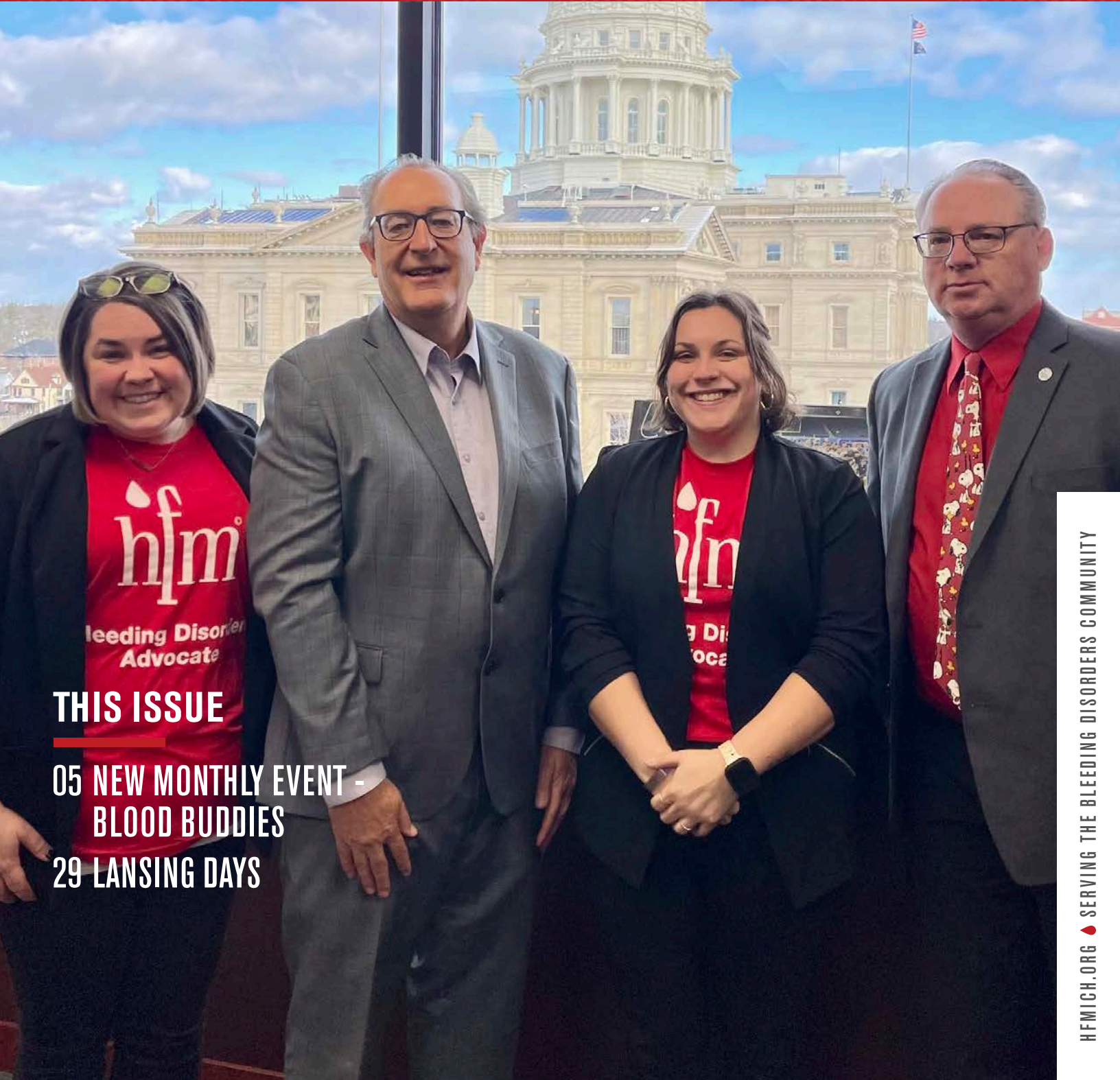




THE
ARTERY

SPRING/SUMMER 2024



THIS ISSUE

**05 NEW MONTHLY EVENT -
BLOOD BUDDIES**

29 LANSING DAYS



© Brian Sevald Photography

DEAR HFM FRIENDS,

As we embrace the blossoming of spring, I am overwhelmed with a sense of gratitude for our incredible community. HFM's extraordinary team of staff, leadership volunteers, community members, healthcare providers, family members, various sponsors and supporters, have come together to provide connection, information, education, and assistance in fulfilling our mission:

