the artery

Serving Michigan's bleeding disorders community

Fall 2020

EAGLE JOURNEYS CAMPING PROGRAMS

HFM's Eagle Journeys exists to educate and empower kids with bleeding disorders to live a life of freedom and independence

hfm©

HFM exists to enhance the quality of life for all affected by bleeding disorders

Camp Bold Eagle at Home is a Huge Hit!

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

page 24

INSIDE THIS ISSUE

We are here for you.

"When we are no longer able to change a situation, we are challenged to change ourselves."

~Victor Frankl

Dear HFM family and friends,

2020 continues to be a year we will never forget.

Most of our lives have changed dramatically these last many months. **HFM remains here for you and yours.**

This issue of HFM's *The Artery* shares information regarding ongoing support efforts for Michigan's bleeding disorders community: financial assistance, continued online education, opportunities for friendship and connection. If you would like to participate online yet are struggling to learn Zoom/other platforms or are facing other challenges with virtual activities please let us know – hopefully we can help.

There are many virtual opportunities coming up through the remainder of this year, including our two Michigan Unite Walks in September and the 3rd annual National Conference for Women and Teens with Hemophilia, October 9th and 10th.

No surprise, our annual camp issue looks a bit different this fall. **Heartfelt gratitude to ALL involved, including more than 100 campers who 'tuned in'** – many together with at-home supporters. Much appreciation to everyone who served and participated throughout the month of July.

An area our camp leadership and counselors always include during training is the significance of inclusion. We agree that every camper, counselor, and staff member should feel safe and welcome at any program. HFM recognizes that as our world continues to grapple with the pandemic – inequities and social justice issues have come front and center.

Most of us know that hemophilia, and other bleeding disorders, occur in all races and ethnic groups, typically following the racial distribution within a given population. Yet, across the country hemophilia and bleeding disorders' structures and systems – organizations, treatment centers, industry partners, etc. – are far from representative.

We must listen, learn, and act. True communication is hard, riddled with mistakes and misunderstandings. I ask us to find ways to come together, share our stories – both negative and positive. I believe that with truth we will find ways to move forward to build a more just and inclusive future.

My hope is that we each find silver linings in the many changes and challenges that fill our lives. Please feel free to email me **slerch@hfmich.org** or call **313-407-7652**.

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

COVID-19: Adjusting to the Times

Published on August 25, please be advised that information may have evolved by the time you are reading this.

HFM Programming Virtual Through 2020

Due to COVID-19 health challenges, and based on consultation with many physicians in the bleeding disorders community, as well as the recommendation of the National Hemophilia Foundation, **all of HFM's 2020 events and programs will be virtual rather than in-person this year.** We miss seeing you all but we are grateful that we have the technology to connect, learn, and be together. Please keep up to date with all of our many programs through the rest of the year. Event information is posted on our webpage and is updated on Facebook. We hope you will join us! While the HFM office remains closed to visitors to protect the safety of our staff and you, we are making safety upgrades for our eventual return.

Do you need some extra support? www.hfmich.org/mental-health/

HFM's Office Upgrades

HFM has spent much of the summer preparing for when staff members can safely return to our office and to when we can welcome you back. The HFM building is not just a place to work, it truly is a community center where we host events and programs such as Days for Girls, Infusion U, and camp alumni gatherings. We miss seeing our co-workers, and most of all, we miss seeing you!

To create a safer environment, we have made significant upgrades to our HVAC system, installed an exterior mailbox, and purchased a touchless water dispenser. We also have directional signage, masks, and hand sanitizer to maintain a healthy work environment. While the HFM staff is still primarily working from home, we are moving forward to best create an office space where we can return when it is safe to do so.

HFM was able to make these changes thanks to the National Hemophilia Foundation's COVID-19 Relief Fund Bridge Grant. NHF worked with Genentech, Pfizer, and Sanofi Genzyme to create an opportunity for chapters to apply for funds that address needs related to this pandemic. We are grateful for their collaborative efforts and support. We are also thankful to the Hemophilia Alliance Foundation who matched these funds and allowed us to maximize our impact. Thank you all – your investment in HFM and the Michigan community truly makes a difference!

SPECIAL THANKS TO:

National Hemophilia Foundation
for all bleeding disorders

The Hemophilia Alliance

Genentech
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Pfizer Hemophilia

SANOFI GENZYME

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NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

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Achieving Excellence

We are exceptionally proud to be

honored in the following categories:

Programs and Services

Chapter Partnership

Fundraising and Development

Public Policy and Advocacy

The National Hemophilia Foundation (NHF) recognizes chapters each year that have achieved excellence in serving the bleeding disorders community. The Hemophilia Foundation of Michigan was honored to receive four awards this year at NHF's annual Bleeding Disorders Conference. NHF's review process was rigorous and wide reaching. Our work to compile the information allowed us an opportunity to reflect on the work that we do to serve the Michigan community every day and all of the ways that we work together and in partnership to improve the lives for all people with bleeding disorders.

These awards designate chapters that excel in serving the bleeding disorders community by providing robust educational opportunities, creating national partnerships, inspiring philanthropy and giving, and implementing strong advocacy initiatives. We want to thank you, our community, for showing on a national stage what we can do together as a Michigan community. Thank you!

HFM honors and celebrates the work of our fellow chapters and awardees across the country.

Safety and Your Information

On July 12, 2020 we were notified that a security breach occurred to our donor and community member database and our accounting software. Our software provider, Blackbaud, Inc., is a leader in providing software systems to non-profit organizations both large and small. Blackbaud informed us that we, along with many of their clients, had been exposed to a cyber attack. To protect their clients' data, Blackbaud paid the cybercriminal's demand and confirmed that the copy the cybercriminal removed had been destroyed. No credit card numbers, social security numbers, usernames or passwords were accessed because that information is encrypted.

