



THE ARTERY

WINTER 2023

THIS ISSUE

12 MAKING MEANINGFUL
CONNECTIONS

24 NATIONAL WOMEN AND
TEEN GIRLS CONFERENCE



© Brian Sevald Photography

DEAR HFM FRIENDS,

As another year draws to a close, we consider the many opportunities we've had in 2023 to come together with our community, care providers, and supporters.

November 12 – 14, in our service as the Regional Core Center for the federal Great Lakes Region HTC Network, HFM hosted our largest Regional Meeting to date with nearly 170 treatment center providers in attendance representing physicians, advanced practitioners, nurses, social workers, pharmacists, physical therapists, data managers, dental hygienists, and educators. Collaborating with our Indiana, Michigan, and Ohio centers together with federal partners was exciting and educational. The meeting included a celebration of Sue Adkins, BSN, RN, HFM regional program manager, in anticipation of her retirement at the end of this year following more than 40 years of service to the bleeding disorders community.

As you review this issue, please take a moment to read about HFM's 6th annual National Conference for Women and Girls with hemophilia and other rare factor deficiencies. This distinguished conference has made a significant impact on advocacy and care for those whose symptoms have been ignored or dismissed due to their label as a carrier. While the need for further education and empowerment remains, the difference HFM's national conference has made, and continues to make, in treatment and advocacy for women is truly remarkable. We are extraordinarily proud to have been leaders in this recognition and impact.

Within our Michigan community, opportunities for connection in person and virtually via our Community Night events, Ruby Connections, Dinner Talks, and retreats has continued throughout the fall culminating with our End of the Year Gathering and Camp Holiday Party. Plans are well underway for 2024 and your engagement, ideas, and participation are most welcome!

As tremendous advancements in treatment continue to develop, HFM keeps our community and our history close to our hearts as we consider the profound impact living with a bleeding disorder has for individuals and families.

I wish you great joy during this special season and as we begin a New Year with compassion, grace and kindness.

In love and friendship,

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

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PAID CONSUMER OUTREACH INCLUDED
IN THIS NEWSLETTER

ADVOCACY

BEING AN EFFECTIVE ADVOCATE: FROM YOUR STORY TO THE DISTRICT

On Thursday September 14, HFM was joined by the National Bleeding Disorders Foundation's (NBDF) Government Relations Manager, Josie Gamez, to discuss ways to engage with legislators and their staffers. Josie shared stories from her time in the Texas Legislature as well as from traveling around the country advocating at the state level with NBDF. Attendees were able to hear stories of what it means to be an "active constituent" and how they can apply it to their advocacy efforts when speaking with legislators and their staff.

In her presentation, Josie highlighted that legislators and their staff are often working on multiple issues at a time, and they most often only remember who they met with and where they're from, what issue they were advocating for, and the story. That is what makes your story one of the most powerful advocacy tools you have, and it is what resonates with your legislators and their staff.

How you tell your story can vary depending on how you're engaging with your legislators or their staff and there are strategies to make your outreach more effective. In-person events such as office hours, community events, or in-district

coffee hours are great to be able to talk about an issue more generally, and how it impacts you. One-on-one scheduled meetings can allow for more in-depth discussion of your issue. Regardless of how you connect with your elected official, remember to follow up with the office afterwards to thank them for their time and highlight the most important takeaways from your conversation. Legislators and their staff will almost always have business cards on hand, so feel free to take one, and follow up!

If you would like to get more involved with HFM's advocacy work or if you have any questions, please reach out to Zach Ryan, HFM's Advocacy Manager at zryan@hfmich.org.

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LAUNCH

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Started in 2019, and with the support of social workers in Michigan's hemophilia treatment centers, HFM's LAUNCH program provides individual support and assistance for members of the community who are seeking further education or career program certification to assist in the job readiness and employment process.

HFM pairs this practical support with one-on-one guidance and mentorship through our staff so that LAUNCH is designed to meet the specific needs and goals of each participant. By participating in LAUNCH, community members have reported new levels of confidence and financial stability, leading to better quality of life outcomes.

We are proud of all of the accomplishments of our graduates this year and those who are continuing to build on the education and support that they received through LAUNCH in previous years. If you are interested in exploring what possibilities LAUNCH may open up for you, please reach out to Travis Miller, HFM's Associate Camp Director and Program Services Manager at tmiller@hfmich.org.

