptoms, and 66% reported having functional impairment due to their depressive symptoms.[1] The authors of the study concluded that the comprehensive care of adults with hemophilia should include depression screening for the potential to improve overall health outcomes.[1]

Education and support for people living with bleeding disorders and their families is one component of managing psychological wellness. Having control over life decisions and self-advocacy can also be important. For some living with hemophilia, past experiences may serve as a motivator to continue to work toward personal objectives. Others may find the journey more difficult to navigate. Self-help seminars and support groups are some of the resources that may help adults set and attain realistic goals.

> "[A reminder to] older adults that there is always somewhere to turn, even in times of immense hardship. All you need to do is ask, and you should never feel ashamed for doing so."
>
> — Judy Bagato
>
> RN, BSN, Hemophilia Specialist

Finding Support for Complex Issues

For people who acquired human immunodeficiency virus (HIV) and/or hepatitis C (HCV) from virally contaminated blood products, there may be feelings of anger and resentment. The adversity caused by a lack of family or social support during younger years or changes later in life, such as changes in one's capacity for employment or altered family dynamics, may also contribute to these feelings. Learning effective ways to cope with the stresses of living with hemophilia in older age may help an individual to be resilient to these challenges. If you are experiencing stress that is affecting your day-to-day outlook, it is important to seek help. Reach out to your treatment team to discuss your situation and learn about what help and support may be available.

Reference: 1. Iannone M, Pennick L, Tom A, et al. Prevalence of depression in adults with haemophilia. *Haemophilia.* 2012;18:868-874. doi: 10.1111/j.1365-2516.2012.02863.x.

PATIENT AFFAIRS LIAISONS

Patient Affairs Liaisons are Pfizer employees who are dedicated solely to providing support to the community. Your Pfizer Patient Affairs Liaison is available to help you access the support and information you need. To find your Patient Affairs Liaison, go to hemophiliavillage.com/support/patient-affairs-liaison-finder or call Pfizer Hemophilia Connect at 1.844.989.HEMO (4366).

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September 2019

Pfizer

2022 KHF Activities Calendar

08 March	9th Annual KHF Advocacy Day (Virtual)
20-22 May	KHF Family Camp at Camp Discovery, Cedar Ridge Camp, Louisville, KY (in person)
13 June	Play a Round for a Cure Golf Scramble, Glen Oaks Country Club, Prospect, KY (in person)
25 June	KHF Family Day at the Louisville Zoo, Louisville, KY (in person)
24-28 July	Camp Discovery for Children and Teens, Cedar Ridge Camp, Louisville, KY (in person)
17 Sept.	Summer Family Event, Hyatt Regency Louisville, Louisville, KY (in person)
22 Oct.	9th Annual KHF Unite Walk, E. P. “Tom” Sawyer State Park, Louisville, KY (in person)
4 Dec.	Year-End Family Event, Holy Trinity Clifton Campus, Louisville, KY (in person)

Before you know it....

The KHF Unite Walk might not be until October 22, but now is the perfect time to put together your team, plan your strategy, and start fund-raising. You know the winning teams get great prizes, and that the money you raise goes to a great cause.

Support the bleeding community, and mark your calendars to be a part of a fun and important event.

Kentucky Hemophilia Foundation