TO ENHANCE THE QUALITY OF LIFE FOR ALL AFFECTED BY HEMOPHILIA, VON WILLEBRAND DISEASE, OTHER COAGULATION DISORDERS AND RELATED COMPLICATIONS.

Throughout this issue of *The Artery*, we recognize the multitude of activities and programming that have recently taken place, and those that are coming up, and share pertinent updates and helpful information for those living with a bleeding disorder and their loved ones. We hope additional folks may be enticed to participate with in-person as well as virtual programming as you peruse the pictures and articles. One goal of our programming is to truly support and uplift one another on our journey with bleeding disorders. Together, we've weathered tremendous challenges, celebrated victories, and forged bonds that strengthen our resolve.

Looking ahead, I am excited by the events and initiatives we have planned. From educational workshops, multiple Eagle Journey summer camps, to various retreats and gatherings, we hope to offer something for everyone to engage with and enjoy. Our programming is designed to create opportunities for us to come together, share experiences, and grow even stronger as a community.

Please know, your participation and support make all the difference. Lending a hand at an event, sharing your story to inspire others, providing financial support, or simply "being there" for a fellow community member—your contributions make a difference.

As we continue to navigate the road ahead, let's continue to support one another on this journey.

Together, we flourish.

With friendship,

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

Front Cover: Community members Becky Steele, Allie McComber, and Ken Martin with Michigan State Senator Roger Victory during Lansing Days 2024.

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PAID CONSUMER OUTREACH INCLUDED IN THIS NEWSLETTER

WITH SINCERE GRATITUDE

THANK YOU TO OUR INDIVIDUAL FINANCIAL DONORS. THIS LIST REPRESENTS CONTRIBUTIONS RECORDED FROM JANUARY 1, 2023, THROUGH DECEMBER 31, 2023, OUTSIDE OF PROGRAM OR REGISTRATION FEES. HFM IS GRATEFUL TO OUR MANY SUPPORTERS WHO MAKE OUR COMMUNITY PROGRAMS AND SERVICES AVAILABLE. WE WOULD LIKE TO ACKNOWLEDGE THE FOLLOWING INDIVIDUALS AND FAMILIES WHO SUPPORTED OUR EFFORTS THROUGHOUT THE 2023 CALENDAR YEAR. PLEASE CONSIDER MAKING A DONATION TO HFM IN 2024. YOUR SUPPORT TRULY MAKES A DIFFERENCE. ♡

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UP TO \$100

Not listed are the many individual supporters who donated less than \$100 or those foundations and companies who also support the work of HFM. Thank you for your generosity; every gift makes a difference.



Please accept our apologies for any errors or omissions. Please contact Carrie McCulloch at cmcculloch@hfmich.org or at 734-544-0015 to correct our records.

NEW! BLOOD BUDDIES

Growing up and aging with a bleeding disorder has its ups and downs. You get to be a part of the wonderful bleeding disorders community and participate in events like camp and conferences, but you are also dealing with life and the realities of living with a bleeding disorder. While there are always obstacles that may get in the way, such as getting time off work and finding childcare for your kids, many in our community must also overcome the large hurdle of being physically well enough to participate in the events that bring us joy. Many of us know the struggle of missing out because of an ankle or elbow bleed.

Recognizing these challenges, HFM's Blood Buddies hosts a monthly gathering for men within the bleeding disorders community to join together for connection and camaraderie. Catching up with old friends, sharing stories from camp, or even meeting new friends in the community. We recognize that life, and bleeding disorders, get in the way, but you always have a space at Blood Buddies. If you are interested in learning more about upcoming Blood Buddies events, please visit www.hfmich.org/events or reach out to Travis Miller, HFM's Associate Camp Director and Program Services Manager, at tmiller@hfmich.org. ♡



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Discover what gene therapy is meant to do.