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For additional information please contact:
Lauren Hecht MA, LLP
Senior Manager Coagulation Products
248-310-0202
Lauren.Hecht@CSLBehring.com



2023 UPPER PENINSULA RETREAT

FOR ADULTS AND FAMILIES

After a few years away, HFM made its triumphant return to the Upper Peninsula to host a retreat for our UP families! This year's retreat was held in Sault Ste. Marie, MI with programming space at Lake Superior State University (LSSU). Partnering with us on the retreat was Michigan State University's Center for Bleeding and Clotting Disorders (MSU CBCD) and joining us for the weekend was Karen Boyd, Laura Carlson, Jill Foley, and Christina Orr. We had nine families join us for the retreat for a total of 32 community members ranging from two years old to grandparents! It was a retreat for the entire family and a wonderful opportunity to foster new connections and engage with other individuals in the Michigan bleeding disorders community.

The weekend kicked off with a Sponsor Meet & Greet where families connected with our event sponsors to get more information on products, patient support programs, and more. Families then had the opportunity to get to know each other better as we enjoyed a tasty meal together. After dinner, the competition and fun were palpable as we enjoyed an electrifying evening of bowling and games! Once the activities had wrapped up for the evening, many families visited the hotel pool and sauna for a night swim before going to bed.

Joining us for our keynote on Saturday morning was Margaret Bridges of GutMonkey, to share their Leading

Edge programming which was made possible through the support of Pfizer. Margaret led attendees through a variety of activities to learn more about each other and we discussed the process of building healthy habits. After spending time together in the morning as a large group, we transitioned into separate programming for the adults and youth. The youth tapped into their creative energy and explored a variety of art mediums including watercolors, pastels, and clay, alongside a beloved friend of HFM, Kathy Gerus-Darbison. The adults remained with GutMonkey and went through a caregiver workshop which identified different motivation styles and how adults can use them to better understand and connect with youth.

After lunch and some walks around LSSU's lovely campus, the youth engaged in a hands-on oral hygiene activity led by MSU CBCD. Volunteers dressed up as teeth, as attendees witnessed the effects of sugar on our teeth and practiced brushing and flossing on our human teeth volunteers. To release some energy in the afternoon, Margaret rejoined our youth group for some fun group games and activities! The adults spent the afternoon engaged in a workshop with Kathy to learn about how pain can increase one's feelings of loneliness or depression. Attendees leaned into their vulnerability and shared their personal experiences with pain, while engaging in a tactile creative expression activity by shaping clay.

We ended our time all together as a large group with an incredible live enactment of the human clotting cascade directed by MSU CBCD and acted out by our retreat attendees. We learned about the roles of clotting factors and how they work together, as well as the process of how a fibrin clot is formed. It was a memorable visual and we thank the staff at MSU CBCD for developing such a fun and engaging experience!

HFM would like to express our gratitude to our sponsors and all of the staff, volunteers, and attendees who made this weekend possible! It was a joyous gathering and we look forward to returning to Michigan's beautiful Upper Peninsula soon! 🍷

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CENTER OF CARE:

INTERVIEW WITH BRONSON'S NEW SOCIAL WORKER



JASON WONG, LLMSW, ONCOLOGY SOCIAL WORKER, BRONSON CANCER CENTER – KALAMAZOO

Q: WHERE IS YOUR HOMETOWN?

Seattle, Washington

Q: WHAT INSPIRED YOU TO BEGIN WORKING WITH THE BLEEDING DISORDERS COMMUNITY?

I was inspired to help raise awareness and understanding of the unique needs of the bleeding disorders community. Bleeding disorders are not commonly discussed or understood in the general public, which can create misunderstanding, or worse harm, for those impacted. I hope to act as an ally for members of the community to receive the care and treatment all humans desire regardless of health condition.

Q: WHAT ARE YOU EXCITED ABOUT IN YOUR ROLE AT THE HTC?

I am excited to get to know the local population and learn about each patient and their experience. I am in a unique role where I get to spend dedicated time with each patient to learn about their experience and their lives outside of a clinic or hospital. Each person truly brings something unique with them.

Q: WHAT IS YOUR PERSONAL PHILOSOPHY WHEN IT COMES TO YOUR SOCIAL WORK PRACTICE?

"Be curious, not judgmental." When people reach out in their time of need, there is no way for us to fully understand what someone is going through, nor should we think we can. When we are curious, we ask questions and create space for understanding. Each person has a story to tell, but it is first up to us to ask.

Q: FAVORITE SIGHTS IN KALAMAZOO?

