hfm©

THE ARTERY

FALL 2023

THIS ISSUE

HFMICH.ORG ◆ SERVING THE BLEEDING DISORDERS COMMUNITY

DEAR HFM FRIENDS,

Summertime has been an exciting adventure as well as a transitional period for HFM! In June, new officers were elected to the HFM board–many thanks to our terrific volunteer leaders. You can view information about the current board members on our website at hfmich.org/about-us.

HFM is also celebrating staff who are moving to new adventures and warmly welcomes those joining HFM's team. Some staff colleagues will continue to be involved via special projects so don't be surprised when some familiar faces remain with us for a bit. Read more about our new and departing staff on page 26 and 27.

Throughout this period of change, HFM has continued to provide exceptional educational programs and activities for the bleeding disorders community.

We were excited to welcome back many community members to Eagle Journeys summer camps over eight weeks of camp programs designed to provide age-appropriate fun and learning! You can take a peek at assorted camp photos on page 6 and 7 and on HFM's Facebook and Instagram.

In addition to camp, our summer was filled with a collection of compelling programs throughout the state. We kicked off the summer in June in metro Detroit with a community reunion and prepared for the end of summer with our Back to School Gathering in Grand Rapids. HFM also hosted a weekend UP retreat in Sault Ste. Marie in collaboration with the MSU Center for Bleeding and Clotting Disorders, continued the Men's Support Group and Dinner Talks, provided a weekend of support for one another at the Women's Retreat, and hosted our first Kalamazoo Community Night in late August. In addition to our community programming, HFM has continued our legislative advocacy efforts via the MI All Copays Count Coalition and has remained active with Children's Special Health Care Services via the Michigan Department of Health & Human Services. Planning is completed or in the works for the remainder of 2023 with information listed on the back mailing panel of The Artery.

In addition to our traditional programming, our regional team that supports the Great Lakes Region HTC Network of Michigan, Ohio, and Indiana continues to provide oversight and support via our responsibilities as the Federal Regional Core Center for Health Resources and Services Administration/ Maternal and Child Health Bureau, American Thrombosis and Hemostasis Network, and Centers for Disease Control. We meet regularly with our regional HTCs and federal partners across the United States.

For me, this has been an emotional and gratifying summer as HFM welcomed so many to engage with in-person activities. We will continue to offer online options in many instances to provide access to various learning opportunities. I have much gratitude to those who support HFM's desire and commitment to making a positive difference for all living with bleeding disorders and their loved ones.

Wishing you a lovely fall,

Susan Fenters Lerch
HFM Executive Director
Regional Director, Great Lakes Federal HTC Network

IN THIS ISSUE

THANK YOU TO OUR CONTRIBUTING AUTHORS

Front Cover © Brian Sevald Photography

PAID CONSUMER OUTREACH INCLUDED IN THIS NEWSLETTER

ALL COMMUNITY REUNION AND CAMP SEASON KICK-OFF

Thank you to everyone that joined us at our first annual ALL Community Reunion & Camp Season Kickoff on June 3rd at Kensington Metro Park. The predicted forecast was a hot one, though we enjoyed plenty of shade and a cool breeze off the lake as we played games, did crafts, and ate to our hearts content. Camp families who attended were able to spend time together before campers headed to camp later in the month. They'll be champion packers after a live "what and how to pack" demonstration. Parents and kids also acquired some tools to combat camper homesickness thanks to presentations from one of our new Associate Camp Directors and Program Services Managers: Angellica "Gelli" Kelley. Tim Wicks, HFM's Camp Director, led the group in camp songs, with accompanying dance moves, to the delight of both campers and parents.

While this event included moments with a camp focus, our main purpose of the gathering was to serve as our very own HFM family reunion. When asked to write what their HFM family means to them, attendees shared that this is their second family, that acceptance is a core value, and that we are fun. We couldn't agree more.

To our HFM family: thank you for a wonderful day and we look forward to next year! 🩸

THANK YOU TO OUR SPONSORS

SOARING EAGLE SPONSOR:

sanofi

HAPPY CAMPER SPONSOR:

CSL Behring

FRIENDS OF HFM SPONSORS:

Genentech
A Member of the Roche Group

octapharma

Spark THERAPEUTICS

EVENT SPONSORS:

HEMA Biologics

Takeda

HFM does not endorse any specific product or company.

Women's
RETREAT 2023

TUNING INTO HARMONY

© Sonja McGovern

During the third weekend in May, thirty-four women came together with one another for a hybrid retreat to recalibrate and tune into harmony. Living with bleeding disorders, and/or caring for someone with a bleeding disorder, can be taxing and sometimes lead to burnout or a sense of hopelessness. Through a program that emphasized self-care, attendees received education focused on prioritizing physical, mental, and emotional wellbeing. Women also received tips about how to share their stories by crafting meaningful and compelling personal messages.

Attendees worked to create a macrame coaster during the session Tied up in Knots! This activity proved to imitate the twists and tangles life often takes us through. It was remarkable to see attendees support and encourage one another through this endeavor. Many attendees continued working on unfinished coasters the next morning, receiving assistance from others.

The background throughout the weekend was a special soundtrack, consisting of songs chosen by each attendee. Each tune represented a relevant emotion, anthem, or life experience. We culminated our time together by listening to a portion of each track with attendees sharing how the song they chose reflected their experience. Everyone received a link to the 2023 Women's Retreat soundtrack and a list of the songs and artists to carry the experience with them.

This retreat continues to offer a space for women to form new relationships, nurture previous bonds, and foster lifetime connections. We are so grateful to our speakers, event sponsors, Ann Arbor Sheraton hotel staff, HFM staff, and especially the women that shared in this experience. 🩸

THANK YOU TO OUR SPONSORS

SOARING EAGLE SPONSOR:

sanofi

HAPPY CAMPER SPONSOR:

CSL Behring

FRIENDS OF HFM SPONSORS:

Genentech
A Member of the Roche Group

octapharma

Spark THERAPEUTICS

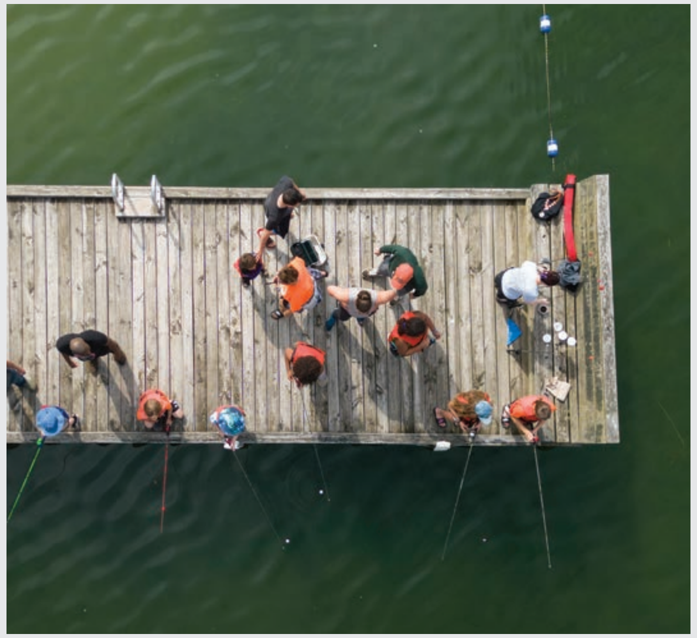
EVENT SPONSOR:

ARJ INFUSION SERVICES

HFM does not endorse any specific product or company.

hfm

EAGLE JOURNEYS
CAMPING PROGRAMS


A view from above! We love to spend time on the waterfront, including fishing from the dock.


Associate Camp Director, Travis Miller, battles his opponent during Pokemon night, a classic counselor hunt game.


Session One camper plays a game of basketball during outdoor rec.


Associate Camp Director, Angellica "Gelli" Kelley, can't keep the smiles in while preparing snacks for the evening program.


Campers from our young girls cabin enjoy ice cold snow cones at our Big Carnival evening program!


Session One campers wait in line to play one of the many carnival games–and win some prizes!


There's nothing like a carpet ball win to make the crowd go wild!


Session One camper enjoying the face painting talents of CBE's counselors.


