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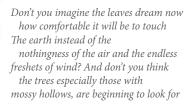
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Song for Autumn

by Mary Oliver

the birds that will come - six, a dozen - to sleep inside their bodies? And don't you hear the goldenrod whispering goodbye, the everlasting being crowned with the first Tuffets of snow? The pond stiffens and the white field over which the fox runs so quickly brings out its long blue shadows. The wind wags Its many tails. And in the evening the piled firewood shifts a little, longing to be on its way.

Dear HFM family and friends,

Yes, we ARE family.

In the bleeding disorders community so often our community friends become family. Bleeding disorders are challenging and who better understands than those affected and their loved ones? We expect to engage with our treatment team, various care providers, HFM staff and consultants—as well as one another—in long-term relationships.

Of course, there are many circumstances where community members are biological family given the hereditary nature of most bleeding disorders. We've also had 'love connections' and deep friendships that have taken place over the years via HFM camp staff, med students, nurses, etcetera! We shouldn't be surprised that caring people attract caring people—to me it makes sense when people come together in compassion and support.

As most things in life, this feeling of 'being family' - both literally and figuratively - has plenty of pros and cons. Typical boundaries can become a bit unclear and there sure are times when we must agree to disagree. Yet, I have experienced time after time when an individual or family needs support and people from our community open their arms to one another.

A few weeks before this summer's Camp Bold Eagle at Home began we determined the importance of creating a statement of inclusivity for all HFM programs and services:

HFM reaffirms what has always been in our hearts and what we aspire to convey through our actions: that each individual has inherent value and is worthy of acceptance and equality. We accept all with this respect and care regardless of their race, sexual orientation, gender identity, religion, disability, or socioeconomic status.

These words are a living document to assure our goodwill and commitment to all in the bleeding disorders community. Yes, we have opportunities for much learning as we strive for all people in our community to flourish, feel acknowledged, and heard. We want to know when we must think and react differently—and we understand this is likely to be very challenging; it will take time and requires listening and cooperating with respect for one another.

I hope you will be interested in engaging on this journey as we expand our community and family's circle of understanding.

Love, Susan



Susan Fenters Lerch HFM Executive Director Federal Great Lakes Region -V-E HTC Network Director

We are here for you.

PAID CONSUMER OUTREACH INCLUDED IN THIS NEWSLETTER.

Thoughts on the FDA approved **COVID-19 Vaccine** Susan Fenters Lerch, HFM Executive Director; Federal

Great Lakes Region - V-E HTC Network Director

I am heartbroken that the prevalence of COVID and its variants have impacted most communities across Michigan. Now with fall and the new school year upon us we need renewed vigilance to safely get through the pandemic. Our HFM Board of Directors and staff team, HTC care providers, together with vaccinated community members, invite those of you who have not yet been vaccinated to once again consider the benefit to yourself and others.

If you have questions regarding concerns with becoming vaccinated, I assure you that your hematologist and primary care physician can provide solid, helpful information.

I understand that some folks have had concerns about the emergency use

authorization by the FDA and the safety of the COVID vaccine. Of course, we remember the tragedy of tainted blood products that devastated our hemophilia community nearly four decades ago. That is an awful time in our history with lasting impacts on our trust. We have now become comfortable with recombinant products and other excellent treatment modalities, as well as finally seeing the real possibility of gene therapy. Medicine and science have proven in our community that longer and healthier lives can become reality.

On August 23, 2021, the Pfizer vaccine was formally approved by the Food and Drug Administration (FDA)*. In a statement, acting FDA Commissioner Janet Woodcock said "the public can be very confident that this vaccine meets the high standards for safety, effectiveness, and manufacturing quality the FDA requires of an approved product."

We hope that this approval eases some of your concerns and that you will consider vaccination for yourself and your family. Together, we can do this.

*The FDA's full approval applies to people 16 and older. Those ages 12 through 15 can still receive the vaccine under the existing emergency use authorization. Pfizer's vaccine accounts for about 56% of all doses administered, Moderna's COVID-19 vaccine is still under review by the FDA, but its approval is expected to follow soon.

Information & Resources You Can Use

Help us keep you informed of important information by sharing or updating your contact information with our data manager, Laura Olson at lolson@hfmich.org. We will never share or sell your name and personal information to anyone. Our team is committed to supporting you with valuable updates and resources.

AN UPDATE **FROM OUR EXECUTIVE DIRECTOR**





Dear Friends,

HFM cares deeply about the health and safety of our community members and is guided by our mission to enhance the quality of life for all affected by bleeding disorders.

As COVID-19 began to spread in Michigan in early 2020, HFM made the difficult decision to transition all our programming online. Throughout the COVID pandemic, we have continuously evaluated our offerings to ensure we are providing the safest option for education and connection based on recommendations from the CDC, the National Hemophilia Foundation, and hemophilia treatment center medical teams in addition to our staff and Board of Directors.

In Michigan, all broad epidemic orders have been lifted, including mask mandates and capacity limits. While HFM joins the community in our excitement for a possible return to pre-pandemic activities, we continue to move forward with caution recognizing children as well as immunocompromised and unvaccinated teens and adults remain at risk of contracting COVID-19 and/or variants.

This message was shared with the community via email 6/30/21

HFM will continue to provide all programming and events virtually through the end of calendar year 2021 as approved by the HFM Board of Directors.