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WE ARE SO PLEASED THAT OUR HFM MEMBERSHIP INCLUDES BOTH LIFETIME MEMBERS AND ANNUAL MEMBERS WHOSE GIFTS HELP SUPPORT HFM'S WORK EVERY DAY. EACH OF THESE INDIVIDUALS HAS MADE A SPECIAL COMMITMENT TO THE MICHIGAN BLEEDING DISORDERS COMMUNITY. WE ARE VERY APPRECIATIVE OF OUR NEW AND RETURNING 2023 ANNUAL MEMBERS AND WE ARE ESPECIALLY GRATEFUL FOR OUR LIFETIME MEMBERS. YOUR SUPPORT, INSIGHT, AND ENGAGEMENT TRULY MAKE A DIFFERENCE. THANK YOU! 💧

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YOU CAN MAKE AN **IMPACT!**

HFM MEMBERS ENJOY PRIVILEGES SUCH AS:

- Voting for the HFM Board
- Member reception at SpringFest
- Special recognition in print, online, and more!



Register at:
www.hfmich.org/membership
Scholarships Available



255

MEMBERS OF THE BLEEDING DISORDERS COMMUNITY ATTENDED ONE OF HFM'S 7 IN-PERSON, SUMMER CAMPING PROGRAMS

39

TEENS PARTICIPATED IN THE BLEEDER AND A BUDDY AND SPRING TEEN RETREAT WEEKENDS

29

PEOPLE MADE 34 VISITS TO MICHIGAN LAWMAKERS DURING HFM'S LANSING DAYS, A TOTAL OF 50 LEGISLATIVE VISITS WERE MADE THROUGHOUT 2023

408

COMMUNITY MEMBERS JOINED HFM IN YPSILANTI, MICHIGAN FOR OUR ANNUAL PATIENT AND FAMILY EDUCATION CONFERENCE—SPRINGFEST!

07

ADULTS WITH BLEEDING DISORDERS WERE PROVIDED WITH SUPPORT IN THEIR PURSUIT OF VOCATIONAL TRAININGS AND EMPLOYMENT VIA THE LAUNCH PROGRAM

158

COMMUNITY MEMBERS ATTENDED ONE OF HFM'S FIVE COMMUNITY NIGHTS TO RECEIVE EDUCATION AND CONNECTION

IN 2023

WHILE WE DON'T HAVE THE SPACE NECESSARY TO LIST ALL OF HFM'S 2023 PROGRAMS—OR ALL THE SMILES THAT WERE CAPTURED AS WE GATHERED TOGETHER—HERE ARE SOME OF OUR HIGHLIGHTS THAT YOU MADE HAPPEN!

34

WOMEN FROM THE MICHIGAN BLEEDING DISORDERS COMMUNITY RECEIVED EDUCATION, SUPPORT, AND CONNECTION AT THE WOMEN'S RETREAT

79

MEN WITH BLEEDING DISORDERS PARTICIPATED IN THE MEN'S ACTIVITY GROUP

179

WOMEN FROM ACROSS THE UNITED STATES ATTENDED HFM'S NATIONAL CONFERENCE FOR WOMEN AND TEENS WITH HEMOPHILIA AND RARE FACTOR DEFICIENCIES

795

INDIVIDUALS WITH BLEEDING DISORDERS RECEIVED A COMPLEMENTARY MEDICAL ID TAG VIA HFM'S MEDICAL ID PROGRAM

36

MEMBERS OF THE BLEEDING DISORDERS COMMUNITY WHO LIVE IN THE UPPER PENINSULA RECEIVED EDUCATION AND CONNECTION CLOSE TO HOME AT OUR UP RETREAT