I love exploring the pop-up fairs and events on the Kalamazoo downtown mall. Bronson Park is also a great place for socializing and enjoying live music with the local community.

Q: WHAT ARE YOU LOOKING FORWARD TO IN THE UPCOMING YEAR?

I am looking forward to learning more about Kalamazoo and Michigan as a whole! Being new to the area, it is fun to explore the various places that surround Kalamazoo and see how each season brings a new feel to the community and space. It's an exciting place to call home and to work with such a diverse and engaging community.

Q: MSU OR U OF M?

Michigan State University!

Q: WHAT ARE YOUR HOBBIES?

Playing sports such as soccer, volleyball, and basketball; but I also enjoy photography!

Q: IF YOU COULD TRAVEL ANYWHERE, WHERE WOULD YOU GO?

I would definitely travel to Japan. The mixture of such a rich culture and history with all of the modern technology is such an interesting dynamic. The temples and shrines look incredible while also being able to see a car vending machine in the city is crazy!

Q: FAVORITE BOOK?

Being Mortal by Atul Gawande



WE'RE IN THIS TOGETHER.

Sunday 2:16 pm

Jogging in the park
with his girlfriend

Ben, living with
hemophilia A

Not an actual patient

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.



TOOTH TIME

JENNIFER KERNS, BS, RDH
DIRECTOR OF HEALTH INITIATIVES,
UNITED WAY OF NW MI
DENTAL CONSULTANT, NORTHERN
REGIONAL BLEEDING DISORDER CENTER

MY DENTIST KEEPS TELLING ME I NEED TO DO BETTER AT BRUSHING, BUT I KEEP TELLING HIM I HAVE A BLEEDING DISORDER AND THAT'S WHY I BLEED WHEN THEY CLEAN MY TEETH. THEY ALWAYS POKE ME AND I BLEED OR THEY CLEAN MY TEETH AND I BLEED, BUT I KNOW THAT WITH MY VWD I'M GOING TO BLEED MORE THAN THEIR OTHER PATIENTS. SHOULD I FIND A NEW DENTIST THAT UNDERSTANDS MY BLEEDING DISORDER BETTER?

– FRUSTRATED MOUTH BLEEDER, NORTHERN MICHIGAN

That does sound frustrating if you can't seem to have a dental visit without bleeding. Patients will often bleed in the dental chair from inflamed gums that are infected with old food and bacteria, but patients can also bleed if the dental provider cuts their gums with a bladed instrument by accident. If you look in the mirror that should help you figure out what happened. If you pull up on your lip and look at the gums, you should see light pink, flat gums that point sharply into the in-betweens of the teeth like a "knife" point and those would not bleed unless injured. If instead, you see red swollen areas, then there is inflammation present from debris not getting cleaned out routinely enough and you would bleed from the infection itself.

Either way, it is important for your dental provider to thoroughly explain your condition to you, answer all your questions, and make sure you understand their in-office treatment as well as home care recommendations—you should not have to leave your appointments frustrated and uninformed. I hope this helps you decide what to do, thank you for such a great question! 💧

Contact Jennifer
231-844-4601
jen@unitedwaynwmi.org

NEED DENTAL INSURANCE?

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

QUESTIONS?

Contact Kaite Scott, LLMSW, Program Social Worker, at
kscott@hfmich.org or **734.292.5267**

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

In order to be eligible for this program you must:

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

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

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IN 2020, AT THE START OF THE COVID-19 PANDEMIC, HFM BEGAN OFFERING ONLINE OPPORTUNITIES TO BRING COMMUNITY MEMBERS TOGETHER. WHILE MUCH OF HFM’S PROGRAMMING HAS RETURNED TO IN PERSON, RUBY CONNECTION REMAINS A VIBRANT ONLINE SPACE. ON THE FOURTH TUESDAY OF MOST MONTHS, WOMEN IN THE MICHIGAN BLEEDING DISORDERS COMMUNITY GATHER FOR ONGOING SOCIAL SUPPORT AND EDUCATION.

By continuing to offer virtual programming, we are able to bring together a larger number of women from across the state without the barriers of location and transportation. Participants learn from speakers and one another, share their struggles, and celebrate joys as a community. Education is conducted by expert speakers and creative projects are interspersed throughout the year. The combination of topics, speakers, and creativity allows for women with different needs to attend as is most helpful for them. Past topics and activities have included: tai chi, book club readings, addressing chronic pain and bleeding disorders, string art crafts, financial wellness, facilitated conversations, cooking healthy meals, and more.