Based on the nature of the incident and law enforcement investigation, we have no reason to believe that any data went beyond the cybercriminal, was or will be misused, or will be disseminated or otherwise made available. In accordance with regulatory requirements and in an abundance of caution, we are notifying you of this incident. None of our data was lost or corrupted as a result of this incident.

HFM takes your confidence in us and the safety of the information you share with us very seriously. We will continue to monitor this situation. If you have any questions or concerns about the safety of your personal information, please contact Laura Olson, Database Manager, at lolson@hfmich.org, or 734-961-3513 to discuss the matter further.

SAY HELLO TO JAMES

He has hemophilia A and has gone through two major surgeries while keeping to his factor regimen with the support of his hemophilia care team

"RECOVERY WAS TOUGH, BUT I LEARNED I HAD MORE SUPPORT THAN *I THOUGHT POSSIBLE*."

HELLO FACTOR

Read stories like James' in *Hello Factor* magazine:
BleedingDisorders.com

Takeda

Going Back to the Dentist

Karen Ridley, RDH, MSDH, Michigan Health Center for Bleeding and Clotting Disorders

COVID-19 has brought many changes to our daily lives, including the way dentists are providing care. While there are certainly many changes in dental procedures, these all contribute to creating a safe environment for patients. Ignoring dental care will lead to more complex dental problems. It's time to get back on the dental track.

In March, the American Dental Association and Michigan Dental Association followed recommendations from the Centers for Disease Control and Prevention (CDC) and advised all dentists to postpone elective dentistry, oral surgery, and all non-urgent dental care. While waiting for the CDC and Governor to give them the "go ahead" to reopen, dentists prepared their offices and staff to provide the best and safest care for their patients. You may have received an email or letter from your dentist explaining many changes in their office.

Going to the Dentist Will Feel Different

Instead of completing registration and medical history forms in the waiting room you will be asked to "register" for your appointment online ahead of time, update your medical history, insurance information and any changes in your address and phone number. If you do not have access to a computer, tell the appointment person so that they can assist you. Add your treatment center contact information to your medical history.

The Waiting Room Has Changed

Instead of coming into the waiting room, you will be asked to call the office when you arrive for your appointment but wait in your car until directed to come in. Most likely there will not be a waiting room. Toys, magazines, videos and other "entertainment" will be gone and unless you need assistance or are bringing a small child for a dental appointment, you should plan to come into the office by yourself. When the dentist or hygienist is ready for you, you will be escorted from the door directly into the treatment room. You will have your temperature taken and will be required to wear a face mask until it's time to start your treatment. If you need to remain with a child or another person, you will be asked to stand outside the treatment room. You could elect to wait in your car. The dentist or dental hygienist will call you when the appointment is over or if they need assistance or have questions.

Personal Protective Equipment

Dentists have been using personal protective equipment (PPE) for many years including special jackets, face masks, and eye protection. But your dental staff may now be wearing more PPE. You may notice head and shoe covers, N95 face masks under face shields, and scrub gowns. You may be asked to wear protective eyewear or a head cover.

Teeth Cleaning

You will be asked to wash your hands thoroughly and rinse your mouth with an oral disinfectant such as hydrogen peroxide for at least one minute at the beginning of the appointment. During teeth cleaning, you may notice that the hygienist is scaling teeth (you may call it scraping) and not using the power scaler. To decrease aerosols, CDC guidelines recommend that hygienists do not use power scalers or polish teeth which creates a saliva saturated aerosol and droplets which may be in the air for a long time. If you have stain on your teeth the dentist may provide you with a small cup of "prophy paste," a more abrasive type of toothpaste used by the hygienist. You can use this at home with your toothbrush.

Dental Procedures

There are changes in other dental procedures as well. The dentist may use a rubber dam to isolate a tooth they are filling to prevent saliva from pooling around the tooth being treated and decrease the production of aerosol. The oral surgeon may delay extraction of wisdom teeth that are not symptomatic. Following teeth cleaning your dental exam may be done by video with an intraoral camera. Your dentist may contact you by video to assess an acute dental problem.

While dental care may seem different, rest assured that dentists want to provide their patients with the best possible care. They have made changes to benefit their patients and continue to provide training for their staff. Dentists are screening patients for symptoms, limiting the number of appointments in a day, implementing stringent disinfection protocols, and wearing more protective equipment to guard against respiratory disease. If you are uncertain about any of the new policies or procedures, ask questions. Your dental team is following strict guidelines and wants you to be comfortable with the care they are providing.

Continued on next page

If you have switched to Hemlibra or one of the new extended factors, be sure to consult your treatment team about dental recommendations. There may be changes! If this is your first visit with the dentist, ask your treatment team to send a letter of introduction and their contact information to the dental office in advance of your appointment.

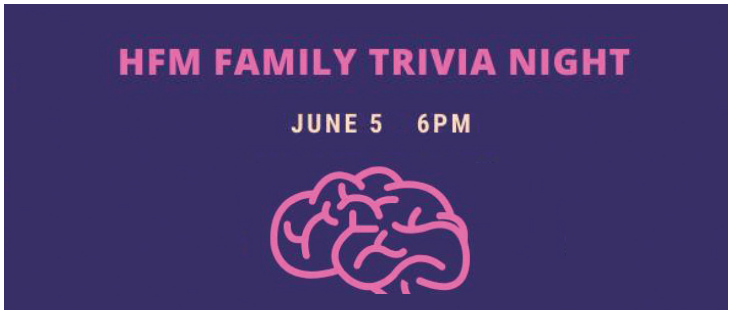
AND REMEMBER

- Take good care of your teeth.
- Brush thoroughly for at least two minutes.
- Use an antibacterial and/or fluoride mouth rinse once a day.
- Avoid sweetened beverages.
- Water is best.
- Don't ignore your teeth. Good dental care is not expensive but ignoring your teeth is.

dental

HFM has partnered with Cascade Hemophilia Consortium to offer **free dental insurance** to eligible community members.