We appreciate your understanding and recognition that this ongoing health challenge has been difficult for all. We look forward to continuing to offer excellent educational and social programming to our community. We anticipate that 2022 will allow for in-person as well as online engagement.

With gratitude,





2021 National Conference for Women and Teens with Hemophilia and Rare Factor Deficiencies*

Hear Our Voices: Setting the Agenda

October 8-9, 2021 ~ presented virtually

*Conference attendance is open to women and teens with hemophilia A and B, and **new this year**, women and teens diagnosed with a rare factor deficiency including fibrinogen (I/1), prothrombin (II/2), V/5, VII/7, X/10, XI/11, or XIII/13 (excluding Factor 5 Leiden) **Go to www.hfmich.org/rareeligibility to learn more.**

Conference Information

Women, teens and young women who are eligible to join our **special two-day virtual program** will learn from national experts and health care providers, and have numerous opportunities to connect with other attendees who each bring their own unique wisdom and experience of living with hemophilia and rare factor deficiencies.

- There is **NO CHARGE** for this two-day experience
- Accepted attendees will receive our conference-enhancement package if they apply by the September 19 deadline.
- **Questions?** Contact Patrice Thomas at pthomas@hfmich.org, 734.544.0015

www.hfmich.org/womens-conference

View our speakers and get a glimpse of our sessions.

New & Oh So Fun this Year!

We don't want to spoil the surprise, and we're excited for you to be a part of creating a memorable piece that will be revealed toward the end of the conference. We're sure it'll be "music to your ears!"



Also, for Teens & Young Women

There are a lot of people who have a lot of opinions about what teen girls and young women should do with their bodies. Who do you listen to when it comes to your extra-special bleeding disorder body? Do you have a squad of smart, trustworthy women who know what you're going through? Come to the National Conference for Women and Teens with Hemophilia and Rare Factor Deficiencies and find your people.

Sessions



Social Challenges for Girls Living with a Bleeding Disorder A highly interactive session for girls and young women to discuss life with a chronic condition, including disclosure, coping with heavy periods, and self-care.



Ask the Expert: Bleeding Disorders and Medical Challenges In a relaxed, laid back session, our amazing expert nurse will answer all questions related to any medical aspect of living with a bleeding disorder! Questions can be submitted anonymously.

Apply Today! Closes September 19, 2021

In English

www.hfmich.org/wc2021apply

En Españo

www.hfmich.org/wc2021aplicacion

Algunas sesiones serán interpretadas al español. www.hfmich.org/womens-conference

Regional Sponsor



Community Lead Sponsors







What makes us unique in the world, unites us as a bleeding disorders community!

Highlighting Rare Bleeding Disorders

Jim Munn, MS, BSN, RN-BC, Program Nurse Coordinator, University of Michigan Hemophilia Treatment Center

The Mission

The Hemophilia Foundation of Michigan's (HFM) mission states it "strives to improve the quality of life for all people affected by hemophilia, von Willebrand disease, other coagulation disorders and related complications." To some it may seem the emphasis is on hemophilia - since this word is part of the foundation's name - however, nothing could be further from the truth. SpringFest, camp, retreats, holiday parties, fundraising efforts and more are open and welcome to all people affected by a bleeding disorder and their families. In an effort to recognize people affected by a rare bleeding disorder (RBD), HFM's publication, The Artery, will dedicate a section in upcoming issues to highlight RBDs. This new section will address the history of a particular RBD, its symptoms, diagnosis, treatment, and future directions of care.

Rare diseases, or disorders, in the United States (US) are any condition affecting fewer than 200,000 people, a definition created by Congress in 1983 under the Orphan Drug Act. There are about 7,000 conditions under this definition affecting as many as 25-30 million people in the US. Hemophilia A and B would be classified as rare by this definition since there are about 30,000-33,000 males with either form of hemophilia in the US. The numbers may be higher as we consider how to define

and discuss women with hemophilia who have previously been labeled as carriers. RBDs are even more rare than hemophilia, some affecting only one in three million people in the US. We will be sharing more information on RBDs such as plasma protein deficiencies, platelet disorders, and defects of the fibrinolytic system (our body's way of removing clots once an injured blood vessel has healed).

Besides being fewer in number, RBDs differ from hemophilia in several ways:

- Inheritance usually occurs from a genetic change on a chromosome other than a sex chromosome (X or Y chromosome), called an autosome (of which there are 22 pairs in humans).
- Females and males often are affected equally.
- Because inheritance typically is recessive, both parents must pass on their affected gene to their child (girl or boy).
- Bleeding symptoms are often subtle and can vary in RBDs.
- Diagnosis can be delayed due to the subtle bleeding symptoms.
- Treatment may not be disorder-specific and generally involves plasma-derived products.

 Research in RBDs lags behind that in hemophilia.

We look forward to showcasing RBDs in The Artery. We hope you will be involved with this section of the newsletter by reading each issue, asking questions about the content, and providing feedback on content you would like to see included. Please use the information to enhance your knowledge, strengthen your advocacy skills, and share with family, friends, school personnel, and others who may be involved in helping you, your child, or a family member live with a rare bleeding disorder. What makes us unique in the world, unites us as a bleeding disorders community!