A Session One camper learns the string method of making BIG bubbles.


CBE counselor, Dawson, enjoys a snow cone with his cabin.

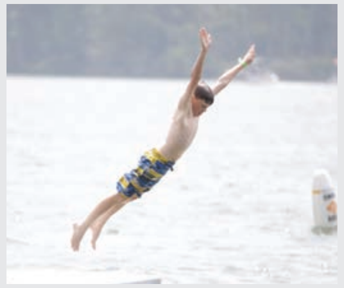

We love this twinning moment between Associate Camp Director, Angellica "Gelli" Kelley, and one of our Session One campers.


Camp Bold Eagle campers LOVE gaga!

©Brian Sevald Photography and ©SonjaMcGovern


Session Two campers can participate in a variety of outdoor activities at camp, including fishing!


Swim buddies! Safety is a priority at Camp Bold Eagle. All campers are required to have a swim buddy anytime they enjoy Big Blue Lake.


We love when campers take 'Eagle Steps' at camp, and sometimes an Eagle JUMP!


Program Director, Anne Henningfeld, gets caught in the midst of chalk bombs during the Session Two evening program, Chalk Chase.


An Eagle's Nest camper shows off his camp buttons.


Each camp session starts with an opening campfire where campers share a song or skit!


Camp Director Tim Wicks and his wife and son share a skit with the Eagle's Nest family campers!


Eagle's Nest counselors and staff show our campers how to BE camp by singing songs, being silly, and having fun!


Does anyone know what song they are singing? Hint: It includes a Buffalo and His Brother!


Families at Eagle's Nest spent time on Big Blue Lake kayaking, canoeing, and swimming!


An Eagle's Nest family enjoys watching the opening campfire skits.

THANK YOU TO OUR SPONSORS

BIG BLUE LAKE SPONSORS:

CASCADE HEMOPHILIA CONSORTIUM SINCE 1994 • CSL Behring • galens tag days • Genentech A Member of the Roche Group • Takeda

CAMPFIRE SPONSORS:

CK Colburn Keenan Foundation, Inc. • CVSHealth.

POLAR BEAR SPONSORS:

novo nordisk® • sanofi

ARTS AND CRAFTS SPONSORS:

THE ALLSTATE FOUNDATION • BAYER • GRIFOLS • PFIZER • YOUTH FOUNDATION OF AMERICA

HFM does not endorse any specific product or company.

TOOTH TIME

JENNIFER KERNS, BS, RDH, NORTHWEST MICHIGAN HEALTH SERVICES

HELLO AND HAPPY ORAL HEALTH! THIS ISSUE OF TOOTHTIME IS DEDICATED TO TOOTHPASTE. THERE ARE MANY OPTIONS OUT THERE, BUT PERSONAL PREFERENCE IS PROBABLY THE MOST IMPORTANT ASPECT TO PROMOTE PLEASURABLE HABIT FORMATION INSTEAD OF TURNING TOOTHBRUSHING INTO A DREADED DAILY CHORE. TOOTHPASTE CAN INCLUDE A VARIETY OF INGREDIENTS FOR PATIENT SATISFACTION, BUT NOT ALL INGREDIENTS ARE BENEFICIAL. I'LL BREAK DOWN WHAT THE COMMON INGREDIENTS ARE AND HOW THEY MIGHT IMPACT YOUR TEETH AND ORAL HEALTH.

Silica are tiny little microbeads that are added for abrasiveness. This can force plaque, food debris, and stains off your teeth, but once you brush through those layers of debris or if you don't have much debris, then you begin wearing away the enamel of the tooth. This scratching can turn teeth yellow over time and create tooth sensitivity and/or recession of the gums. Whitening toothpaste usually has more abrasives added and I do not recommend whitening toothpaste for this reason.

Sodium lauryl sulfate is the ingredient that makes toothpaste foam and bubble, giving you that clean fresh feeling. Many patients are sensitive to this ingredient, especially in the brands with lower acidity, creating a slight burning sensation. Patients suffering from dry mouth or those going through chemotherapy/radiation therapy are at risk of increased sensitivity to this ingredient.

Fluoride is another ingredient added to paste and can be found in various forms. Stannous fluoride is more acidic, so it can be irritating to crowns and bridges and tissues over time. Sodium fluoride is less acidic, so it is the more commonly used fluoride additive. Toothpaste without fluoride will not protect your teeth from daily acid attacks leading to cavities, so make sure your toothpaste includes some form of fluoride.

Whatever toothpaste you choose make sure you enjoy the flavor. If you suffer from any of the above side effects, or have questions about your toothpaste, talk to your dental provider. Happy brushing! 💧

Contact Jennifer
231-721-5337
jkerns@nmhsi.org

NEED DENTAL INSURANCE?
If you are uninsured or underinsured with your dental coverage, we may be able to help. We understand that our community faces challenges obtaining dental care to meet unique and individual needs. HFM has partnered with Cascade Hemophilia Consortium to offer free dental insurance to those who need it.

QUESTIONS?
Contact Ashley Fritsch, Delta Dental & Medical ID Assistant, at **afritsch@hfmich.org** or **734.544.0015**

You can find the application here: **www.hfmich.org/dental-health**

In order to be eligible for this program you must:

- Have a bleeding disorder
- Be a Michigan resident
- Have no dental insurance or only Children's Special Health Care Services
- However, if you have Medicare, Medicaid, or an employer based private insurance plan you may be eligible for limited-time coverage based on special circumstances – these exceptions are limited and determined on a case-by-case basis. Please call us for more information. 💧

**To maintain your coverage, you must visit the dentist two times during the calendar year for regular teeth cleanings.*

CASCADE HEMOPHILIA CONSORTIUM SINCE 1994
DELTA DENTAL
hfm

DO YOU HAVE A DENTAL QUESTION WEIGHING ON YOUR MIND? CONFUSED ABOUT YOUR DENTAL CARE? EMAIL ASHLEY FRITSCH WITH YOUR QUESTIONS! AFRITSCH@HFMICH.ORG

CENTER OF CARE

HENRY FORD OUTREACH CLINICS

THANK YOU TO CONTRIBUTING AUTHORS: ELLEN KACHALSKY, LMSW, ACSW, INTEGRATED CASE MANAGER/SOCIAL WORKER, HENRY FORD HEALTH SYSTEM, HEMOPHILIA AND THROMBOSIS TREATMENT CENTER AND M. LINDA MUELLER, MSN, RN, NURSE COORDINATOR, HENRY FORD HEALTH SYSTEM, HEMOPHILIA AND THROMBOSIS TREATMENT CENTER

In 1993, Henry Ford Health started the Adult Bleeding Disorder Center based in Detroit. Through a research project, it was discovered that there was a large population of persons with bleeding disorders living north-east of Detroit. To better serve that population, we decided to establish an outreach clinic.

While the decision was easy, the planning was more challenging than one would expect. We worked with the hospital system, which has many clinics throughout southeastern Michigan, to determine a location for our outreach clinic. The team decided to partner with the Richmond clinic that allowed us to rent space, including our own specific clinic area with exam rooms and an office. Due to the distance, the whole treatment center team travels to Richmond for a day long clinic–compared to the half day we operate our Detroit clinic.

(Left to right) Nazir Ahmed, PT; Ellen Kachalsky, LMSW, ACSW, Social Worker; Linda Mueller, MSN, RN, Nurse Coordinator; Philip Kuriakose, MD; and Laura Gusba, NP

The team, including the physician, nurse practitioner, physical therapist, social worker, and nurse, sees each patient as we do in our Detroit location. Routine bloodwork is drawn and sent by courier to our nearest system hospital lab, and we ship out blood to the CDC. We have a pre-clinic planning meeting with staff at the Richmond center about labs, personnel, CSR (customer service representatives), and special transport to ensure labs are completed in a timely manner. We also hold a post-clinic meeting to review any problems and improve workflow for future clinics.

Using this clinic, we are able to refer patients to primary care, physical therapy, lab and x-ray services in the area that they live, thus saving patients the lengthy drive time to get to Detroit. Another great advantage to hosting an outreach clinic is the ability to educate providers and their staff at that location about bleeding disorders and the appropriate treatment and care. Prior to our partnership with the Richmond clinic, many staff did not even know how to pronounce hemophilia!