Visit **www.hfmich.org/dental** to learn more.



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GO AHEAD.

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Discover your sense of go. Discover HEMLIBRA®.

What is HEMLIBRA?

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

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

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. HEMLIBRA may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). 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.

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

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

Medication Guide
HEMLIBRA® (hem-lee-bruh) (emicizumab-kxwh) injection, for subcutaneous use

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

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

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

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

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

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

What is HEMLIBRA?

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

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

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

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

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

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

How should I use HEMLIBRA?

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

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

What are the possible side effects of HEMLIBRA?

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

The most common side effects of HEMLIBRA include:

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

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

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

How should I store HEMLIBRA?

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

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

General information about the safe and effective use of HEMLIBRA.

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

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

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

Manufactured by: Genentech, Inc., A Member of the Roche Group,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048

For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised: 10/2018

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

Genentech
A Member of the Roche Group

Community Advocates

In 2016, HFM developed an Advocacy Committee to strengthen our advocacy activities through collaboration and communication between stakeholders including community members, national organizations, medical providers, manufacturers, and other nonprofit organizations.

We are so thankful for the HFM community members who participate on the committee and volunteer their time for the betterment of all those with bleeding disorders. Three of our members share who they are and why they participate.

We invite all individuals in our community to get involved.

SUZAN HIGGINS

How are you connected to the bleeding disorders community?
My husband has severe hemophilia A with an inhibitor and we have a daughter.

How long have you been on HFM's Advocacy Committee?
Several years... since its inception in 2016.

Why is bleeding disorders advocacy important to you?
Advocacy touches all aspects of our lives, from getting proper care and treatment, to education, our careers and so much more. We advocate to keep the future bright.

JIM SEMISKI

How are you connected to the bleeding disorders community?
I am afflicted with hemophilia B, factor IX deficiency.

How long have you been on HFM's Advocacy Committee?
One week, I just joined.

Why is bleeding disorders advocacy important to you?
I felt that now that I am retired, it was time to give back to this community which throughout my life has always been there for me.

LARRY WEST

How are you connected to the bleeding disorders community?
I have hemophilia type A severe, I'm on HFA's Advocacy Leadership Council, Hope for Hemophilia Group leader, and HFM's Advocacy Committee.

How long have you been on HFM's Advocacy Committee?
Several months.

Why is bleeding disorders advocacy important to you?
Hemophilia limited my activities as a child and as a young adult it limited my options for employment. I feel it's important to advocate for the hemophilia community so that the youth today have the freedom and ability to be whatever they want in life. I also want to give back after all that HFM has done for me, including advocating for me when I faced difficulties in getting the proper health care.

Matt Manzo

Information specialist

About Matt

Matt is a Hemophilia Community Liaison with almost 16 years of experience working within the hemophilia community. The commitment of patients and families to learning about this condition motivates him to be an information source for those living with hemophilia in the Midwestern area.

Hobbies

- Cross-country skiing
- Cycling

"It really is a privilege to get to know people living with hemophilia and everyone in the community."

Connect with Matt

ZZMQ@novonordisk.com
(248) 303-5848

Hemophilia Community Liaison

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

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The Social Work Working Group

Congratulations to **Ashley Parmerlee, MSW, LCSW**, Medical Social Worker, Indiana Hemophilia and Thrombosis Center, on her new role as the Great Lakes region representative on the Social Work Working Group! The Social Work Working Group (SWWG) is a professional working group under the organizational auspice of the Medical and Scientific Advisory Council (MASAC) of the National Hemophilia Foundation (NHF). The SWWG is made up of representatives from each of the 12 federal regions. The Social Work Working Group representatives provide input for ongoing and future projects of the SWWG.

NHF's larger Social Work Network is a professional organization open to all HTC social workers providing coordination and treatment to people with bleeding disorders. Social Work Network regional representatives to the Social Work Working Group are elected from federally funded hemophilia treatment centers.

GREAT LAKES REGION

What's New?

By Sue Adkins, BSN, RN and Lisa Clothier, LMSW, ACSW

The Hemophilia Foundation of Michigan (HFM) serves as the Regional Core Center for the Great Lakes Regional Hemophilia Network. The region includes 19 federally-funded hemophilia treatment centers (HTCs) in Indiana, Michigan, and Ohio. As the Regional Core Center, HFM has several responsibilities; one of the most important is that HFM works to ensure patients with bleeding disorders and their families have access to comprehensive, multi-disciplinary care. HFM also has administrative and fiduciary duties over the federal funding from the Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC).

Like most everyone, the pandemic has required us to become creative in ways to communicate and come together to achieve goals. HFM and the HTC staff in the Great Lakes region have always worked diligently to serve the bleeding disorders community. However, at the onset of the pandemic we understood that we would need to add additional activities to support the HTCs and the bleeding disorders community including:

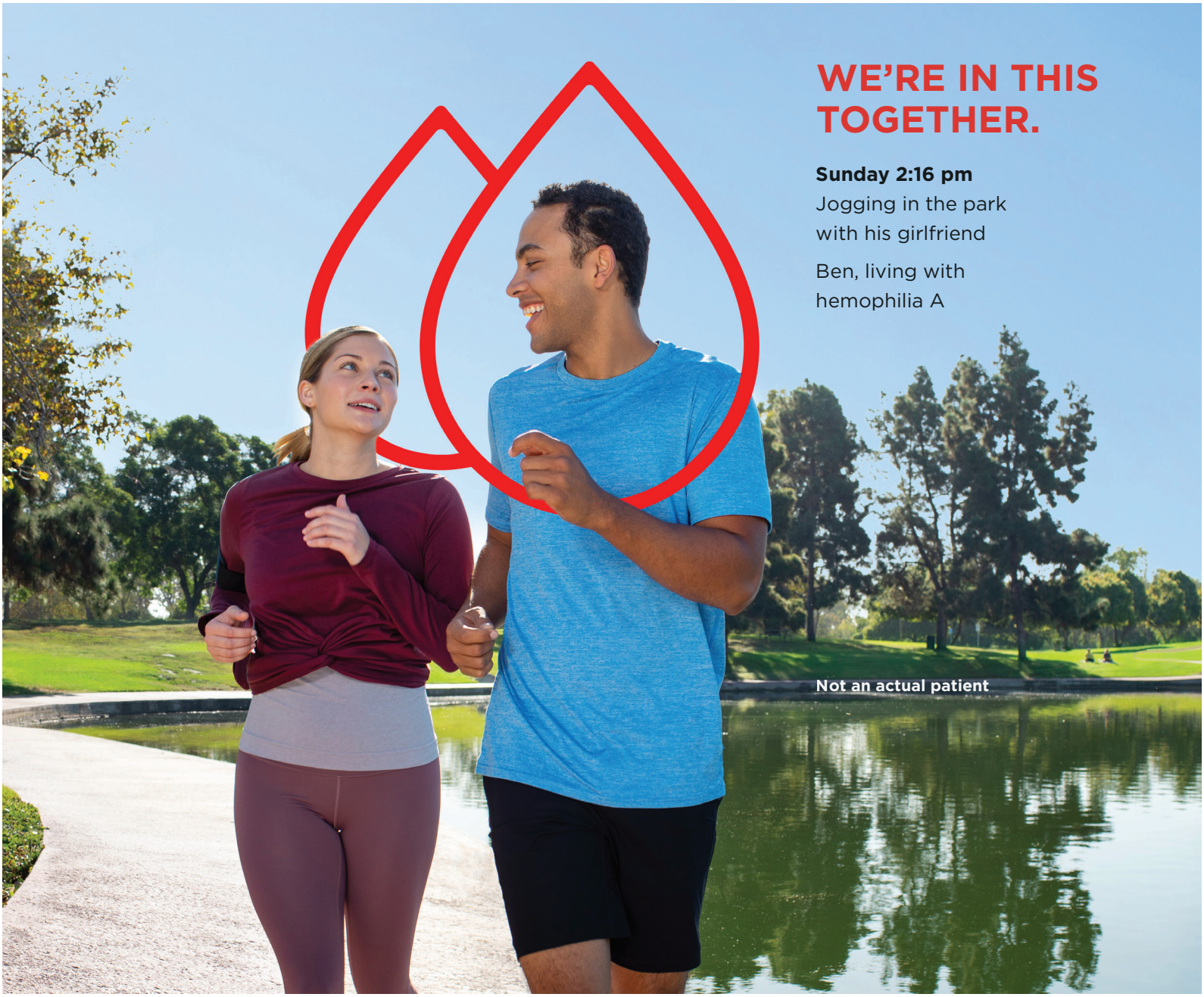
- Regular Regional 'HTC Huddles' to share what was happening in each center, discuss best practices, and pandemic challenges
- Drop in meetings by discipline for HTC social workers, nurses, physical therapists, and data managers
- Engagement with HTC staff to provide virtual health education for Camp Bold Eagle campers and other health education offerings

As a region, we realized the benefits of these enhanced collaboration activities and will carry this momentum forward beyond the pandemic. If you have any questions about regional activities please contact **Sue Adkins, BSN, RN**, Regional Core Specialist at sadkins@hfmich.org.

Thank You Elizabeth Sandon-Kleiboer RN, BA!

A big thank you to Elizabeth Sandon-Kleiboer RN, BA, Pediatric Coagulation Program Manager at Helen DeVos Children's Hospital for over 25 years of service to the bleeding disorders community.

Beth has provided support not only to her Helen DeVos kiddos, as she would call them, and their families, but also to the bleeding disorders community at large. She has provided leadership and nursing skills to Camp Bold Eagle for 20 summers ensuring campers have safe and exciting summers. She has also participated in many other HFM sponsored events, served on the HFM Medical Advisory Council, shared her expertise with other HTC staff members, and served on the Hemophilia Alliance Board of Directors. In the past Beth has received HFM awards for outstanding service to the bleeding disorders community. Recently, she was awarded the Grand Rapids Magazine 2020 Excellence in Nursing Award recognizing her extraordinary contribution to healthcare. We wish her the best in her next adventure. We will miss you Beth!



Let's make today brilliant.

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

bleedingdisorders.com | Takeda

Did you know that HFM has an Emergency Financial Assistance Program?

By Lisa Clothier, LMSW, ACSW, HFM Outreach and Community Education Manager

The bleeding disorders community has a long history of resiliency, however, the pandemic has created unimaginable challenges, especially financially. These challenges create ripple effects into all corners of our lives. As a result of lost jobs, furloughs, reduced hours, closed schools and day care, and the inability to obtain some goods and services, many people are facing significant financial hardships.

Fortunately, we have been joined by community organizations to support this program through the generous partnership with Cascade Hemophilia Consortium, the Hemophilia Alliance Foundation, and industry partners such as Novo Nordisk. Through their partnership we are able to support even more members of the bleeding disorders community facing financial hardship.

The financial assistance program supports temporary financial emergency situations such as (but not limited to) eviction, utility shut off, and financial challenges including those related to the COVID-19 pandemic. Each situation is evaluated on a case-by-case basis. Availability of the program is subject to the status of the financial assistance program fund.

We work in conjunction with you and your treatment center social worker, or other health care provider, to understand your unique needs and evaluate if you meet the criteria for our financial assistance program.

Special thanks to these sponsors for their support

The Hemophilia Alliance · Cascade Hemophilia Consortium Since 1994 · novo nordisk®

The Hemophilia Foundation of Michigan (HFM) does not endorse any specific product or company.