New members are always welcome. If you are interested in joining us, please find our current schedule at hfmich.org/events.

Thank you!

HFA's programming is sponsored by:

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BIDDING WARS:
MAKING MEANINGFUL
CONNECTIONS AND
BUILDING RELATIONSHIPS

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

When we think of “bids,” we might think of making purchases on eBay, or a fast-talking auctioneer selling cars. When talking about your relationships with family, friends, and coworkers, a bid takes a different form. Relationship expert John Gottman and seasoned journalist Joan DeClaire identify bids as an expression, either verbal or nonverbal, that says, “I want to feel connected to you.” Gottman and DeClaire identify three general responses when someone tries to connect with a bid: turning towards, turning against, and turning away. While turning towards the bid compassionately by engaging and positively reflecting is the desired outcome, we can sometimes turn against and away. By turning against a person’s bid, we can outwardly hurt someone with our words, tone, and body language. Turning away from someone’s bid generally means ignoring someone, focusing on ourselves in a conversation, and being dismissive. We may not even be turning against or away from someone on purpose. By turning against and away, we can find our relationships frequently tested, strained, or even broken. What do we do about it?

Fortunately, Gottman and DeClaire offer several skill building tips to turn towards the people in our lives. One tip is to be aware of how tuned in you are to the conversation, and to tune in with all of your attention. Are you nodding, offering small and empathetic comments, and making eye contact? Or are you looking at your phone, looking past the person, and sending the non-verbal (or verbal) message that you would rather be somewhere else? Another tip is to “find shared meaning” in the areas that matter. You and your

coworker may not have the same religious beliefs, but you may both feel passionate about a work project. This can be a great opportunity to turn toward one another and work towards a shared goal. Another great tip is to focus on being interested, not interesting. Gottman and DeClaire reference Dale Carnegie’s quote, “You can make more friends in two months by becoming genuinely interested in other people than you can in two years by trying to get other people interested in you.” Everyone wants to be appreciated, and showing genuine attention shows people that they are valued.

By using these tips, you can build and rebuild strong bonds with the people that matter most. Practicing these skills may take conscious effort. Over time, these skills will become more natural, and the results will yield more fruitful, connected, fulfilling relationships.

Please note that this is not a substitute for therapy. If you are experiencing a mental health crisis, please dial 911 or go to your nearest emergency room. If you are in need of therapy resources, please contact your HTC social worker or your insurance carrier for resources. 💧

**This is not a comprehensive list of skills. This article is adapted from The Relationship Cure: A 5 Step Guide to Strengthening Your Marriage, Family and Friendships by John Gottman and Joan DeClaire. Please consult this book for more information.*



THE ARTERY

BACK TO SCHOOL GATHERING

HFM kids started the school year well prepared thanks to HFM’s first Back to School Gathering at Robinette’s Apple Haus in Grand Rapids on Saturday, August 26th. The event was fun, educational, and full of excitement for the upcoming school year and the many new beginnings it brings!

Helen DeVos Children’s Hospital nurse, Allison “Allie” Postma, spoke to parents and children about who within a school system should know about a child’s bleeding disorder, and how they should be notified. Through personal stories, Allie approached the topic in a way that was understood by everyone regardless of age.

Kids were also able to pick out a backpack to decorate and then head to the school supplies table where they were able to “shop” for just about anything they might need for the school year. Along with carnival

games and the famous Robinette’s doughnuts, the morning proved to be a wonderful time shared by our community.

We want to thank not only our sponsors, but the following community members who joined us as volunteers for this event. We appreciate their willingness to jump in and help where needed! Allison Postma; Jeri, Noah, and Allison Levering; Carolyn Wicks; Dan Lerch; Elizabeth Minard; Haley Powers; Sarah Spencer; and Matt Sterling. Thank you, all! 💧



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BLEEDS PER YEAR‡

Mean annual bleed rate observed in 128 people previously treated with prophylaxis therapy.†