Today, we get calls from providers in the area who would like to refer patients to us, or have questions about product, treatment, surgery and procedures, and coordination of care.

Outreach clinics are a valuable way to bring quality care and education to underserved populations. We are grateful for this partnership! 🩸

CRAIG'S CRUISERS COMMUNITY NIGHT

To kick-off summer, HFM and community members gathered on the west side of Michigan for an evening of fun at Craig's Cruisers in Grand Rapids. From infants to grandparents, it was an event for the entire family as we began our evening by sharing a meal together. Everyone's dinner was unique as attendees filled their plates at the buffet which included pizza, tacos, salad, pasta, and so much more!

Allison Postma, from the Helen DeVos Children's Hospital HTC, joined us to discuss what someone with a bleeding disorder should pack when traveling for the summer. Kids shared what items they'd bring with them to summer camp and adults spoke about supplies one might need on a family vacation or perhaps a cruise or trip abroad. An important takeaway for all was the need to plan ahead and discuss travels in advance with your HTC to review documents, medication, and other items needed when traveling.

Following our group activity, attendees had the opportunity to further connect with Allison and also visit with sponsors. Families then ventured out to explore Craig's Cruisers and enjoy the variety of attractions and giant arcade. Some attendees floated around the bumper boat pond while others raced on go-karts, rode the Cruiser Coaster, and soared over the mini-golf course on a zip line. To end the evening on a sweet note, folks indulged in the cookie and ice cream buffet, and some made root beer floats for dessert. We appreciate everyone who joined us for this informative and lively Community Night! 🩸

HFM does not endorse any specific product or company.

THANK YOU TO OUR SPONSORS:

SOARING EAGLE SPONSOR:

sanofi

HAPPY CAMPER SPONSORS:

CSL Behring

novo nordisk®

FRIENDS OF HFM SPONSORS:

Genentech
A Member of the Roche Group

octapharma®

Spark
THERAPEUTICS

EVENT SPONSORS:

BAYER

BIOMARIN

Pfizer

ARJ INFUSION SERVICES

DROPPING ANCHOR:
STAYING STEADY IN LIFE'S EMOTIONAL STORMS

STEVE EDWARDS, LMSW
MICHIGAN STATE UNIVERSITY CENTER FOR BLEEDING AND CLOTTING DISORDERS

Do you ever feel as though you are losing a battle with your own thoughts and feelings? And no matter how much you try, fighting just seems to make it worse? Many people struggle with getting rid of negative thoughts and feelings. Some people turn to negative coping methods and try to use alcohol or drugs to stop their thoughts and feelings. Other people might avoid situations that make them feel bad or use video games and social media to escape reality. While these strategies might have some short-term payoff and success, they also have long-term consequences for physical, mental, and spiritual health. Sometimes it feels as though we're stuck in a storm with no end in sight. How do we get through these storms? The same way a boat stays steady in a storm: by dropping anchor.

In the acceptance and commitment therapy (or ACT) model, "dropping anchor" is a strategy to address the "storms" that come in our lives. A good formula to remember is ACE:

ACKNOWLEDGE YOUR THOUGHTS & FEELINGS

CONNECT WITH YOUR BODY

ENGAGE WITH THE WORLD

Acknowledging can mean saying to yourself "I notice that I am upset" or "I notice that I have anxiety." While this doesn't make those symptoms go away, it can help to acknowledge that they are there, and reduce their painful impact by naming them.

Connecting with your body can mean utilizing deep breathing, muscle relaxation exercises, and stretches (please be mindful of any physical limitations that you may have, and do not cause pain to yourself). This can help you stay in control of what you can control – your own body – and help you act effectively during the storm.

Engaging with the world means using your five senses to be fully present focused in your surroundings, and noticing what you can see, hear, smell, taste, and touch in your environment. This is not to distract you or attempt to avoid your negative feelings. Rather, this is for you to notice that you are still in your environment, and that the world still exists even in the presence of negative thoughts and feelings. This can help you be less overwhelmed during storms. It is recommended that you practice this exercise when there is no storm in order to become comfortable with the skills.

Please remember, dropping anchor doesn't make the storm go away, but it does help keep us steady until the storm passes. 🩸

For more information, including audio recordings of dropping anchor exercises, please visit **https://www.actmindfully.com.au/** and click on the "Free Stuff" tab. Please note that this is not a substitute for therapy. If you are experiencing a mental health crisis, please dial 911 or go to your nearest emergency room. If you are in need of therapy resources, please contact your insurance carrier or your HTC social worker for resources.

ALTUVIIIO™
Antihemophilic Factor (Recombinant),
Fc-VWF-XTEN Fusion Protein-ehtl

FACTOR UP with ALTUVIIIO™

Higher-for-longer Factor VIII levels in the near-normal to normal range **(over 40%)** for most of the week

HIGHER FACTOR LEVELS FOR LONGER
Above 40% for most of the week (near-normal to normal range).[*,†]

48 HOUR HALF-LIFE IN ADULTS
In a Phase 3 study,[†] ALTUVIIIO offered adults the longest half-life of any Factor VIII therapy.

0.7 BLEEDS PER YEAR[‡]
Mean annual bleed rate observed in 128 people previously treated with prophylaxis therapy.[†]

In people taking ALTUVIIIO in the XTEND-1 study, 21% of people had headache, 16% had joint pain, and 6% had back pain

[*] Average trough levels were 18% for adults 18 years and older, 9% for adolescents aged 12 years to under 18 years, 10% for children aged 6 years to under 12 years, and 7% for children aged 1 year to under 6 years.
[†] 159 adults and adolescents with severe hemophilia (aged 12 years and older) were enrolled in the XTEND-1 study; 133 people were in Group 1 and switched to ALTUVIIIO prophylaxis from prior prophylaxis therapy. Efficacy of prophylaxis was evaluated in 128 of these patients.
[‡] Data based on treated bleeds.

CONNECT WITH YOUR CoRe TODAY

Learn more about ALTUVIIIO, living with hemophilia, and treatment options from your local CoRe.

Angel Guess
angel.guess@sanofi.com
586-942-5485
Serving MI

INDICATION

ALTUVIIIO™ [antihemophilic factor (recombinant), Fc-VWF-XTEN fusion protein-ehtl] is an injectable medicine that is used to control and reduce the number of bleeding episodes in people with hemophilia A (congenital Factor VIII deficiency).

Your healthcare provider may give you ALTUVIIIO when you have surgery.

IMPORTANT SAFETY INFORMATION

What is the most important information I need to know about ALTUVIIIO?
Do not attempt to give yourself an injection unless you have been taught how by your healthcare provider or hemophilia center. You must carefully follow your healthcare provider's instructions regarding the dose and schedule for injecting ALTUVIIIO so that your treatment will work best for you.

Who should not use ALTUVIIIO?
You should not use ALTUVIIIO if you have had an allergic reaction to it in the past.

What should I tell my healthcare provider before using ALTUVIIIO?
Tell your healthcare provider if you have had any medical problems, take any medications, including prescription and non-prescription medicines, supplements, or herbal medicines, are breastfeeding, or are pregnant or planning to become pregnant.

What are the possible side effects of ALTUVIIIO?
You can have an allergic reaction to ALTUVIIIO. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.

Your body can also make antibodies called "inhibitors" against ALTUVIIIO. This can stop ALTUVIIIO from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

The common side effects of ALTUVIIIO are headache, joint pain, and back pain.

These are not the only possible side effects of ALTUVIIIO. Tell your healthcare provider about any side effect that bothers you or does not go away.

Please see brief summary of Prescribing Information on the next page.

sanofi

Patient Information **Rx Only**
ALTUVIIIO™ (al too'vee oh)
[antihemophilic factor (recombinant), Fc-VWF-XTEN fusion protein-ehtl] for intravenous use after reconstitution only

Single-dose vial
Please read this Patient Information carefully before using ALTUVIIIO and each time you get a refill, as there may be new information. This Patient Information does not take the place of talking with your healthcare provider about your medical condition or your treatment.