In order to qualify for the program:

- You, or a family member living in your household, must have a hereditary bleeding disorder.
- You must be a Michigan resident.
- You must not have received financial assistance from HFM in the past twelve months. *(Please note: During the COVID-19 pandemic we are accepting applications on a case by case basis even if you have received assistance within the last 12 months.)*

If you would like to apply to our confidential financial assistance program, please contact **Lisa Clothier, LMSW, ACSW**, Outreach and Community Education Manager at lclothier@hfmich.org or 734-961-3512.

ADDITIONAL RESOURCES: Go to **www.hfmich.org/get-help/** for additional financial resources from other national organizations.

Colburn Keenan Foundation
www.colkeen.org/individual-financial-assistance-grants/
phone: 1-800-966-2431
Provides financial assistance to individuals and families living with chronic conditions, with priority placed on those living with bleeding disorders. Individual Financial Assistance Grants provide up to $2,000 to cover unexpected medical expenses, utility bills, small appliances, transportation to treatment, rent, and medical alert jewelry.

Hemophilia Federation of America (HFA) COVID-19 Emergency Assistance
www.hemophiliafed.org/our-role-and-programs/assisting-and-advocating/financial-assistance/covid-19-relief-fund/
phone: 202-675-6984
HFA provides assistance with urgent basic living expenses, medically necessary items, plus medical travel and educational support for people with inhibitors.

Patient Access Network (PAN) Hemophilia Treatment Assistance
www.panfoundation.org/disease-funds/hemophilia/
phone: 1-866-316-7263
Financial assistance up to $2,900 per year for co-payments, co-insurance and deductibles to financially and medically qualified patients, including those insured through federally administered health plans such as Medicare.

Patient Services Inc. (PSI) Financial Assistance
www.patientservicesinc.org/
phone: 1-800-366-7741
PSI can assist with health insurance premiums, copayments/co-insurance, travel expenses, ancillary items, infusion and nursing services. Click “Patients” and “Illnesses” to look up the programs available based on your type of insurance and illness. PSI has a “first come, first served” policy so assistance is based on eligibility and availability of funds.

Special thanks to our 2020 Virtual Camp sponsors!

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Galens Medical Society
The Youth Foundation of America

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

The Hemophilia Foundation of Michigan (HFM) does not endorse any specific product or company.

You deserve the best care, support and medical treatment available! Join us, and together with an amazing group of medical practitioners and hemophilia sisters, we'll continue the journey of learning how to best advocate for ourselves and each other.

The Hemophilia Foundation of Michigan (HFM) is pleased and excited to host the

2020 National Conference for Women & Teens with Hemophilia

Hear Our Voices: Continuing to Thrive

October 9-10, 2020

Through a distinctive virtual experience

To learn more about this unique conference, go to: **hfmich.org/womens-conference**

SPECIAL THANKS

Regional Sponsor

INDIANA HEMOPHILIA & THROMBOSIS CENTER, INC.

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The Hemophilia Foundation of Michigan (HFM) does not endorse any specific product or company.

www.hfmich.org/walkvideo1

www.hfmich.org/walkvideo2

YOUR walk! Designed by YOU.

You matter. Your support matters. Walk with us virtually. Register for FREE today.

Join one or both of HFM's virtual fundraising walks from anywhere in Michigan, and support the bleeding disorders community!

Unite Walk Grand Rapids
Sat., Sept. 19
Meet online: 10am
www.hfmich.org/unitegrandrapids

Unite Walk SE Michigan
Sat., Sept. 26
Meet online: 10am
www.hfmich.org/unitedetroit

Unite for Bleeding Disorders

hfm

For more information, contact **Carrie McCulloch** Special Events Manager at cmcculloch@hfmich.org

When it comes to your hemophilia A treatment

Move beyond the threshold[a]

A simple switch to Esperoct® can give you high factor levels for longer.[b]

Extend half-life beyond the standard

22-hour average half-life in adults[c]

High factor levels in adults and adolescents

At or above 3% for 100% of the time[a,d]

At or above 5% for 90% of the time[a,e]

Flexible on the go[c]

The only extended half-life product with stability up to 104°F[f]

[a]Trough level goal is 1% for prophylaxis.
[b]Compared with standard half-life products.
[c]Data shown are from 42 adults who received a pharmacokinetic (PK) assessment around the first Esperoct® 50 IU/kg dose.
[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 PK modeling.
[f]For 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 pages.

Discover more at Esperoct.com.

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

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 from the date of manufacture until the expiration date stated on the label.

ESPEROCT® may be stored at room temperature (not to exceed 86°F/30°C), for up to 12 months within the 30-month time period. Record the date when the product was removed from the refrigerator. The total time of storage at room temperature should not exceed 12 months. Do not return the product to the refrigerator.

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: 02/2019

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

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

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

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

US19ESP00010 August 2019

novo nordisk®

Copay Accumulators

Access to Copay Assistance for Your Out-of-Pocket Costs

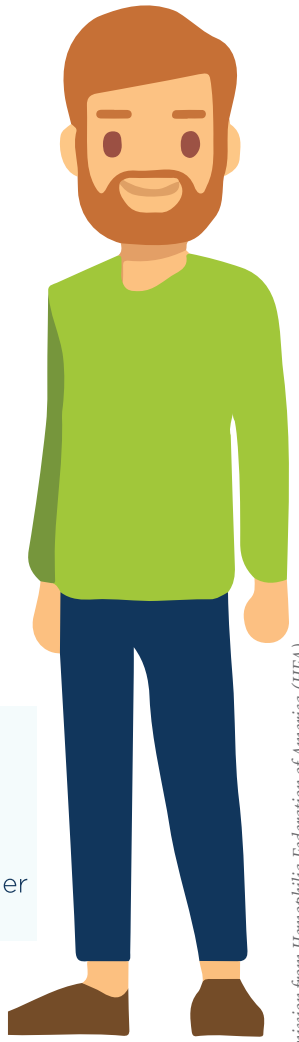
A few years ago, pharmacy benefit managers (PBM) started providing Accumulator Adjuster Programs (AAP) to large self-insured employers that apply to patients who use drug copay assistance cards from manufacturers.