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

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



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

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

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

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

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

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

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

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

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

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



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

Single-dose vial
Please read this Patient Information carefully before using ALTUVIIIIO and each time you get a refill, as there may be new information. This Patient Information does not take the place of talking with your healthcare provider about your medical condition or your treatment.
What is the most important information I need to know about ALTUVIIIIO?
Do not attempt to give yourself an injection unless you have been taught how by your healthcare provider or hemophilia center. You must carefully follow your healthcare provider’s instructions regarding the dose and schedule for injecting ALTUVIIIIO so that your treatment will work best for you.
What is ALTUVIIIIO?
ALTUVIIIIO is an injectable medicine that is used to control and reduce the number of bleeding episodes in people with Hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ALTUVIIIIO when you have surgery.
Who should not use ALTUVIIIIO?
You should not use ALTUVIIIIO if you had an allergic reaction to it in the past.
What should I tell my healthcare provider before using ALTUVIIIIO?
Talk to your healthcare provider about:

- Any medical problems that you have or had.
- All prescription and non-prescription medicines that you take, including over-the-counter medicines, supplements or herbal medicines.
- Pregnancy or if you are planning to become pregnant. It is not known if ALTUVIIIIO may harm your unborn baby.
- Breastfeeding. It is not known if ALTUVIIIIO passes into the milk and if it can harm your baby.

How should I use ALTUVIIIIO?
You get ALTUVIIIIO as an injection into your vein. Your healthcare provider will instruct you on how to do injections on your own, and may watch you give yourself the first dose of ALTUVIIIIO. Contact your healthcare provider right away if bleeding is not controlled after using ALTUVIIIIO.
What are the possible side effects of ALTUVIIIIO?
You can have an allergic reaction to ALTUVIIIIO. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash or hives.
Your body can also make antibodies called “inhibitors” against ALTUVIIIIO. This can stop ALTUVIIIIO from working properly. Your healthcare provider may give you blood tests to check for inhibitors. The common side effects of ALTUVIIIIO are headache, joint pain, and back pain.
These are not the only possible side effects of ALTUVIIIIO. Tell your healthcare provider about any side effect that bothers you or does not go away.
What are the ALTUVIIIIO dosage strengths?
ALTUVIIIIO comes in seven different dosage strengths with 3 mL sterile water for injection (sWFI). The actual number of international units (IU) of Factor VIII activity in the vial will be imprinted on the label and on the box. The seven different strengths are as follows:

Strength	Cap Color
250 IU	Yellow
500 IU	Red
750 IU	Garnet
1000 IU	Green

(continued)

Strength	Cap Color
2000 IU	Royal Blue
3000 IU	Mist Grey
4000 IU	Orange

Always check the actual dosage strength printed on the label to make sure you are using the strength prescribed by your healthcare provider.
How should I store ALTUVIIIIO?

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

After mixing with the diluent:

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

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

Manufactured by:
Bioverativ Therapeutics Inc.
Waltham, MA 02451
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AHF-PPI-SL-FEB23

OLD BEAGLE

Every fall, HFM hosts a weekend retreat at Pioneer Trails for Eagle Journeys alumni to gather and reconnect. Cleverly named, Camp Old Beagle is open to any previous camper and/or counselor of HFM’s camping programs.

This year, Camp Old Beagle saw the largest turn-out in recent memory with 24 alumni joining us at the home of Camp Bold Eagle for a weekend full of bonding, traditional camp activities, and exploring the familiar locations of camp, as well as some new additions. Attendees participated in scavenger hunts that tested their knowledge of the campgrounds, a night hike through nature solely relying on their natural night vision, a kickball tournament, and laying on the dock watching a meteor shower. Of course, we can’t forget about the camp classics: making s’mores around the campfire, singing camp songs, and making lanyards and friendships bracelets; and what Midwest camp would be complete without a euchre tournament! Our group had a wonderful weekend sharing laughter, memories, and good times. 🍷



No matter how long you have been away, Camp Bold Eagle stays in the hearts of all who experience it and Camp Old Beagle will always welcome you back.

THANK YOU TO OUR SPONSOR



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Tuesday 3:24 pm
Practicing yoga with her mom
Mariana, living with von Willebrand disease

Not an actual patient

WE’RE IN THIS TOGETHER.

Let’s make today brilliant.

Takeda is here to support you throughout your journey and help you embrace life’s possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to adult patients with von Willebrand disease is stronger than ever.

bleedingdisorders.com

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

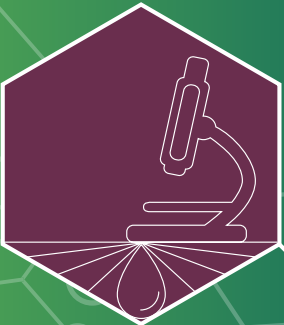


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DAYS FOR GIRLS

Many women and girls around the world lack access to safe and affordable menstrual products. These situations, referred to as period poverty, can create health challenges, lead to stigma and shame, and significantly impede women and girls' potential to advance in school and work due to absenteeism. Days for Girls (DfG) was established to increase access to menstrual health products and education to advance equity, health, and opportunity for all.