"Mission Statement." Hemophilia Foundation of Michigan, 2018, hfmich.org/mission-statement/.

"Faqs about Rare Diseases." Genetic and Rare Diseases Information Center, U.S. Department of Health and Human Services, rarediseases. info.nih.gov/diseases/pages/31/faqs-about-rarediseases.

Soucie, John Michael, et al. "Occurrence Rates of Haemophilia among Males in the United States Based on Surveillance Conducted in SPECIALIZED Haemophilia Treatment Centres." *Haemophilia*, vol. 26, no. 3, 2020, pp. 487–493., doi:10.1111/hae.13998.





Many of our camp photos were captured as part of our month-long scavenger hunt that inspired campers to continue the camp fun outside of the set Zoom hours. Can you guess which pictures came from which mission?

- Backwards Hoodie
- Chalk It Up
- Arts and Crafts Wrap Up Medic Alert
- Blip of Happiness
- Counselor Dress Up
- Wood Cookie Selfie
- COVID Quilt
- Polar Bear
- Positive Vibes
- Camp Tshirt

Special thanks to our 2021 Virtual Camp sponsors!

Virtual Campfire Sponsors





Virtual Polar Bear Plunge Sponsors



CSL Behring





Virtual Arts and Crafts Sponsors

Allstate Foundation

Grifols

Pfizer

Sterling Heights Kiwanis Club Warren Rotary Club

Thank you to all our many individual supporters who attended and participated in HFM's events and fundraisers throughout the year!





Gelli's Journey at CBE

Angellica "Gelli" Kelley, Head Counselor, CIT Director, Camp Bold Eagle at Home

I was twelve years old when I first attended Camp Bold Eagle (CBE). I was diagnosed with VWD Type 1 when I was eleven and I remember my nurse telling me about this summer camp I should go to. Little did I know how much this camp would change my life.

I continued to attend Camp Bold Eagle, as well as HFM's other summer camping programs including Eagle Outpost and Eagle Expedition. When I was sixteen, I returned to CBE as a counselor-intraining (CIT). Now, I serve as the CIT director, giving guidance and training to the young leaders of the bleeding disorder community.

The last two summers, we've had Camp Bold Eagle at Home. This online program allows us enjoy camp activities, like arts and crafts, nature, and recreation, while still participating in CBE traditions, and most importantly, making friends with others with bleeding disorders. We were able to continue our CIT program the past two years at CBE at Home. Five amazing teens dedicated their entire month of July to growing as leaders and creating

a fun and engaging camp experience. I am so proud to have been able to work and grow alongside them.

This year at Camp Bold Eagle at Home, I also ran a week of Creative Arts programming. Creative Arts was new for us this year. In this program, campers had fun experiencing theatre, color wheel activities, and photography. During my week, we created time capsules. When developing my activity, I thought about these two summers, spending every day for four weeks on Zoom, singing camp songs and playing fun games in our own homes. I wanted everyone to be able to remember these two years of Camp Bold Eagle at Home fondly; years that brought us so much closer together. Campers and staff wrote down goals, favorite memories of camp, and a letter to their future selves. We put crafts and other fun projects from CBE in our time capsules. The campers will be given their time capsule back when they become a counselor-intraining in the future.

Seeing the campers and staff on the screen every morning always brought a smile to my face; they are my "blips of happiness." To me, and I am sure to many others at CBE at Home, every single day getting on that computer screen was worth all the hard work and planning it took to recreate the camp experience in the virtual space. Thanks to CBE at Home, I was able to make even more great friends that I only know virtually. I miss the camp people who haven't been able to come to camp the past two years, and I can only hope that when we return to camp in-person, we can see all of the people that make Camp Bold Eagle the wonderful place that it is. I can't wait to see all of your smiling faces!

I have grown so much since that first day at camp. These experiences in the HFM community have shaped me into the person I am today. I am so thankful I get to continue to return to camp and share the gift of camp with younger generations. Every year gets better than the last, and I look forward to July when I get to see my camp family again.



At Camp Bold Eagle we celebrate taking a step outside of your comfort zone, and challenging yourself to do something that might be a little scary. We call this an Eagle Step. During CBE at Home, we challenged our campers to take an Eagle Step, write it on their dry erase board, and snap a selfie so we could all celebrate with them!



Camp is not the place, it's the people!

Although, we rrrreeeaaaallllyyy do miss the place and seeing everyone in person.

teen transition teen transition Teens with bleeding disorders learning new roles and responsibilities for adult independence.

High School Sophomores Wanted!

Teen Transition into Adulthood

An 8 month Zoom program, plus a fun weekend retreat.