Insurers who utilize this program use the full value of the patient's copay card (usually around $12,000) but once the manufacturer assistance runs out, the patient will still be responsible for the entirety of their deductible and out-of-pocket costs.

This places a huge burden on patients with high cost disorders who may be required to pay thousands of dollars out-of-pocket for their medication all at once.

Continued on next page

ACCUMULATOR ADJUSTERS

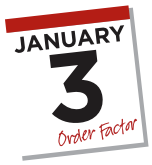


Jack has a high deductible health plan (HDHP) with a deductible of **$4,000** and a limit on his maximum out-of-pocket spending of **$6,000**.

- Jack has to pay the **full cost** of all doctors' appointments and prescription drugs (including clotting factor) until he meets his $4,000 deductible.
- After he meets his deductible, Jack pays **30% coinsurance** on his prescription drugs (including clotting factor) until his out-of-pocket (OOP) spending reaches the $6,000 maximum.

Jack has a copay card from the manufacturer who makes his clotting factor. The card has a value of up to $15,000.

Without Accumulator Adjuster (copay card counts toward patient deductible and OOP):

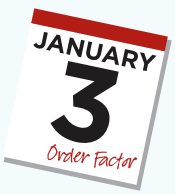


$30,000:	Cost of January clotting factor order
- $4,000:	Manufacturer copay card is used to satisfy Jack's deductible
$26,000	Remaining cost of January clotting factor order
x30%	
$7,800	Potential coinsurance amount owed on January clotting factor order
-$2,000	Manufacturer copay card is applied toward coinsurance amount

Jack has met his annual OOP maximum ($6,000). Using his copay card, he has satisfied his $4,000 deductible plus the additional $2,000. He does not owe any more in copayment or coinsurance for January or for the rest of the plan year.

With Accumulator Adjuster (copay card does NOT count toward patient deductible or OOP):

$30,000:	Cost of January clotting factor order
- $15,000:	Health plan draws down full value of manufacturer copay card $0 of that manufacturer copay assistance counts toward Jack's deductible
- $4,000	Jack must pay full deductible in order to get his factor order AND what's more...
$11,000:	Remaining cost of January clotting factor order
x30%	→ $3,300: Potential coinsurance amount owed on January clotting factor order
$3,300:	Potential coinsurance amount owed on January clotting factor. Jack has already paid $4,000 toward his $6,000 maximum OOP, so he *only* has to pay $2,000 toward the $3,300 coinsurance amount.



Jack has to pay $6,000 in personal funds in order to get his first shipment of clotting factor in January.

Copay Accumulators continued

Advocacy in Action

The bleeding disorders community and other patient groups have been educating employers and PBMs on the dangers of Accumulator Adjuster Programs. In 2019, we received a small win for the bleeding disorders community when the Centers for Medicare and Medicaid Services (CMS) released the final Notice of Benefit and Payment Parameters (NBPP) for 2020–a rule released each year to set policies for private insurance plans (marketplace plans and people in employer large group plans [self-funded] in the US). CMS ruled that insurers are only allowed to enact copay accumulator programs for brand name drugs with generic alternatives. Since clotting factor has no generic alternative, our patients would still have access to the assistance.

However, on May 7, 2020 CMS released the final NBPP Rule for 2021 that gives more allowance to insurers in determining when and how to utilize copay accumulator programs. This means they WILL be allowed to use AAP on drugs with no generic alternative.

The Fight Continues

Since reform at the federal level is unlikely, advocates are turning towards states to protect patients. (It is important to remember that these reforms will only protect patients in small group plans not large self-insured employers.)

West Virginia, Virginia, and Illinois have passed legislation prohibiting copay accumulators and several other states are in the process of introducing legislation.

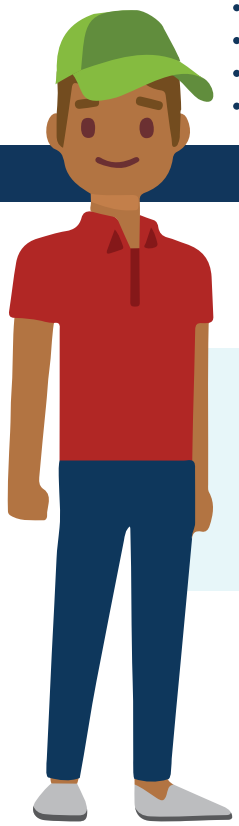
Michigan Update – August 2020

The Michigan House of Representatives has recently introduced legislation regarding copay accumulators as part of a larger drug pricing package. The bill is currently moving through a draft process that will determine whether or not the bill will protect patients. HFM will update the community once the bill language has been finalized and share how this would impact the bleeding disorders community if passed.

Have you received a letter from your insurance stating that your copay card will no longer be applied to your deductible?

Let HFM know by emailing **Sarah Procario** at sprocario@hfmich.org.

Let's say Ted is not an adult with his own insurance, but a child (with lower factor dosing and lower Rx costs).



- Ted's monthly factor shipment costs $10,000
- Ted's family's plan also has a $4,000 deductible
- Ted's family's plan also has a $6,000 individual OOP maximum/$12,000 family OOP maximum
- Ted's family also has a $15,000 manufacturer copay card

With Accumulator Adjuster (copay card does NOT count toward patient deductible or OOP):

$10,000: Cost of January clotting factor order
- $10,000: Manufacturer copay card is applied to cover full amount, but $0 counts to deductible

$10,000: Cost of February clotting factor order
- $5,000 Health plan draws down the $5,000 remaining on the copay card

$5,000 Remaining cost of February clotting factor order
-$4,000 Ted's family owes full deductible (assuming no earlier health expenses)

$1,000
x30% → Ted's family owes an additional $300 (30% coinsurance on remaining $1000)

Ted's family needs to pay $4,300 in personal funds to get Ted's February shipment of factor.