In 2015, HFM joined this mission by creating the HFM Days for Girls Ypsilanti MI program with a specific focus on women and girls with bleeding disorders who may experience more significant barriers due to heavier and longer menstrual cycles. HFM's DfG (non-sewing) Team, in coordination with the Farmington/Livonia MI Chapter, focuses on the assembly of reusable menstrual kits. HFM then partners with Save One Life to distribute the kits to women in developing bleeding disorders communities.

HFM is proud to support women across the world and thankful to our partners for assisting this mission. When menstruators have health, education, and opportunity, communities and the world are stronger.

For more information, please contact Shari Luckey at sluckey@hfmich.org.

THANK YOU TO OUR SPONSOR

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WHAT'S NEXT? YOU DECIDE.



At Genentech, we're committed to creating programs for you, with you. From a web series focused on finding the *magic* in life, to a tournament for gamers, to workshops designed to help you think well, do well, and be well, we're here to help you take on what comes next.

VISIT [GENENTECHHEMOPHILIA.COM](https://www.genentechhemophilia.com)
TO SEE HOW WE'RE CREATING
WHAT'S NEXT, TOGETHER.



When the temperature rises above 86°F Esperoct® has you covered

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

Be prepared with

Proven protection against bleeds in adults and adolescents

- **1.2** overall bleeds per year^b

EHL=extended half-life.

^aFor up to 3 months.

^b175 previously treated patients with severe hemophilia A received Esperoct® 50 IU/kg every 4 days for 76 weeks based on median annualized bleed rates shown.

^cTrough level goal is 1% for prophylaxis.

^dData 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.

^eSteady-state FVIII activity levels were estimated in 143 adults and adolescents using pharmacokinetic modeling.

What is Esperoct®?

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

- Esperoct® is not used to treat von Willebrand Disease

IMPORTANT SAFETY INFORMATION

Who should not use Esperoct®?

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

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

- **Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center**

- **Call your healthcare provider right away or get emergency treatment right away if you get any signs of an allergic reaction, such as:** hives, chest tightness, wheezing, dizziness, difficulty breathing, and/or swelling of the face

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

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

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

- Before taking Esperoct®, you should tell your healthcare provider if you have or have had any medical conditions, take any medicines (including non-prescription medicines and dietary supplements), are nursing, pregnant or planning to become pregnant, or have been told that you have inhibitors to factor VIII

- Your body can make antibodies called “inhibitors” against Esperoct®, which may stop Esperoct® from working properly. **Call your healthcare provider right away if your bleeding does not stop after taking Esperoct®**

What are the possible side effects of Esperoct®?

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

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

Discover more at **Esperoct104.com**.

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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US19ESP00168 December 2019