What is the most important information I need to know about ALTUVIIIO?
Do not attempt to give yourself an injection unless you have been taught how by your healthcare provider or hemophilia center.
You must carefully follow your healthcare provider's instructions regarding the dose and schedule for injecting ALTUVIIIO so that your treatment will work best for you.

What is ALTUVIIIO?
ALTUVIIIO is an injectable medicine that is used to control and reduce the number of bleeding episodes in people with Hemophilia A (congenital Factor VIII deficiency).
Your healthcare provider may give you ALTUVIIIO when you have surgery.

Who should not use ALTUVIIIO?
You should not use ALTUVIIIO if you had an allergic reaction to it in the past.

What should I tell my healthcare provider before using ALTUVIIIO?
Talk to your healthcare provider about:
- Any medical problems that you have or had.
- All prescription and non-prescription medicines that you take, including over-the-counter medicines, supplements or herbal medicines.
- Pregnancy or if you are planning to become pregnant. It is not known if ALTUVIIIO may harm your unborn baby.
- Breastfeeding. It is not known if ALTUVIIIO passes into the milk and if it can harm your baby.

How should I use ALTUVIIIO?
You get ALTUVIIIO as an injection into your vein. Your healthcare provider will instruct you on how to do injections on your own, and may watch you give yourself the first dose of ALTUVIIIO.
Contact your healthcare provider right away if bleeding is not controlled after using ALTUVIIIO.

What are the possible side effects of ALTUVIIIO?
You can have an allergic reaction to ALTUVIIIO. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash or hives.
Your body can also make antibodies called "inhibitors" against ALTUVIIIO. This can stop ALTUVIIIO from working properly. Your healthcare provider may give you blood tests to check for inhibitors.
The common side effects of ALTUVIIIO are headache, joint pain, and back pain.
These are not the only possible side effects of ALTUVIIIO. Tell your healthcare provider about any side effect that bothers you or does not go away.

What are the ALTUVIIIO dosage strengths?
ALTUVIIIO comes in seven different dosage strengths with 3 mL sterile water for injection (sWFI). The actual number of international units (IU) of Factor VIII activity in the vial will be imprinted on the label and on the box. The seven different strengths are as follows:

Strength	Cap Color
250 IU	Yellow
500 IU	Red
750 IU	Garnet
1000 IU	Green
2000 IU	Royal Blue
3000 IU	Mist Grey
4000 IU	Orange

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 ALTUVIIIO?
- Keep ALTUVIIIO in its original package.
- Protect it from light.
- Do not freeze.
- Store refrigerated 2°C to 8°C (36°F to 46°F) up to 48 months or at room temperature [not to exceed 30°C (86°F)], for a single period up to 6 months. Do not use ALTUVIIIO after the expiration date printed on the label and carton of each vial.
- When storing at room temperature:
  - Note on the carton the date on which the product is removed from refrigeration.
  - Use the product before the end of this 6-month period or discard it.
  - Do not return the product to the refrigerator.

After mixing with the diluent:
- Do not use ALTUVIIIO if the mixed solution is not clear and colorless to slightly yellowish.
- Use mixed product as soon as possible.
- You may store mixed ALTUVIIIO at room temperature, not to exceed 30°C (86°F), for up to **3 hours**. Protect the mixed ALTUVIIIO from direct sunlight. Discard any mixed ALTUVIIIO not used within 3 hours.

What else should I know about ALTUVIIIO?
Medicines are sometimes prescribed for purposes other than those listed here. Do not use ALTUVIIIO for a condition for which it was not prescribed. Do not share ALTUVIIIO with other people, even if they have the same symptoms that you have.

Manufactured by:
Bioverativ Therapeutics Inc.
Waltham, MA 02451
A SANOFI COMPANY
US License Number 2078

AHF-PPI-SL-FEB23

HOW PRIVILEGE IMPACTS PATIENT CARE

DEAN M. HINDENLANG, PHD
DIRECTOR OF PUBLIC POLICY AND STRATEGIC INITIATIVES
CASCADE HEMOPHILIA CONSORTIUM

The Hemophilia Foundation of Michigan (HFM) has long valued its diverse community, working collaboratively with hemophilia treatment centers (HTCs) across the Great Lakes Region to ensure that every member of the bleeding disorders community is appropriately represented. As the Regional Core Center, which offers administrative oversight and guidance to the region's 19 HTCs, HFM is particularly interested in making certain that every person living with a bleeding disorder is receiving holistic, comprehensive care, wherever they may live within the region's three states. Moreover, the region's HTCs have included a grant goal, as part of their new five-year federal grant award, to help create a diversity and inclusion plan to identify and address health equity issues for persons receiving care at an HTC within Michigan, Ohio, and Indiana.

However, as with any effort that seeks to address access to care issues, especially within the areas of diversity, equity, and inclusion (DEI), it is essential to ensure that those offering patient care have the education, tools, vocabulary, and resources to help facilitate such an ambitious grant goal. That's why in June 2023, HFM hosted "How Privilege Impacts Patient Care," a workshop that engaged participants in a candid, yet respectful discussion, about personal privilege and how best to facilitate meaningful and action-oriented discussions with patients, family members, co-workers, and institutional leadership, in important change efforts—even if incremental, at first. The workshop was built around the idea that each of us possesses a level of privilege that is unique unto ourselves, such as education, race, gender, or job title that may grant us an advantage. Knowing when and how to effectively recognize and utilize personal privilege is an essential learned skill, especially when advocating for our bleeding disorders patients, which takes a bit of practice and candid dialogue.

Being inclusive has been central to the bleeding disorders community for many years. The community has long known that welcoming everyone that is impacted by a bleeding disorder is the best possible way of ensuring patients and families are cared for most effectively. However, as topics of race, sexual orientation, gender identity and expression, age, disability, and socio-economic status continue to percolate across the United States, the Great Lakes Region is addressing these social issues candidly, directly, and through ongoing educational opportunities.

Those in attendance acknowledge that a workshop such as "How Privilege Impacts Patient Care" is a starting place and not an endpoint. The hard work happens behind closed doors, during patient consultations, and in being okay with having conversations that may be uncomfortable, even while understanding that they are well-intentioned, and meant to offer every member of the bleeding disorders community a respectful, all-inclusive place at our big community table.

Inspired by community feedback, and to build upon programming that was supported through a Genentech charitable grant, HFM applied for grants from the Hemophilia Alliance Foundation and the National Hemophilia Foundation to develop a four-part virtual series centered on the needs and concerns of adults aging in the bleeding disorders community. To design the Aging Together program, HFM collaborated with community members, HTC staff, and an art therapist. Each session explored a different topic through educational presentations, group dialogues, and a variety of creative expression activities.

To introduce the format and encourage participation in the series, a preview session was held in January where attendees learned about diverse cultural aging practices and kintsugi–the Japanese art of repairing broken pottery with lacquer dusted with gold, silver, or platinum. Attendees used this technique to repair a broken ceramic dish while our art therapist guided us through the sensations and feelings arising in our bodies as we discussed the challenges and beauty that can be found in repairing what's been broken.

The four-part Aging Together series officially began in February and creative expression activity supplies were shipped to attendees' homes. Throughout the series, we were joined by more than 40 adults from Michigan's bleeding disorders community who gathered virtually to build understanding and connection online during the frigid winter months. The first two sessions were facilitated by HTC social workers and included a presentation on mental health and aging and a group dialogue on moving through vulnerability to create new connections and opportunities for oneself. We explored the use of collaging to create a map of our life's journey and used watercolors to express ourselves. Our next session was facilitated by a beloved community member who discussed how pain can increase one's feelings of loneliness or depression. While sharing a personal conversation on their unique experiences with pain, attendees engaged in a tactile creative expression activity by shaping clay into an object or expression of their pain.

For our final session, we were joined by an occupational therapist to discuss home safety, universal design, and prevention tips for someone aging with a bleeding disorder. To close the evening, we held an intergenerational panel comprised of adults and elders in the Michigan bleeding disorders community. They shared their experiences of growing up with a bleeding disorder, including the evolution of treatment and education, and what they drew upon for sources of strength and resiliency. It was a beautiful display of how the courageous act of vulnerability can lead to new community connections and understanding for others.