$10,000: Cost of January clotting factor order
x30% → Ted's family owes potentially $3,000 (30% coinsurance)

Family has paid $4,300 toward Ted's OOP maximum,* therefore **Ted's family needs to pay $1,700 in personal funds to get Ted's March shipment of factor.**

Note *: Once spending on Ted's care reaches the individual OOP maximum, the health plan must bear all costs for Ted, even if spending on other family members' health care has not yet reached the combined family OOP maximum.

Camp Bold Eagle at Home

HFM and Camp Bold Eagle (CBE) staff have a saying, “Camp is not the place, it’s the people.”

This summer truly put that saying to the test. More than changing camp grounds, our staff and campers had to transition to a fully virtual experience.

HFM and CBE staff were tasked with reimagining and re-planning camp. What’s the schedule? What will cabin groups and program areas look like? What materials do kids need? Our staff dedicated hours of planning to ensure this online experience provided the same social, emotional, and educational impacts as CBE usually does.

Unlike camp at Pioneer Trails, where kids attend camp for 5-7 days, Camp Bold Eagle at Home ran four weeks in July, Monday through Friday. Kids ages 6-12 joined camp staff in the mornings and teens joined in the afternoons. Camp staff went above and beyond to make CBE at Home feel just like camp. At the start of each daily session, a video of Karl (Pioneer Trails Camp Manager) welcomed the campers and counselors, everyone did their ‘morning’ stretches, and got in the camp spirit with a song.

From the comfort of their own homes, campers engaged in all the typical camp experiences including singing camp songs, arts and crafts, and some very creative programming for waterfront and archery. Campers received large packages of camp supplies with everything they would need for arts and crafts, mini basketball hoops, and even food!

We could not be happier with the success of HFM’s first Camp Bold Eagle at Home. Thank you to everyone who participated and supported this new experience. As we say, the people are what make camp great.

Health Education Videos

Camp Bold Eagle at Home

As soon as HFM made the difficult decision to host our summer camping programs online due to the ongoing COVID-19 pandemic, HFM staff, counselors, and medical professionals went to work rethinking camp and planning a unique online experience.

Health education is a central component of HFM's bleeding disorders camps and supports our mission of cultivating freedom and independence in children so they are not limited by their disorder. Camp's medical center staff, typically including hemophilia treatment center staff such as hematologists, nurses, medical students, physical therapists, and social workers share education on a variety of topics related to campers' bleeding disorders during HI-C (health information center). Just as most program areas at camp look different this year, so does HI-C.

Embracing our new virtual world, HFM's medical center volunteers filmed educational 'infomercials' for the campers to watch throughout their time online. In all, we had firemen, nurses, social workers, nurse practitioners, data coordinators, physicians, physical therapists, dental hygienists, and a dietician participate in the educational videos.

Exploring Bee Keeping

Many thanks to community members **Bill Darbison** and **Kathy Gerus-Darbison** for sharing their time and talents with Camp Bold Eagle campers and staff! They shared a series of videos exploring all aspects of bee keeping.

Campers viewed and discussed videos on the following topics through the month of July:

General Health
The importance of physical activity, hydration, dental health, and sunscreen for overall health.

Safety
How to keep safe through diet and eating all the food groups, understanding stranger danger, using mouth guards, calling 911, and car safety.

Bleeding Disorders
Including symptoms, nosebleeds, RICE, the emergency room, and bleeding when brushing teeth.

COVID-19
Medical professionals also shared an overview of COVID-19, the importance of washing hands and protecting ourselves against COVID-19 germs. Campers also learned about psychosocial impacts and visiting grandparents.

Other informercial topics included bee keeping (above, right), exercise, helmet safety, and the polar bear plunge – aka jumping into the chilly lake in the morning to help us wake up.

We are so thankful for the medical staff who continue to give back to our community by volunteering their time for HFM's summer camping programs. Thank you for your creativity, passion, and joy you share with our campers.

Camp Bold Eagle
AT HOME ~ 2020

Links to some of CBE's videos

www.hfmich.org/cbe1
physical activity

www.hfmich.org/cbe2
5 food groups

www.hfmich.org/cbe3
nosebleed management

www.hfmich.org/cbe4
hydration

www.hfmich.org/cbe5
stranger danger

www.hfmich.org/cbe6
rice

www.hfmich.org/cbe7
oral health

www.hfmich.org/cbe8
dental protection

www.hfmich.org/cbe9
going to the ER

www.hfmich.org/cbe10
sunscreen

www.hfmich.org/cbe11
sunscreen pt 2

PAID CONSUMER OUTREACH

EXPERIENCE MATTERS

BeneFix is FDA approved for once-weekly prophylaxis and on-demand use to fit your dosing needs—from the only recombinant factor IX supporting individuals with hemophilia B for more than 20 years.*

Not actual patients.

- **More than 20 years* of experience—**the first recombinant treatment for individuals with hemophilia B
- **Dosing options to meet your needs—**for once-weekly prophylaxis and on-demand use
- Designed with viral safety in mind. More than 150 quality control tests are done on each batch of BeneFix
- The convenience of the BeneFix Rapid Reconstitution (R2) Kit with a range of vial sizes

What Is BeneFix?

BeneFix, Coagulation Factor IX (Recombinant), is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Your doctor might also give you BeneFix before surgical procedures.

BeneFix is **NOT** used to treat hemophilia A.