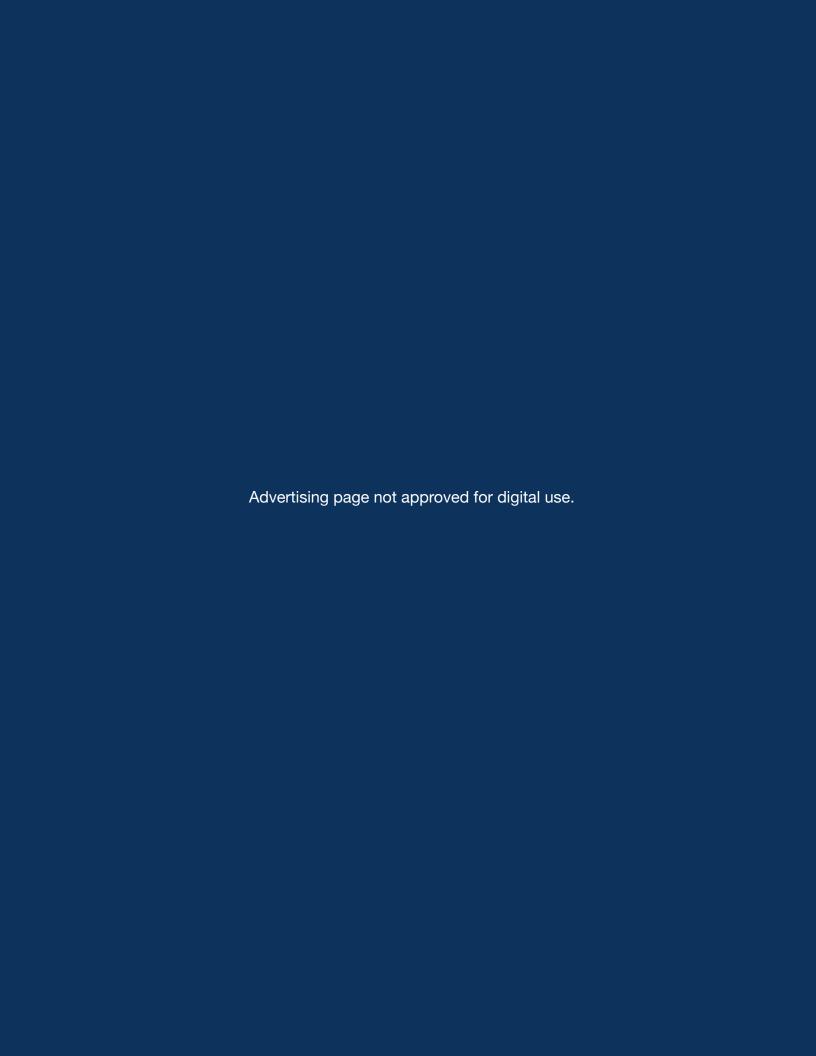
Meet other high school sophomores with bleeding disorders, participate in interactive activities, and learn some valuable things about becoming more independent.

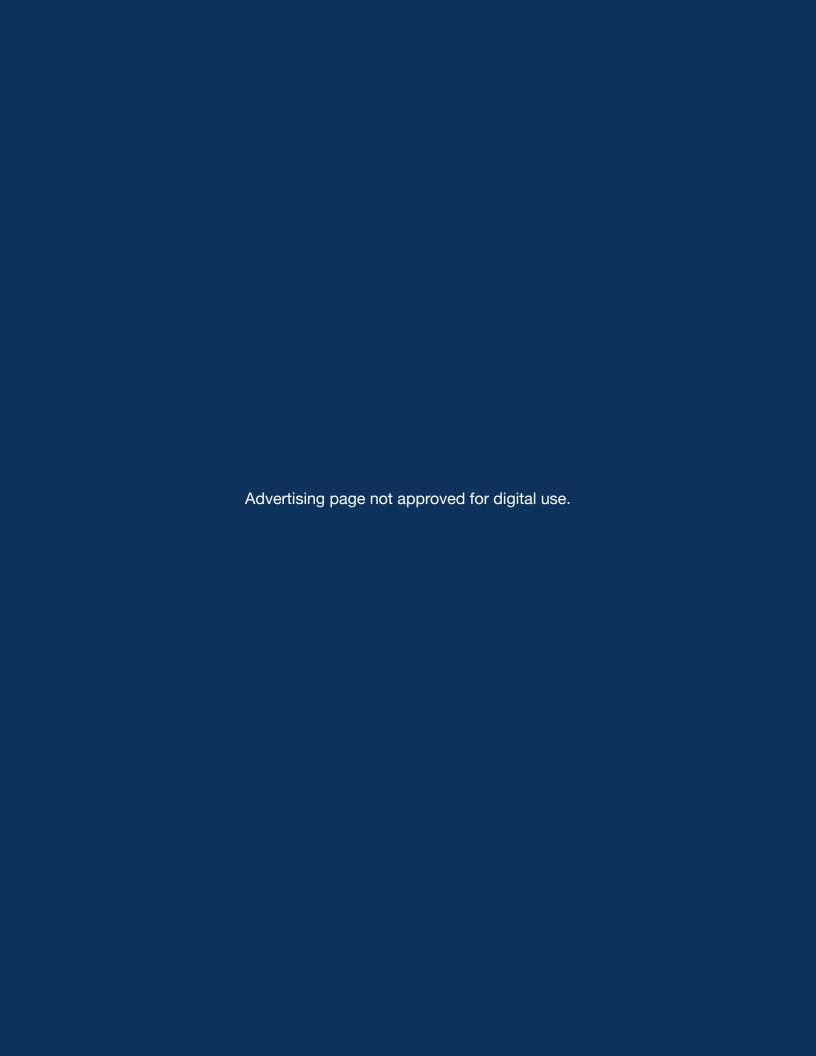
- One hour monthly meetings will be held the second Tuesday of the month starting on **October 12, 2021 at 7pm EST** via Zoom.
- The first meeting will introduce you and your parent/guardian to the program.
- Parents/guardians may have their own meetings at a different time.
- If you sign up by September 21, we will send you a box of supplies for meeting activities.
- This program culminates in a fun weekend retreat June 3-5, 2022 at Trine University, Angola, Indiana.
- You must attend a Hemophilia Treatment Center (HTC) in Michigan, Indiana, or Ohio.
- Program is free of charge.