The Aging Together series was just one part of HFM's commitment to continuing conversations on the experiences of those aging with a bleeding disorder. The feedback we received from this series will continue to inspire sessions and new areas to explore at future HFM events. ●

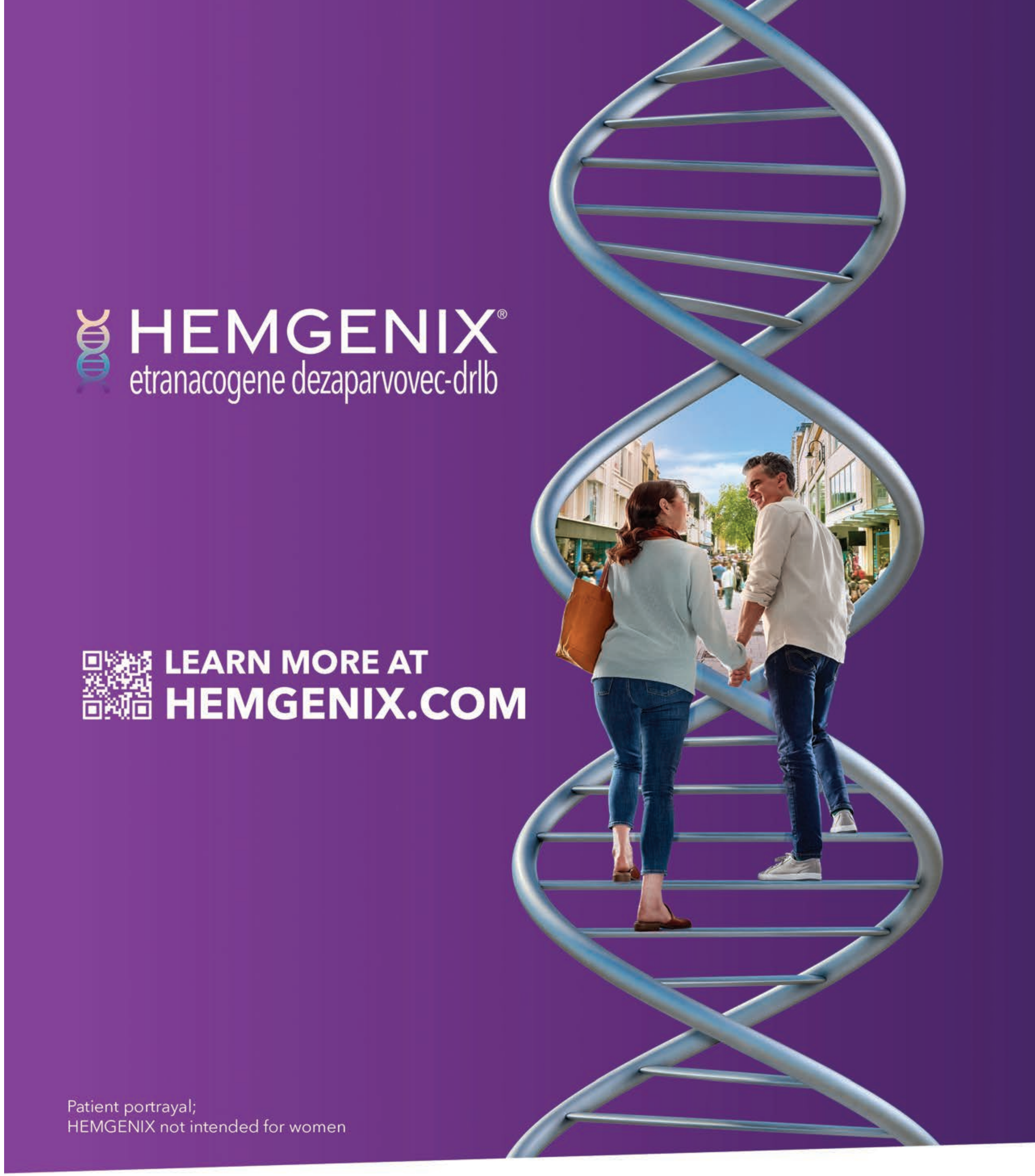
THANK YOU TO OUR SPONSORS:

Genentech
A Member of the Roche Group

Hemophilia Alliance Foundation

National Hemophilia Foundation
for all bleeding disorders

HFM does not endorse any specific product or company.



BE READY FOR THE UNEXPECTED

ONCE-WEEKLY REBINYN® HELPS YOU KEEP FACTOR 9 LEVELS HIGHER FOR LONGER[a]

Expect higher factor levels and bleed protection with once-weekly Rebinyn®.[b]

~80% With once-weekly Rebinyn®, adults and adolescents with hemophilia B can spend approximately 80% of their week with Factor 9 levels in the non-hemophilia range (greater than 40%).[b]

115 hour half-life in adults treated with Rebinyn® 40 IU/kg[c]

103 hour half-life in adolescents treated with Rebinyn® 40 IU/kg[c]

Visit www.rebinyn.com to learn more about once-weekly Rebinyn®

---

[a] Rebinyn® achieved and maintained higher factor levels than recombinant Factor 9 based upon a phase 1 study comparing 25, 50, and 100 IU/kg doses of Rebinyn® to a 50 IU/kg dose of standard half-life recombinant Factor 9 in 7 adults and a 50 IU/kg dose of plasma-derived Factor 9 in 8 adults. For Rebinyn®, estimated average Factor 9 activity is adjusted to a dose of 50 IU/kg. Incremental recovery at 30 minutes (IR_{30}) and half-life were higher and longer with Rebinyn® than recombinant Factor 9 (IR_{30} 0.0131 vs 0.0068 (IU/mL)/(IU/kg) and half-life 93 vs 19 hours). The clinical relevance of these pharmacokinetic differences is unknown.

Incremental Recovery: The increase in plasma concentration per IU/kg of factor administered.

Half-life: The time it takes for the level of factor in the blood to fall by half (50%).

[b] Data represent mean steady-state pharmacokinetic (PK) profiles from previously treated adolescent/adult patients with moderate-to-severe hemophilia B (N=9) taking repeated doses of Rebinyn® 40 IU/kg once weekly. Factor 9 levels were within the non-hemophilia range (greater than 40%) for 5.4 days (about 80% of the week).

[c] Based on analysis using a 1-stage assay in patients (N=6) aged 18 and older, the half-life at steady state was 115 hours following once-weekly (40 IU/kg) dosing; in patients (N=3) aged 13 to 17, the half-life at steady state was 103 hours. Following single-dose administration (40 IU/kg) in the same patient population, the half-life was 83 hours (adults) and 89 hours (adolescents).

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, prevent, or reduce the frequency (number) of bleeding episodes in people with hemophilia B. Your healthcare provider may give you Rebinyn® when you have surgery. Rebinyn® is not used 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 healthcare provider before using Rebinyn®?

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, 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** infusion site reaction (bruising, bleeding, swelling, pain, or redness), itching, and rash.
- Your body can also make antibodies called "inhibitors" against Factor IX, including Rebinyn®, which may stop Rebinyn® from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.
- **Call your healthcare provider right away or get emergency treatment right away if you get, for example, any of the following signs of an allergic reaction:** hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.
- 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) in certain cells in 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.

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

Printed in the U.S.A. US22REB00167 October 2022

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, as 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, prevent, or reduce the frequency (number) of bleeding episodes in people with hemophilia B.

Your healthcare provider may give you REBINYN® when you have surgery.

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. It is not known if REBINYN® passes into breast milk or if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if REBINYN® may harm your unborn baby.
- Have been told that you have inhibitors to Factor IX (because REBINYN® may not work for you).

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 speak to your healthcare provider if you have any questions or concerns.

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:

- infusion site reaction (bruising, bleeding, swelling, pain, or redness)
- itching
- rash

Your body can also make antibodies called "inhibitors" against Factor IX, including REBINYN®, which may stop REBINYN® from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

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, for example, any of the following signs of an allergic reaction:** hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.

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.

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 four 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 four 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
Dark Gray	3000 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.

For more information about REBINYN®, please call Novo Nordisk at 1-844-REB-INYN.