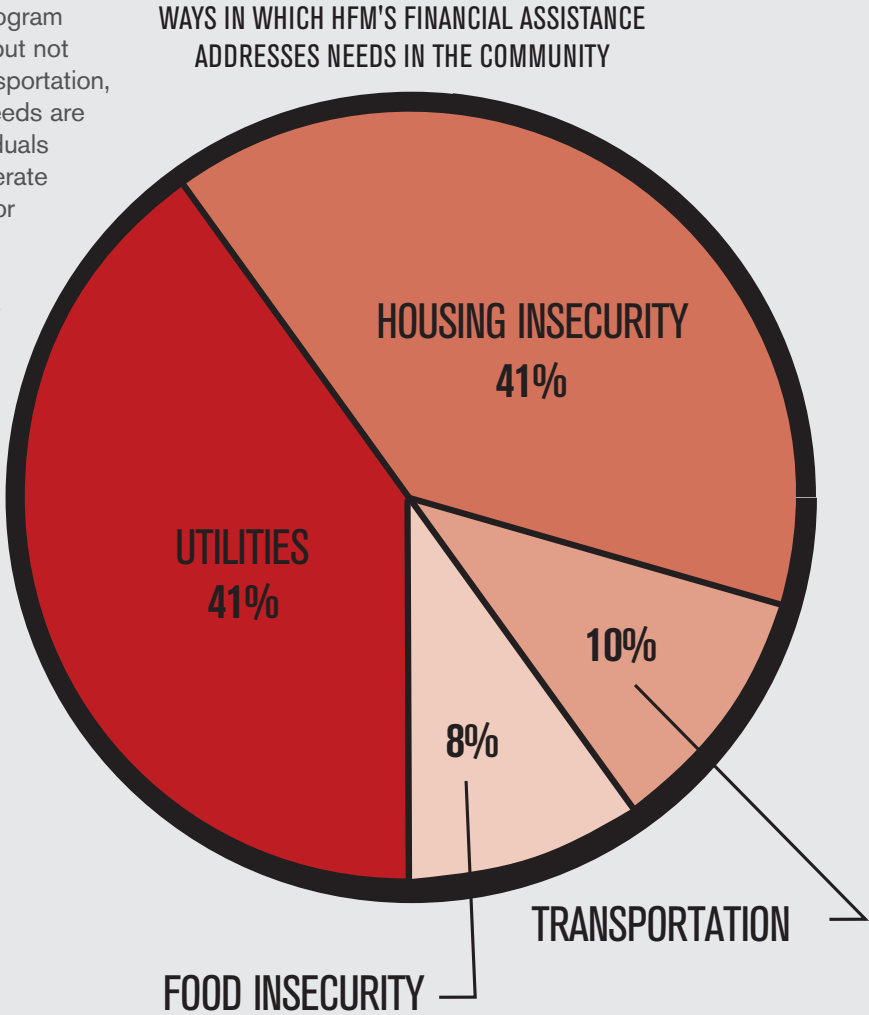
FINANCIAL ASSISTANCE

In 2023, HFM with support from partner organizations provided financial assistance to 217* community members. The financial assistance program is an HFM program that runs quietly alongside all of the other programming events, often going unnoticed because HFM values the privacy of community members and keeps specific details of this program confidential.

For those who qualify, the financial assistance program can provide support for various needs including but not limited to housing insecurity, food insecurity, transportation, and support with utility payments. These basic needs are essential for the health and wellbeing of all individuals and specifically allow community members to operate medical equipment, store food, maintain a warm or cool home, and provide a positive environment for children to reside in. While it is our bleeding disorders that bring us together, HFM recognizes that it is the whole person, in their own unique circumstances that we serve, especially when times are tough.

If you find yourself in need of financial assistance and think you may qualify for the program, it is required that you contact your hemophilia treatment center's social worker. If you find yourself with an abundance and feel called to share with our financial assistance program, you may direct your year-end giving to this impactful and necessary program. ♦

**Numbers reported from January through October 2023*



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HEMGENIX not intended for women



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2023 NATIONAL CONFERENCE FOR WOMEN AND TEENS

WITH HEMOPHILIA AND RARE FACTOR DEFICIENCIES

The National Conference for Women and Teens with Hemophilia and Rare Factor Deficiencies took place in early October, bringing together a diverse group of attendees, ranging from 14 to 81 years old. This year's theme reflected on our conference's beginning in 2018 and examined the remarkable progress made for individuals who have or had the potential to menstruate, while acknowledging areas of need for the future. HFM once again offered the conference both in-person and virtually. A total of 179 women from 36 states and Puerto Rico participated, our largest in-person gathering ever.

Our opening evening was a vibrant event as friends new and old gathered for an opportunity to connect, learn, and empower themselves. As the evening unfolded, attendees placed personal milestones from their journey with a bleeding disorder along a timeline, deepening the connection to their shared experiences. The joy in connecting with others created a profound sense of camaraderie and reinforced the message: you are not alone in your quest, and there is immense strength in unity.

Inclusivity and diversity were intricately woven into the fabric of this year's conference. Our diverse lineup of speakers and unwavering commitment to equity and inclusion resonated deeply with participants. All mainstage sessions, as well as selected breakout sessions, were simultaneously translated into Spanish. Sessions for women of color and a special track for teens were among the most popular programs.

As part of HFM's commitment and conference goals, medical information as well as advances in diagnosis and treatment were at the forefront of educational sessions. The conference began with a panel discussion, focusing on how care and treatment has progressed from 2018 through 2023. Representatives from national organizations supporting individuals with bleeding disorders provided updates on

their efforts to address the needs of women across the nation. Throughout the conference, medical professionals provided the latest insights pertinent to attendees. Dr. Amy Dunn shared information about using MASAC's (the National Bleeding Disorders Foundation's Medical and Scientific Advisory Council) recommendations to educate healthcare providers and advocate for proper care. Dr. Robert Sidonio presided over an open forum question and answer session, catering to the unique medical needs of attendees. Participants also gained valuable insights into the work of Drs. Lynn Malec and Angela Weyand, who are building a nationwide network focused on research, advocacy, innovation, support, and education.