To register, or if you have questions, contact your HTC or Sue Adkins, sadkins@hfmich.org or 734.544.0015.









"Free" Factor

HFM and Cascade staff

Throughout the past few years, there have been an increasing number of changes to the way health insurers provide coverage, and to the cost-sharing requirements of patients, as an attempt to manage health care and prescription drug costs.

The alternative funding model is the latest program to target high-cost, specialty drugs. Alternative funding brokers sell plans to employer groups that exclude high-cost drugs from coverage – including bleeding disorders treatments/medications. The brokers claim to reduce the employer's specialty drug costs by up to 100% by moving

patients into new "innovative" programs that provide free medication.

Employers and patients are not told that they are being signed up for manufacturer patient assistance programs to obtain their "free product" and will no longer be able to receive services from their current pharmacy. If a patient does not qualify for a manufacturer program, the plan will then make a "medically necessary exception" to cover the medication or require the patient to use any other available insurance including Medicaid or Michigan's Children's Special Health

Care Services. In other cases, they will require a change to a lower cost drug.

Like copay accumulator adjustment programs and copay maximizer programs, the alternative funding model uses purposefully confusing language to market and communicate with patients and employers, including falsely stating that "there will be no changes in how your members receive their medication."

These deceptive practices harm the bleeding disorders community and may result in the loss of coverage.

Health Insurance is the Lifeline to Medication for Patients with Bleeding Disorders.

We have shared several tips to help make sure your health insurance continues to work for you.

Examples of language used to describe copay accumulators:

- Out of Pocket Protection Program
- True Accumulation
- Coupon Adjustment: Benefit Plan Protection Program

Know Your Insurance Plan

Review your plan documents to answer the following questions.

- Does your insurance cover your factor product or other treatment?
- What is your deductible?
- What is your co-insurance or copayment?
- Do you have an accumulator on your plan?
 i.e. will copay assistance count toward your out of pocket maximum?

To access Cascade Hemophilia Consortium's valuable 2020 insurance guide, which is still relevant today, go to www.hfmich.org/chc_insuranceguide

Open Your Mail

- Snail mail' is the primary line of communication between your health insurer and you.
- Any changes to your plan will be communicated to you in writing most likely via USPS.

Open Your Mail continued

- Open, read, and save all correspondence and documents.
- Make sure your health insurer has your current address. If you have recently moved, you will need to update your address with your health plan.

Communicate with Your HTC or Pharmacy Provider

- Share any updates or changes to your insurance plan with your HTC and/or pharmacy provider to ensure there will be no disruption to your current treatment plan.
- Even if your insurer claims nothing will change in how you receive coverage, make sure you review insurance communication with your healthcare providers.

QUESTIONS?

If you have questions regarding any change in your insurance plan, please contact your hemophilia treatment center, Cascade Hemophilia Consortium, or HFM staff. Together, we work to ensure patients have access to the care you need.

Looking for Employment Support?

Launch and other programs are available to you

As individuals in the bleeding disorders community find themselves looking for work, HFM's Launch program may be able to assist. Launch connects community members to resources and tools to find job options related to each person's areas of interest with consideration of long-term joint health and overall sustainability of their physical well-being.

HFM's Launch program would like to highlight a recent investment of \$3.8 million to Michigan Works! that will provide reemployment services to help eligible unemployed Michiganders return to work. "The [Michigan Works!] program has a proven track record of helping unemployed Michiganders return

to work quicker," said Susan Corbin, acting director of the MI Department of Labor and Economic Opportunity.

Michigan Works! can offer resources that will help you find the job that is right for you and your overall health. To contact the nearest Michigan Works! Service Center, call 800-285-WORKS (9675) or visit MichiganWorks.org.

Throughout the year, Launch also provides interview and resume workshops, clothing and transportation allotment for interviews and trainings, resources that can help you achieve certifications for potential careers, and technological tools to assist in job searches or trainings. If you have

found yourself unemployed or under employed, please touch base with **Anthony Stevens at 734.544.0015** and astevens@hfmich.org and allow HFM to work alongside you in finding and utilizing available resources.

HFM's Launch Sponsor

GenentechA Member of the Roche Group

HFM does not endorse any specific product or company.



Protecting Your Dental Health

Did you know that your dental health offers clues about your overall health — or that problems in your mouth can affect the rest of your body? Protect yourself by learning more about the connection between your dental health and overall health.

Visit our website for more information about ways to protect your dental health at: www.hfmich.org/dental-health/.

Check out our dental health videos starring HTC staff at www.hfmich.org/healthyteeth

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.

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

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.