Revised: 08/2022

For Patent Information, refer to: http://novonordisk-us.com/products/product-patents.html

Manufactured by:
Novo Nordisk A/S
Novo Allé, DK-2880 Bagsværd, Denmark

More detailed information is available upon request.

Available by prescription only.

For information about REBINYN® contact:
Novo Nordisk Inc.
800 Scudders Mill Road
Plainsboro, NJ 08536, USA

US22REB00153 August 2022

novo nordisk®

In June 2023, Representative Carrie Rheingans announced legislation to reform copay accumulator programs in Michigan.

MACC COALITION CELEBRATES INTRODUCTION OF MI COPAY ACCUMULATOR LEGISLATION

The Michigan All Copays Count Coalition (MACC) is happy to share that we have secured Representative Carrie Rheingans (D) from the 47th district to sponsor the 2023-2024 accumulator legislation. Our previous sponsor, Representative Bronna Kahle, termed out at the end of 2022 which required us to find a new champion for our issue. Representative Rheingans has a strong background in health policy and a history of patient advocacy work—we are very excited to be working with her!

HFM joined Representative Rheingans, along with patient advocates from the Michigan All Copays Count Coalition (MACC), in Lansing on June 6 to announce the legislation. Representative Rheingans shared, "No Michigander should ever have to go without their life saving medication because of the cost. By ensuring that all copays count, we'll get one step closer to making this a thing of the past."

Shortly after our press conference, the legislation was introduced in the Michigan House with 29 cosponsors, including three Republican representatives keeping our legislation a bipartisan issue.

The legislation (House Bill 4719) has been referred to the House Insurance Committee. The MACC steering committee has started outreach to committee members to provide in-depth education on the bill and to ask for a hearing as soon as possible.

We look forward to working with Representative Rheingans to pass copay accumulator reform and add to the growing lists of states who are stepping up to protect patients!

SPRINGFEST 2023

SPRING INTO HARMONY

HFM held our biggest community event, SpringFest, on May 6 and 7, at the Eagle Crest Marriott hotel in Ypsilanti, Michigan. Over three hundred and twenty participants attended this year's event, with an additional 50 community members who joined SpringFest through a virtual connection. The opening keynote address was delivered by Tim Ringgold, a music therapist and nationally known speaker. Egg shaped shakers were handed out to all attendees, and Tim conducted the audience in shaking their eggs in coordinated rhythm. His inspirational talk encouraged audience members to incorporate music into their lives, which can lead to reduced stress and increased enjoyment of life.

Across Saturday and Sunday, there were more than twenty-five educational programs that attendees could choose from through breakout sessions, teen programming, and various speakers. Topics ranged from information and treatment of different diagnoses such as factor VII and von Willebrand disease to gene therapy research, aging with a bleeding disorder, challenges for children diagnosed as mild or moderate, and more. A very special panel presentation shared information about emergency response in Michigan and the risks for people with bleeding disorders, with HTC staff and family members sharing personal stories and ways in which to best advocate for ourselves and others in emergency situations. On Saturday afternoon, teens attended a session facilitated by University of Michigan staff who set up experiential challenges seeking to teach cooperation and teamwork. Other sessions for teens included Communication and Consent, Failure is Not an Option, and Mental Health for Teens.

On Saturday evening Believe Limited hosted a Science Fair with exhibits that presented teens, adults, and families alike the opportunity to learn about the science behind bleeding disorders by combining the interactivity of a true "science center" exhibit with the visual style of the classic science fairs we all grew up with.

SpringFest was evaluated through online feedback forms and paper evaluations. Many participants found the breakout sessions very interesting and appreciated the diverse topics, whether they participated in person or virtually:

"I enjoyed all the sessions I attended, and I enjoyed that everyone was so nice and were genuinely happy that we were there. I liked that all the breakout sessions seemed interesting, it was hard for me to choose which ones I wanted to go to."

"I enjoyed the educational parts being said in ways I could understand, and having relevant, relatable topics, like the physical therapy session, and the stress management music therapy. It was also nice being able to talk to the other online participants to hear their stories and thoughts even though we weren't in the same place."

HFM is planning to rotate SpringFest to different locations in the state in the future. Stay tuned to find out where we will be traveling to in 2024!

THANK YOU TO OUR SPONSORS

SOARING EAGLE SPONSORS

BIOMARIN
sanofi
Takeda

PROGRAM SPONSORS

CASCADE HEMOPHILIA CONSORTIUM SINCE 1994
THE HEMOPHILIA ALLIANCE
HFA Hemophilia Federation of America
NATIONAL HEMOPHILIA FOUNDATION for all bleeding disorders

HAPPY CAMPER SPONSORS

CSL Behring
novo nordisk®

FRIENDS OF HFM SPONSORS

EthicalFactorRX
Genentech A Member of the Roche Group
octapharma®
Pfizer
Spark THERAPEUTICS

SPRINGFEST DISPLAY SPONSORS

ACCREDO • ARJ INFUSION SERVICES • BAYER • BIOMATRIX • CVS SPECIALTY HEMA BIOLOGICS • MEDEXUS • OPTUM

HFM does not endorse any specific product or company.

© Sonja McGovern Photography

STAFF UPDATES

HFM IS PLEASED TO WELCOME FIVE NEW STAFF MEMBERS TO OUR TEAM, SAYDI DAVIS, ANGELLICA KELLEY, TRAVIS MILLER, ZACH RYAN, AND KAITE SCOTT. SAYDI DAVIS IS THE NEW REGIONAL PROGRAM MANAGER. ANGELLICA AND TRAVIS ARE WORKING AS ASSOCIATE CAMP DIRECTORS AND PROGRAM SERVICES MANAGERS. ZACH RYAN IS THE NEW ADVOCACY AND POLICY MANAGER AND KAITE SCOTT IS JOINING US AS A SOCIAL WORK AND PROGRAM SERVICES MANAGER.

SAYDI DAVIS, LLMSW

Saydi has a master's degree in social work from the University of Michigan School of Social Work. Saydi focuses her social work practice on community change to achieve sustainable, equitable, comprehensive, and accessible health care for everyone. Prior to joining HFM, she worked with various nonprofits to develop and foresee programs to advance social justice. She currently instructs yoga for individuals and families impacted by substance use disorders, and therapeutic yoga classes for those struggling with grief and loss in Washtenaw County. Saydi adores being surrounded by her family, friends, her cats, Opal & Dale, and her husband, Carson.

ANGELLICA "GELLI" KELLEY, BSN, RN

Prior to joining HFM as Associate Camp Director and Program Services Manager, Angellica "Gelli" Kelley worked as a Hematology/Oncology floor nurse, which provided invaluable experience working with patients impacted by chronic health concerns. Gelli is living with type 1 von Willebrand disease and became involved with HFM Eagle Journeys as a camper in 2012. As she continued her camp experiences, Angellica served as a counselor for HFM camping programs, eventually attaining roles as head counselor and Counselor-in-Training (CIT) director at Camp Bold Eagle where she developed a passion for encouraging the growth of other leaders in HFM's camp community. Angellica prioritizes compassionate care, inclusivity, and acceptance in all that she does.

TRAVIS MILLER, MEd

Travis Miller graduated from Ohio University with a master's degree in secondary education and a bachelor's in history. Passionate about education and creating inclusive environments for learning and growth, Travis is committed to utilizing this commitment at camp as he has in the classroom. Travis relocated to Michigan from Hawaii, where he was teaching social studies, to serve as Associate Camp Director and Program Services Manager. Travis is living with severe hemophilia A and first met the HFM team as a 14-year-old camper. He went on to volunteer at Camp Bold Eagle from 2010 to 2016 and received the Spirit of the Eagle Award which had a wonderful, positive impact on his life.

ZACH RYAN, MPP

Zach comes to us with more than 5 years of policy and advocacy experience from his time working at several nonprofit organizations. Zach holds a bachelor's degree in political science from Roanoke College in Salem, VA, and a Master of Public Policy from Northeastern University in his hometown of Boston, MA. He has lived in Ann Arbor for the past year and has enjoyed exploring all that Michigan has to offer. Zach looks forward to utilizing his advocacy experience to enhance access to care for Michiganders living with bleeding disorders. He recently participated with the National Bleeding Disorders Conference.