A WORD ABOUT INCLUSIVE LANGUAGE:

This year, the phrase "those who have or had the potential to menstruate" was frequently heard throughout the conference. This phrase is currently our best way to recognize and respect the diversity of individuals in attendance at our event. It acknowledges that not all people who are biologically predicted to menstruate will necessarily experience it. Further, inclusive language considers a wide range of experiences and identities.

For example, this language is inclusive of individuals who have not yet begun or are past menstruating, those with medical conditions that delay or interrupt menstruation, and transgender men who were assigned female at birth but identify as men. This language acknowledges the experiences of individuals without making assumptions about their menstrual cycles and respecting the experiences of those going through various life stages and diverse gender identities. In doing so, it contributes to creating a more welcoming and supportive environment for everyone while avoiding making assumptions based on a person's appearance or assigned sex at birth.



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Physical therapy was highlighted this year with particular attention given to joint pain management. A panel of the country's top physical therapists specializing in bleeding disorders addressed attendees' specific questions. Other educational topics encompassed pelvic health, bone density, and mental health. A notable addition to this year's conference was the real-time research conducted throughout the weekend, specifically focusing on ultrasound imaging for joint bleeds.

Activity and mindfulness sessions included yoga, Tai Chi, basic karate movements, and a captivating karate demonstration by our very own bronze medal-winning world champion, Parker Higgins. These sessions blended information with interactive experiences, leaving attendees with valuable knowledge to carry forward.

Saturday evening's Butterfly Bazaar featured games, music, butterfly beading, painting, chair massages, and henna, with each station staffed by volunteer committee members, most of whom joined the conference a half day early to connect and develop leadership skills to bring back and serve their home communities. Fun, conversation, and connection was evident throughout the evening.

HFM's National Conference for Women and Teens with Hemophilia and Rare Factor Deficiencies was much more than an event; it was a transformative journey of self-discovery and empowerment. Speakers provided invaluable knowledge, nurtured confidence, highlighted the urgency of addressing systemic issues in the healthcare system, and ignited the spirit of self-advocacy. With newfound confidence attendees are empowered to take control of their healthcare journey. HFM reinforced our unwavering commitment to inclusion and diversity, serving as a beacon of hope for all individuals navigating the challenges of living with bleeding disorders. 💧

ATTENDEES JOINED US FROM THE FOLLOWING STATES:

ARIZONA, ARKANSAS, CALIFORNIA, COLORADO, CONNECTICUT, FLORIDA, GEORGIA, IDAHO, ILLINOIS, INDIANA, IOWA, KANSAS, LOUISIANA, MARYLAND, MASSACHUSETTS, MICHIGAN, MISSOURI, MONTANA, NEBRASKA, NEVADA, NEW HAMPSHIRE, NEW JERSEY, NEW MEXICO, NEW YORK, NORTH CAROLINA, NORTH DAKOTA, OHIO, OKLAHOMA, OREGON, PENNSYLVANIA, SOUTH CAROLINA, TENNESSEE, TEXAS, UTAH, VIRGINIA, WASHINGTON, AND PUERTO RICO

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[Coagulation Factor IX
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REVEL AND ROLL

We had a fantastic turnout at Revel and Roll for our Community Night in Kalamazoo on Friday evening, August 25. Many families joined us to share a meal, learn from our wonderful HTC staff, and have fun bowling. Julie Cooper-McNinch, social worker, and nurses Nancy Inverso and Jen Luitje, joined us from the Bronson Hemophilia Treatment Center to share a presentation on transitioning back to school. They specifically shared how to work with school administrators and advocate for the unique needs of your child with a bleeding disorder.

A big thank you to everyone who attended and participated at our first Community Night in Kalamazoo!

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**Make an Impact
this
Holiday Season**

Your support provides hope and connections in all the ways our community comes together.

88 cents of every dollar raised supports programs and services delivered to families living with bleeding disorders!

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1921 West Michigan Ave.
Ypsilanti, Michigan 48197

UPCOMING EVENTS

March 8
Community Night
Virtual Date Night 📺

March 19-20
Lansing Days
Lansing Capitol 🧑

April 20-21
SpringFest
Ann Arbor 📺 🧑

Spring 2024
Women's Retreat
Kalamazoo 🧑

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

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