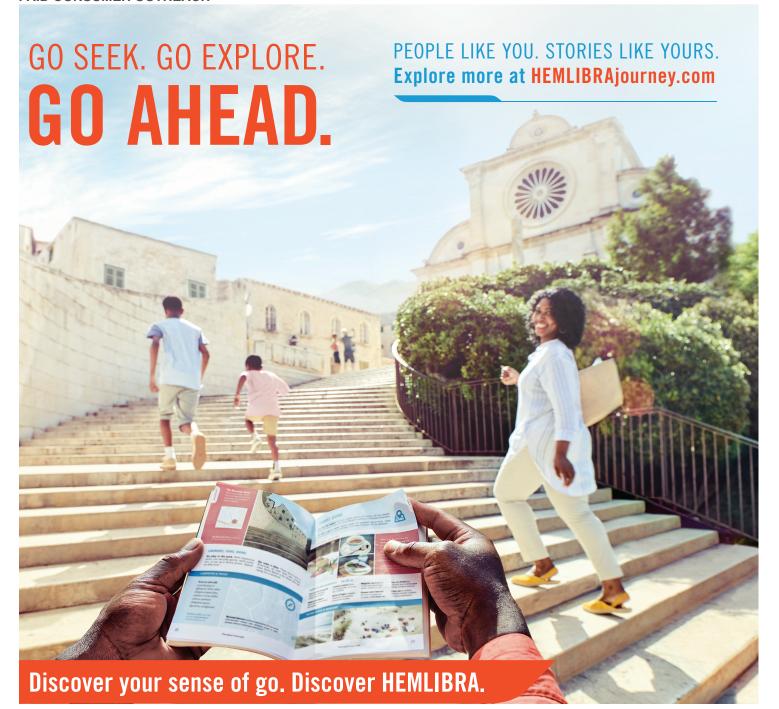
Questions? Contact **Lisa Clothier**, LMSW, ACSW, LCSW, Outreach and Community Education Manager, at **Iclothier@hfmich.org** or 734.961.3512.

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









What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

What is the most important information I should know about HEMLIBRA?

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

These serious side effects include:

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

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



Medication Guide HEMLIBRA® (hem-lee-bruh) (emicizumab-kxwh)

injection, for subcutaneous use

What is the most important information I should know about **HEMLIBRA?**

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:

- Thrombotic microangiopathy (TMA). This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRAS
 - confusion
 - weakness
 - swelling of arms and legs
 - yellowing of skin and eyes
- stomach (abdomen) or back pain
- nausea or vomiting - feeling sick
- decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
 - swelling in arms or legs pain or redness in your
 - arms or legs shortness of breath

 - chest pain or tightness
 - fast heart rate
- cough up blood
- feel faint - headache
- numbness in your face
- eye pain or swelling
- trouble seeing

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

See "What are the possible side effects of HEMLIBRA?" for more information about side effects.

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I use HEMLIBRA?

See the detailed "Instructions for Use" that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

- Use HEMLIBRA exactly as prescribed by your healthcare
- provider.

 Stop (discontinue) prophylactic use of bypassing agents
- the day before starting HEMLIBRA prophylaxis. You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis. HEMLIBRA is given as an injection under your skin
- (subcutaneous injection) by you or a caregiver.

- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider. You will receive HEMLIBRA 1 time a week for the first four
- weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. Do not give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

What are the possible side effects of HEMLIBRA?

See "What is the most important information I should know about HEMLIBRA?

The most common side effects of HEMLIBRA include:

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total
- of 7 days or at a temperature greater than 86°F (30°C). After HEMLIBRA is transferred from the vial to the syringe,
- HEMLIBRA should be used right away. Throw away (dispose of) any unused HEMLIBRA left in the vial.

Keep HEMLIBRA and all medicines out of the reach of children.

General information about the safe and effective use of **HEMLIBRA.**

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048
HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan
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For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised: 10/2018



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Michigan's Von Willebrand Education Day and Symposium

The Hemophilia Foundation of Michigan's Von Willebrand Education Day and Symposium took place via Zoom on Saturday, June 12, 2021. There was a feeling of excitement as 48 men and women from across Michigan connected for this much anticipated event.

The day held (almost!) no rivalry between Spartans and Wolverines as attendees were joined by Michigan's top experts in VWD. Michigan State University HTC physicians Roshni Kulkarni, MD and Shawn Jobe, MD, PhD provided answers and perspectives during Ask the Expert – VWD. Michigan Medicine HTC physician Angela Weyand, MD, explained New National Guidelines for

VWD while Jim Munn, BSN, RN-BC presented VWD in Males. During Jim's session Cody from Arkansas and Donal from Ireland, both of whom participate with the International AFFIRM program, shared their personal experiences as men living with VWD. Cody and Donal advocate to raise awareness of VWD and though each are particularly interested in connecting with other men with the diagnosis they advocate for all affected by VWD.

Skye Peltier, MPH, PA-C from Minneapolis presented The Basics of VWD with an emphasis on advocating for proper care. Other sessions throughout the symposium included treatment product information

via Round Robin Discussions with Industry Partners, The Science Behind VWD, Important Life Milestones for Children with VWD, and an Overview of Von Willebrand Disease.

Presenters were engaging and informative while participants were engaged and inquisitive. The result was a day of open discussion, collaborative learning, and a sense of community. Thank you to our speakers, sponsors, and most importantly our attendees for your involvement with this educational event. We are excited to consider opportunities for future Von Willebrand Education Days.