KAITE SCOTT, LLMSW

Kaite Scott joins the HFM team after spending much of her professional life serving children and families in various capacities ranging from early childhood programming, social justice education, and Clinical Infant Mental Health therapy at Washtenaw County Community Mental Health. In these roles, Kaite strived to empower families, assisted in removing barriers, and facilitated meaning-making experiences for individuals. She hopes to bring this same energy and spirit into her role as Social Work and Program Services Manager at HFM. Kaite previously was a camp counselor at Camp Bold Eagle, where she was moved and inspired by the relationships that existed throughout the bleeding disorder community and the positive, magical experiences that were created and offered to the campers. Katie has a master's degree in social work from Eastern Michigan University and a bachelor of applied arts in child development from Central Michigan University.

HFM IS DELIGHTED GELLI, KAITE, SAYDI, TRAVIS, AND ZACH HAVE JOINED OUR STAFF TEAM.

ANTHONY STEVENS, MSW

Anthony completed his master's in social work from Eastern Michigan University and has begun a new career in private practice via Annie Phillips' Healing Homes.

Anthony began his involvement with HFM via Camp Bold Eagle when he was a teenager. As Associate Camp Director, Anthony provided leadership for HFM's youth retreats, expanded the LAUNCH program, and supported other programs and services. Anthony shared his sense of humor and kindness with all community members and colleagues at HFM events. As we moved programming online during the COVID pandemic, Anthony helped ensure community members had the necessary technology, access, and training needed to engage with HFM programming to stay connected. We are confident Anthony will bring these skills of connection, compassion, and expertise to his new position, helping clients and families.

LISA CLOTHIER, LMSW, ACSW, LSCW

Lisa Clothier joined HFM in 2015 as our social worker and Outreach Education Manager. She developed relationships with Michigan's HTC social workers, served on the program services team, and enhanced the Delta Dental program to provide better access to dental care for community members. Throughout her tenure Lisa's calm, confidential style led her to become a tremendously valued member of the HTC community across the region, as well as with those she worked with to provide HFM's financial assistance. Lisa's role was adjusted in 2019 when she was promoted to serve part-time with the Great Lakes Region in addition to overseeing activities such as HFM's annual scholarship program, financial assistance, and other specialized opportunities. She assisted in developing and implementing virtual region-wide meetings with professional colleagues to meet virtually within their communities of practice. Lisa was editor extraordinaire of the Regional Newsletter. Lisa has been uniquely engaged in the interviewing process for several of our new colleagues and her willingness to support HFM however possible is recognized and appreciated. We wish her all the best as she focuses on family in this next stage of life, especially her dearest grandchildren.

SARAH PROCARIO

After seven and a half years with HFM as the Advocacy Director and Communications Manager, Sarah Procario will be leaving her position to start a master's program at the University of Michigan's Ford School for Public Policy.

During Sarah's tenure, she expanded HFM's advocacy program from a single-day event (Lansing Days) to a robust, year-round program including development of a five-year strategic plan, creation of an advocacy committee, hosting our first – now annual – Advocacy Summit, building relationships across the state, and expanded funding opportunities. Due to her leadership, HFM is now considered a leader in patient advocacy within the bleeding disorders community across the country as well as health organizations across Michigan.

Additionally, Sarah has been the voice behind many of HFM's print materials, including The Artery, coordinated our website refresh, and served as the content creator of HFM's social media.

As Sarah shares, "While I am incredibly proud of what I have accomplished at HFM, I know I did not do it alone. I am grateful most of all to the Michigan bleeding disorders community and hope I gave back as much as was given to me."

ALYSSA SILLETTI, MSW

Alyssa brought innovative ideas for health education, a strong background in community building, a passion for creative expression activities, and an amazing attention to detail to HFM's program services efforts. Alyssa's facilitation skills have been apparent to many, both in person and virtually, as she led much of our teen programming at larger events, HFM's Aging Together series, and the online Dinner Talk Programs over the last year and a half.

Her commitment to social justice and health equity issues has set a strong foundation for our future work and community outreach. Alyssa will continue to host HFM's Dinner Talk programs as she considers new opportunities.

HFM WISHES ALL OF OUR COLLEAGUES THE BEST IN THEIR NEW ADVENTURES, WITH HEARTFELT THANKS FOR THE DIFFERENCE THEY MADE IN THE COMMUNITY.

40 years of octapharma 1983–2023

Contact your Octapharma Representative:

Bri McLaughlin

Phone: 551.502.7007

Email: briana.mclaughlin@octapharma.com

NUWIQ®

Antihemophilic Factor (Recombinant)

www.NUWIQUSA.com

wilate®

von Willebrand Factor/Coagulation Factor VIII Complex (Human)

www.wilateusa.com

factor my way®

Wealth of resources for patients and caregivers to help navigate care

Membership in Factor My Way is complimentary and open to anyone over the age of 18 in the USA.

factormyway.com | 855-498-4260

©2023. Octapharma USA, Inc. All rights reserved.
Date of preparation: 5/2023. NUW-0748-CAD

octapharma

PAID CONSUMER OUTREACH

"NOW MY GOALS ARE MORE ATTAINABLE THANKS TO THE FOUNDATION. I CAN NEVER EXPRESS HOW GRATEFUL I AM."

BRANDON MERCADO FRANCO

BRANDON WILL BE MAJORING IN COMPUTER SCIENCE DURING HIS UNDERGRADUATE STUDIES

"I AM VERY HONORED AND THANKFUL TO BE AWARDED THIS HFM ACADEMIC SCHOLARSHIP. THIS WILL REDUCE THE FINANCIAL BURDENS ON ME AND WILL HELP GIVE ME PEACE OF MIND TO FOCUS ON MY STUDIES. EDUCATION HAS SUCH A HUGE IMPACT ON MY LIFE AND PURSUING A COLLEGE DEGREE WILL HELP ME BE SUCCESSFUL IN TODAY'S SOCIETY. IT ALSO IS A HUGE HONOR TO REPRESENT THE BLEEDING DISORDERS COMMUNITY AND I COULD NOT BE MORE THANKFUL AND BLESSED WITH THIS SCHOLARSHIP."

GIBSON WILKE

GIBSON IS AN ACCOUNTING/FINANCE MAJOR AT CONCORDIA UNIVERSITY ANN ARBOR

CONGRATULATIONS TO OUR SCHOLARSHIP AWARD WINNERS

Tuesday 3:24 pm
Practicing yoga with her mom

Mariana, living with von Willebrand disease

Not an actual patient

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 adult patients with von Willebrand disease is stronger than ever.

bleedingdisorders.com

Not all activities are appropriate for all individuals. Consult your doctor prior to engaging in any activity.

Takeda

Copyright © 2020 Takeda Pharmaceutical Company Limited. All rights reserved. TAKEDA and the TAKEDA logo are trademarks or registered trademarks of Takeda Pharmaceutical Company Limited. US-NON-0471v1.0 03/20

PAID CONSUMER OUTREACH

STORE UP TO 104°F[a]

When the temperature rises above 86˚F

Esperoct® has you covered

The **EHL** product with the **highest** storage temperature for the **longest** time

Be prepared with

Proven protection against bleeds in adults and adolescents

- **1.2** overall bleeds per year[b]

High factor levels from one dose to the next in adults and adolescents[c]

- At or above 3% trough level for 100% of the time[d]
- At or above 5% trough level for 90% of the time[e]

EHL=extended half-life.

[a] For up to 3 months.

[b] 175 previously treated patients with severe hemophilia A received Esperoct® 50 IU/kg every 4 days for 76 weeks based on median annualized bleed rates shown.

[c] Trough level goal is 1% for prophylaxis.

[d] Data shown are from a study where 175 previously treated adolescents and adults received routine prophylaxis with Esperoct® 50 IU/kg every 4 days for 76 weeks. Pre-dose factor activity (trough) levels were evaluated at follow-up visits. Mean trough levels for adolescents (12-<18 years) were 2.7 IU/dL.

[e] Steady-state FVIII activity levels were estimated in 143 adults and adolescents using pharmacokinetic modeling.