ASK YOUR DOCTOR WHICH BENEFIX DOSING OPTIONS MAY BE RIGHT FOR YOU

Important Safety Information

- BeneFix is contraindicated in patients who have manifested life-threatening, immediate hypersensitivity reactions, including anaphylaxis, to the product or its components, including hamster protein.
- Call your health care provider right away if your bleeding is not controlled after using BeneFix.
- Allergic reactions may occur with BeneFix. Call your health care provider or get emergency treatment right away if you have any of the following symptoms: wheezing, difficulty breathing, chest tightness, your lips and gums turning blue, fast heartbeat, facial swelling, faintness, rash, or hives.
- Your body can make antibodies, called "inhibitors," which may stop BeneFix from working properly.
- If you have risk factors for developing blood clots, such as a venous catheter through which BeneFix is given by continuous infusion, BeneFix may increase the risk of abnormal blood clots. The safety and efficacy of BeneFix administration by continuous infusion have not been established.
- Some common side effects of BeneFix are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness, and rash.

Please see the Brief Summary for BeneFix on the next page.

YOUR EXPERIENCE 20+ YEARS* 20 MATTERS

BeneFix®
Coagulation Factor IX (Recombinant)
Room Temperature Storage

*BeneFix was approved February 11, 1997.

BeneFix®

Coagulation Factor IX (Recombinant)

Room Temperature Storage

℞only

Brief Summary

See package insert for full Prescribing Information. This product's label may have been updated. For further product information and current package insert, please visit www.Pfizer.com or call our medical communications department toll-free at 1-800-438-1985.

Please read this Patient Information carefully before using BeneFix and each time you get a refill. There may be new information. This brief summary does not take the place of talking with your doctor about your medical problems or your treatment.

What is BeneFix?

BeneFix is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Your doctor might also give you BeneFix before surgical procedures.

BeneFix is **NOT** used to treat hemophilia A.

What should I tell my doctor before using BeneFix?

Tell your doctor and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal medicines.

Tell your doctor about all of your medical conditions, including if you:

- have any allergies, including allergies to hamsters.
- are pregnant or planning to become pregnant. It is not known if BeneFix may harm your unborn baby.
- are breastfeeding. It is not known if BeneFix passes into the milk and if it can harm your baby.

How should I infuse BeneFix?

The initial administrations of BeneFix should be administered under proper medical supervision, where proper medical care for severe allergic reactions could be provided.

See the step-by-step instructions for infusing in the complete patient labeling.

You should always follow the specific instructions given by your doctor. If you are unsure of the procedures, please call your doctor or pharmacist before using.

Call your doctor right away if bleeding is not controlled after using BeneFix.

Your doctor will prescribe the dose that you should take.

Your doctor may need to test your blood from time to time.

BeneFix should not be administered by continuous infusion.

What if I take too much BeneFix?

Call your doctor if you take too much BeneFix.

What are the possible side effects of BeneFix?

Allergic reactions may occur with BeneFix. Call your doctor or get emergency treatment right away if you have any of the following symptoms:

wheezing	fast heartbeat
difficulty breathing	swelling of the face
chest tightness	faintness
turning blue (look at lips and gums)	rash
	hives

Your body can also make antibodies, called "inhibitors," against BeneFix, which may stop BeneFix from working properly.

Some common side effects of BeneFix are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness and rash.

BeneFix may increase the risk of thromboembolism (abnormal blood clots) in your body if you have risk factors for developing blood clots, including an indwelling venous catheter through which BeneFix is given by continuous infusion. There have been reports of severe blood clotting events, including life-threatening blood clots in critically ill neonates, while receiving continuous-infusion BeneFix through a central venous catheter. The safety and efficacy of BeneFix administration by continuous infusion have not been established.

These are not all the possible side effects of BeneFix.

Tell your doctor about any side effect that bothers you or that does not go away.

How should I store BeneFix?

DO NOT FREEZE the BeneFix kit. The BeneFix kit can be stored at room temperature (below 86°F) or under refrigeration. Throw away any unused BeneFix and diluent after the expiration date indicated on the label.

Freezing should be avoided to prevent damage to the pre-filled diluent syringe.

BeneFix does not contain a preservative. After reconstituting BeneFix, you can store it at room temperature for up to 3 hours. If you have not used it in 3 hours, throw it away.

Do not use BeneFix if the reconstituted solution is not clear and colorless.

What else should I know about BeneFix?

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

If you would like more information, talk with your doctor. You can ask your doctor or pharmacist for information about BeneFix that was written for healthcare professionals.

This brief summary is based on BeneFix® [Coagulation Factor IX (Recombinant)] Prescribing Information LAB-0464-12.0, revised June 2020.

Pfizer

2020 Events/Activities

www.hfmich.org/events

NOTE: Registration Required

Men's Support Group
September 8, 10am

Dinner Talk: Challenge Accepted: Laugh
September 9, 6pm

Advocacy Webinar
September 10, 6pm

Camp Old Beagle Alumni Event
September 11, 7pm

Women's Retreat
September 12, 12-5pm

Dinner Talk: A New Approach to Treating Hemophilia A
September 16, 6pm

Unite Walk Grand Rapids
September 19, 10am

Men's Support Group
September 22, 6:30-7:30pm

Dinner Talk: You Use Your Joints for What's Important to You
September 23, 6pm

Unite Walk Detroit
September 26, 10am

Community Night
October 2, 6pm

National Conference for Women and Teens with Hemophilia
October 9-10

Men's Support Group
October 13, 10-11am

Community Night
October 23, 6pm

Men's Support Group
October 27, 6:30-7:30pm

Community Night
November 6, 6pm

Bleeder and a Buddy
November 7

Men's Support Group
November 17, 10-11am

Advocacy Summit
November 23

End of Year Community Gathering
December 5

Men's Support Group
December 8, 6:30-7:30pm

734. 544.0015
www.hfmich.org
1921 West Michigan Ave.
Ypsilanti, Michigan 48197

All of HFM's events are virtual through **December 31, 2020.**

Please view each event page to learn more.

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