VWD Lead Sponsor



VWD Community Sponsor

CVS specialty

VWD Event Sponsors

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GRIFOLS

HFM does not endorse any specific product or company.



Understanding Copay Accumulator Adjustment Programs 2.0

On May 20, HFM was joined by Kollet Koulianos, Senior Director of Payer Relations at the National Hemophilia Foundation, to take a deeper dive into copay accumulator adjustment programs. Kollet's presentation provided a foundational understanding of insurance, what copay accumulators are, and how legislative changes across the country have been helping patients. With this knowledge, we discussed Michigan House Bill 4353, legislation that requires all copayments made by or on behalf of a patient count toward their out-of-pocket costs.

Go to www.hfmich.org/accumulatormay20 to view a recording of the presentation.

Special thanks to our sponsors











HFM does not endorse any specific product or company.

Register to join us November 19 at 6:30p for a fun Community Night, Cooking Demo: Thanksgiving Leftovers ~ www.hfmich.org/nov19



Mocktail Community Night

Community members enhanced their summer with refreshing beverages thanks to a Zero-Proof Cocktail class (aka: Mocktails, or alcohol-free cocktails) via Zoom. In June, we gathered to muddle, shake, and learn with expert Tammy Coxen of Tammy's Tastings. From a Strawberry Basil Mule to a virgin Bloody Mary, you can be sure that attendees learned delicious new ways to enjoy our Michigan summer and stay HYDRATED! Special thanks to Kathi Sheldon, RNC, from the Munson Medical Center Hemophilia Treatment Center who spoke with our group regarding best ways to stay hydrated.

Thank you to Novo Nordisk, our sponsor for this activity.







Mental Health Support

If you are currently in crisis:



Crisis Line

800-950-NAMI

to reach the National Alliance on Mental Illness Crisis Line



Suicide Prevention

(800) 273-8255

for the National Suicide Prevention Lifeline. Prevención del suicidio en Español: (888) 628-9454



Crisis Text Line

Text "Home" to 741741

to reach the Crisis Text Line

What is a Grounding Exercise?

A grounding exercise is intended to bring you into touch with where you are at this moment – the here and now. It can be a useful tool in coping with disorders like anxiety and post-traumatic stress. **Annie Phillips, LMSW, PMH-C**, licensed therapist, Healing Home Counseling Group, and former Hemophilia Treatment Center social worker, used the following grounding exercise during her presentation to the Regional HTC staff discussing the Long Term Trauma from Continued Physical/Social Distancing and Isolation. If you are struggling, please contact your health care provider to talk about a treatment plan that will be a good fit for you.

GROUNDING EXERCISE

Notice Notice Notice Notice Notice 5 things that you 4 things you can 3 things that you 2 things you can I thing you can can see. Look feel. Bring can hear. Listen for smell. Bring taste. Take a sip of around you and attention to the and notice things attention to scents a drink, chew gum, become aware of things that you're in the background that you usually or notice the your environment. currently feeling, that you don't filter out, either current taste in Try to pick out such as the normally notice. It pleasant or your mouth. unpleasant. Catch something that texture of your could be the birds a whiff of the pine you don't usually clothing or the chirping outside or smooth surface of notice. an appliance trees outside or the table you're humming in the food cooking in resting your hands the kitchen. next room.

The Artery and the content of The Artery are for educational purposes and not intended to be medical advice. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition.

Extend half-life beyond the standard 22-hour average half-life in adults^c

— FOR ADULTS AND ADOLESCENTS

Switching made easy with a standard 50 IU/kg dose every 4 days

-50% fewer infusions if you previously infused every other day

-40% fewer infusions if you previously infused 3x a week

High factor levels

At or above 3% for 100% of the time^{d,e}
At or above 5% for 90% of the time^{d,f}

Flexible on the go

The ONLY extended half-life product that can be stored up to 104°Fg

Please see Brief Summary for complete storage instructions.

Safety Proven across 5 studies, the largest and longest EHL clinical trial program

^aOf 1% trough factor levels for standard half-life (SHL) products in adults and adolescents.

^bCompared with SHL products.

Data shown are from 42 adults who received a pharmacokinetic (PK) assessment around the first Esperoct® 50 IU/kg dose.

^dTrough level goal is 1% for prophylaxis.

Data shown are from a study where 175 previously treated adolescents and adults received routine prophylaxis with Esperoct® 50 IU/kg every 4 days.

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.

^fSteady-state FVIII activity levels were estimated in 143 adults and adolescents using pharmacokinetic modeling. ^gFor up to 3 months.

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 **Esperoct.com**.



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

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esperoct®

antihemophilic factor (recombinant), glycopegylated-exei

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 86°F (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 ESPEROCT® is a trademark of

Novo Nordisk Health Care AG.

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

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Toledo Zoo Community Night

Have you ever gotten close to a hippo munching on its dinner? Have you ever snuck under a giant salamander to look at the bottoms of its feet? If you attended the Toledo Zoo Community Night in July, the answer would be yes! HFM community members got to experience an after-hours personal tour with a zoo insider.

Our group had a lot of fun getting together virtually to learn about the creatures inhabiting the Natural History Museum at the zoo. It was so much fun to hear the questions that the kids in our group presented. Their curiosity was on full display, and our guide from the zoo was more than willing to walk them through the creepy, crawly, and fascinating answers.