What is Esperoct®?

Esperoct® [antihemophilic factor (recombinant), glycopegylated-exei] is an injectable medicine to treat and prevent or reduce the number of bleeding episodes in people with hemophilia A. Your healthcare provider may give you Esperoct® when you have surgery

- Esperoct® is not used to treat von Willebrand Disease

IMPORTANT SAFETY INFORMATION

Who should not use Esperoct®?

- You should not use Esperoct® if you are allergic to factor VIII or any of the other ingredients of Esperoct® or if you are allergic to hamster proteins

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

- **Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center**
- **Call your healthcare provider right away or get emergency treatment right away if you get any signs of an allergic reaction, such as:** hives, chest tightness, wheezing, dizziness, difficulty breathing, and/or swelling of the face

What should I tell my healthcare provider before using Esperoct®?

- Before taking Esperoct®, 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, pregnant or planning to become pregnant, or have been told that you have inhibitors to factor VIII
- Your body can make antibodies called "inhibitors" against Esperoct®, which may stop Esperoct® from working properly. **Call your healthcare provider right away if your bleeding does not stop after taking Esperoct®**

What are the possible side effects of Esperoct®?

- Common side effects of Esperoct® include rash or itching, and swelling, pain, rash or redness at the location of infusion

Please see Brief Summary of Prescribing Information on the following page.

Discover more at **Esperoct104.com.**

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

US20ESP00151 March 2021

esperoct®
antihemophilic factor (recombinant), glycopegylated-exei

PAID CONSUMER OUTREACH

---

esperoct®

antihemophilic factor (recombinant), glycopegylated-exei

Brief Summary information about ESPEROCT® [antihemophilic Factor (recombinant), glycopegylated-exei]

This information is not comprehensive.

- Talk to your healthcare provider or pharmacist
- Visit www.novo-pi.com/esperoct.pdf to obtain FDA-approved product labeling
- Call 1-800-727-6500

Patient Information

ESPEROCT®
[antihemophilic factor (recombinant), glycopegylated-exei]

Read the Patient Information and the Instructions For Use that come with ESPEROCT® before you start taking this medicine and each time you get a refill. There may be new information.

This Patient Information does not take the place of talking with your healthcare provider about your medical condition or treatment. If you have questions about ESPEROCT® after reading this information, ask your healthcare provider.

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

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 ESPEROCT® so that your treatment will work best for you.

What is ESPEROCT®?

ESPEROCT® is an injectable medicine used to replace clotting Factor VIII that is missing in patients with hemophilia A. Hemophilia A is an inherited bleeding disorder in all age groups that prevents blood from clotting normally.

ESPEROCT® is used to treat and prevent or reduce the number of bleeding episodes in people with hemophilia A.

Your healthcare provider may give you ESPEROCT® when you have surgery.

Who should not use ESPEROCT®?

You should not use ESPEROCT® if you

- are allergic to Factor VIII or any of the other ingredients of ESPEROCT®
- 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 ESPEROCT® might not be right for you.

What should I tell my healthcare provider before I use ESPEROCT®?

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 VIII.

How should I use ESPEROCT®?

Treatment with ESPEROCT® should be started by a healthcare provider who is experienced in the care of patients with hemophilia A.

ESPEROCT® is given as an infusion into the vein.

You may infuse ESPEROCT® 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 A learn to infuse the medicine by themselves or with the help of a family member.

Your healthcare provider will tell you how much ESPEROCT® to use based on your weight, the severity of your hemophilia A, 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 ESPEROCT®.

If your bleeding is not adequately controlled, it could be due to the development of Factor VIII inhibitors. This should be checked by your healthcare provider. You might need a higher dose of ESPEROCT® or even a different product to control bleeding. Do not increase the total dose of ESPEROCT® to control your bleeding without consulting your healthcare provider.

Use in children

ESPEROCT® can be used in children. Your healthcare provider will decide the dose of ESPEROCT® you will receive.

If you forget to use ESPEROCT®

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 ESPEROCT®

Do not stop using ESPEROCT® 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 ESPEROCT®?

Always take ESPEROCT® exactly as your healthcare provider has told you. You should check with your healthcare provider if you are not sure. If you infuse more ESPEROCT® than recommended, tell your healthcare provider as soon as possible.

What are the possible side effects of ESPEROCT®?

Common Side Effects Include:

- rash or itching
- swelling, pain, rash or redness at the location of infusion

Other Possible Side Effects:

You could have an allergic reaction to coagulation Factor VIII products. **Call your healthcare provider right away or get emergency treatment right away if you get any signs of an allergic reaction, such as:** hives, chest tightness, wheezing, dizziness, difficulty breathing, and/or swelling of the face.

Your body can also make antibodies called "inhibitors" against ESPEROCT®, which may stop ESPEROCT® from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

These are not all of the possible side effects from ESPEROCT®. 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 ESPEROCT® dosage strengths?

ESPEROCT® comes in five different dosage strengths. The actual number of international units (IU) of Factor VIII in the vial will be imprinted on the label and on the box. The five different strengths are as follows:

Cap Color Indicator	Nominal Strength
Red	500 IU per vial
Green	1000 IU per vial
Gray	1500 IU per vial
Yellow	2000 IU per vial
Black	3000 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 ESPEROCT®?

Prior to Reconstitution (mixing the dry powder in the vial with the diluent):

Protect from light. Do not freeze ESPEROCT®.

ESPEROCT® can be stored in refrigeration at 36°F to 46°F (2°C to 8°C) for up to 30 months until the expiration date stated on the label. During the 30 month shelf life, ESPEROCT® may be kept at room temperature (not to exceed 86°F/30°C) for up to 12 months, **or** up to 104°F (40°C) for no longer than 3 months.

If you choose to store ESPEROCT® at room temperature:

- Record the date when the product was removed from the refrigerator.
- Do not return the product to the refrigerator.
- Do not use after 12 months if stored up to 86°F (30°C) **or** after 3 months if stored up to 104°F (40°C) **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) ESPEROCT® should appear clear and colorless without visible particles.

The reconstituted ESPEROCT® should be used immediately.

If you cannot use the reconstituted ESPEROCT® immediately, it must be used within 4 hours when stored at or below 86ºF (30°C) or within 24 hours when stored in a refrigerator at 36°F to 46°F (2°C to 8°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 ESPEROCT® and hemophilia A?

Medicines are sometimes prescribed for purposes other than those listed here. Do not use ESPEROCT® for a condition for which it is not prescribed. Do not share ESPEROCT® with other people, even if they have the same symptoms that you have.

Revised: 10/2019

For Patent Information, refer to: http://novonordisk-us.com/patients/products/product-patents.html

More detailed information is available upon request. Available by prescription only.

Manufactured by:
Novo Nordisk A/S
Novo Allé
DK-2880 Bagsværd, Denmark

For information about ESPEROCT® contact:
Novo Nordisk Inc.
800 Scudders Mill Road
Plainsboro, NJ 08536, USA
1-800-727-6500

US19ESP00168 December 2019

PAID CONSUMER OUTREACH

734.544.0015
www.hfmich.org
1921 West Michigan Ave.
Ypsilanti, Michigan 48197

UPCOMING 2023 EVENTS

September 26
HFM Ruby Connection
Book Discussion:
Soul Broken by
Stephanie Sarazin 💻

October 2
Men's Support Group 💻

October 6-8
National Conference for Women and Teens with Hemophilia
Westin Hotel, Detroit
Metropolitan Airport and
Online 💻 👤

October 24
HFM Ruby Connection
T-shirt Rug Making 💻

October 27
Community Night:
Pumpkin Decorating 💻

November 3
Community Night:
Incredible Mo's
Traverse City, MI 👤

November 6
Men's Support Group 💻

November 11
VWD Symposium 💻

December 2
Year End Community Gathering
Troy, MI 👤

December 4
Men's Support Group 💻

FOR MORE INFORMATION AND OTHER UPCOMING HFM EVENTS, PLEASE VISIT **HFMICH.ORG/EVENTS**.

www.hfmich.org
@hfmich
www.hfmich.org/facebook
www.hfmich.org/camp

FOLLOW US!