Thank you to our event sponsor, Novo Nordisk, for the opportunity for us to get together for this special experience!

HFM does not endorse any specific product or company.



Stay Tuned for

HFM's Community Survey

Help us understand the needs of the Michigan bleeding disorders community so we can enhance our programming and services.

The survey will be available online October 25 through December 31, 2021.

www.hfmich.org/comm-survey

We will be mailing our survey the week of October 20.



Center of Care Michigan State University Center for Bleeding and Clotting Disorders

MSU HTC Staff



Michigan State University (MSU) Center for Bleeding and Clotting Disorders (CBCD) is located on the beautiful campus of Michigan State University. Our day-to-day operations and academic office are located in the Life Science building. Our clinics are held at the Sparrow Professional Building across from Sparrow Hospital and in several locations around the state or via telemedicine.

What is your catchment area?

MSU CBCD holds clinics in the Lansing area as well as outreach in many locations throughout the state. In person clinics take place in Marquette, Mt. Pleasant, Grand Rapids (adult only) and telemedicine clinics are held in Houghton-Hancock, Marquette, Escanaba, and Iron River. We work with providers in all outreach locations to provide easy access to specialty, comprehensive care.

Do you serve pediatric or adult patients or are you a lifespan center?

MSU is a lifespan center. We see patients of all ages with various clinics designated for specific populations.

How long has your HTC operated or when did it open?

Our center began in 1980 when Dr. John Penner moved to Lansing as an original federal HTC grantee. MSU CBCD has continued to grow for over 41 years.

Do you have any specialty clinics, outreach clinics, or programs that you would like to highlight?

MSU continues to branch out to new sites across the state. We hold comprehensive clinics for adult and pediatric patients in several locations throughout the state. As a National

Hemophilia Program Coordinating Center (NHPCC) pilot site for telemedicine, we expanded to the far northwest corner of Michigan and developed a telemedicine clinic in Houghton-Hancock which is still growing today. Under the direction of Dr. Roshni Kulkarni, we became a leader in Women and Girls Blood Disorder clinics offering comprehensive services to girls and women with blood disorders from menarche through menopause and beyond. We provide outreach clinics that serve the Amish population – in the past we served this population in their own homes. We have additional clinic ideas in mind to pursue next year. The light is always bright, and it is always green at MSU.

Do you have any new team members /staff members?

Our biggest achievement this year was to recruit Shawn Jobe, MD, PhD as our new center director. We are delighted that he joined us in January as faculty of the College of Human Medicine at MSU. He is regionally, nationally, and internationally known. His major interests are platelet disorders and coagulation disorders. He brings new ideas of incorporating basic science research into our activities thus making our center a "bench to trench" operation. Our previous director Roshni Kulkarni, MD plans to decrease her time with the HTC though she will continue to be involved in educational activities, mentoring, and special projects.

We are also extremely excited to welcome the following individuals to our team:

- Christina Orr, RN, Clinical Nurse
- Steven Edwards, LMSW, Clinical Social Worker



 Elizabeth Leipprandt, CMA, BS, MPH, Research Coordinator

What do you see as your biggest strength as a center?

We provide care for all ages, genders, day or night – and at locations near and far to our core CBCD in Michigan. Our motto is "If you can't come to us, we come to you through our outreach clinics, telemedicine clinics, and women and girls' clinics." Our community-based AND innovative approach to care set us apart.

What inspires your staff?

Patients and their families are a continuous source of inspiration and boost morale and creativity. They are at the center and illuminate, inspire, and strengthen us. It is the team members who keep this light of inspiration burning and support each other. Many of our patients go through periods of despair and our team gives them help and hope.

We as a staff are eager to learn and collaborate to offer the best care for our patients. Inspiration comes when patients learn how amazing and precious their body is and take steps to better their health and learn how they can use their own bleeding disorder to help others and become a mentor to offer hope. Continuing to learn from our patients, from colleagues, and from the CBCD staff is inspirational. There is always a new question or challenge arising.

Are you a Sparty or Wolverine fan?

NOT SURE WHY THIS QUESTION IS EVEN BEING ASKED??? THE GRASS IS ALWAYS GREENER AT MSU.

All events remain virtual through December 2021

Go to hfmich.org/events for additional information

September 18, 10a Michigan Unite Walk

September 28, 7-8p HFM's Ruby Connection

October 5, 6:30p Men's Support Group

October 8, 9

National Conference for Women and Teens with Hemophilia and Rare Factor Deficiencies

October 26, 7-8p HFM's Ruby Connection

October 29 Bleeder and a Buddy

November 2021 (dates tba) Patient and Family Upper Peninsula Retreat

November 2, 6:30p Men's Support Group

November 11, 6p Advocacy Webinar

November 19, 6:30p Cooking Demo: Thanksgiving Leftovers!

November 22 Advocacy Summit

November 23, 7-8p
HFM's Ruby Connection: Adult
Women's Preventative Healthcare

Dr. Anne Greist and Dr. Amy Hepper

December 4

End of Year Community Gathering

(aka Holiday Party)

December 7, 7-8p

Men's Support Group 6:30p

December 14, 7-8p HFM's Ruby Connection

December 18HFM's Camp Holiday Party

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