2023 END OF YEAR COMMUNITY GATHERING

The End of the Year Gathering was brimming with joy and delight at Troy High School! The Troy Project LEAD students filled the room with activities for families to enjoy such as cookie decorating, gingerbread house making, face painting, board games, crafts and even a winter story from Mrs. Claus. But the star of the show was the wonderful visit from our very own Santa Antonio! Families were called one by one to visit with Santa, snap a photo, and select their gifts, many of which were generously donated by the Cascade Hemophilia Consortium. When looking around the room, you could see families connecting with old friends, children playing tag and laughing with each other, and cheerful conversations at each of the tables. Tremendous gratitude to all of the families who joined us, the Project LEAD students, Cascade, and our sponsors. We're looking forward to gathering in 2024! 🍷



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FACTOR UP with ALTUVIIITM

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

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



HIGHER FACTOR LEVELS FOR LONGER

Above 40% for most of the week (near-normal to normal range).^{*†}

48

HOUR HALF-LIFE IN ADULTS

In a Phase 3 study,[†] ALTUVIIITM offered adults the longest half-life of any Factor VIII therapy.

0.7

BLEEDS PER YEAR[‡]

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

In people taking ALTUVIIITM 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 ALTUVIIITM prophylaxis from prior prophylaxis therapy. Efficacy of prophylaxis was evaluated in 128 of these patients.

[‡]Data based on treated bleeds.



CONNECT WITH YOUR CoRe TODAY

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



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INDICATION

ALTUVIIITM [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 ALTUVIIITM when you have surgery.

IMPORTANT SAFETY INFORMATION

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

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 ALTUVIIITM so that your treatment will work best for you.

Who should not use ALTUVIIITM?

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

What should I tell my healthcare provider before using ALTUVIIITM?

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 ALTUVIIITM?

You can have an allergic reaction to ALTUVIIITM. 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 ALTUVIIITM. This can stop ALTUVIIITM from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

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

These are not the only possible side effects of ALTUVIIITM. 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

ALTUVIIITM (al too'vee oh)

[antihemophilic factor (recombinant), Fc-VWF-XTEN fusion protein-ehtl] for intravenous use after reconstitution only

Rx Only

Single-dose vial

Please read this Patient Information carefully before using ALTUVIIITM 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 ALTUVIIITM?

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 ALTUVIIITM so that your treatment will work best for you.

What is ALTUVIIITM?

ALTUVIIITM 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 ALTUVIIITM when you have surgery.

Who should not use ALTUVIIITM?

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

What should I tell my healthcare provider before using ALTUVIIITM?

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 ALTUVIIITM may harm your unborn baby.
- Breastfeeding. It is not known if ALTUVIIITM passes into the milk and if it can harm your baby.

How should I use ALTUVIIITM?

You get ALTUVIIITM 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 ALTUVIIITM.

Contact your healthcare provider right away if bleeding is not controlled after using ALTUVIIITM.

What are the possible side effects of ALTUVIIITM?

You can have an allergic reaction to ALTUVIIITM. 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 ALTUVIIITM. This can stop ALTUVIIITM from working properly. Your healthcare provider may give you blood tests to check for inhibitors. The common side effects of ALTUVIIITM are headache, joint pain, and back pain.

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

What are the ALTUVIIITM dosage strengths?

ALTUVIIITM 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 ALTUVIIITM?

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

What else should I know about ALTUVIIITM?

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

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AHF-PPI-SL-FEB23

2023 HFM ADVOCACY & HEALTH POLICY SUMMIT

At the end of each year, HFM hosts our annual Advocacy and Health Policy Summit to gather a variety of stakeholders familiar with patient advocacy, health policy, and insurance trends. These individuals share their expertise about local and national issues impacting the bleeding disorders community with the goal of identifying current state policy and/or health care policy priorities to inform and assist HFM target advocacy efforts for the coming year.

In November 2023, HFM was pleased to return to Zingerman's Roadhouse for our seventh annual Summit. HFM staff, staff from the National Bleeding Disorders Foundation, hemophilia treatment center providers, patient advocates, and industry representatives joined us for this important event.

Each attendee brought their unique knowledge on policy, insurance, and advocacy and contributed to many meaningful conversations throughout the day. HFM shared updates on recent advocacy activities at the state and national level before inviting attendees to participate in a threats and opportunities analysis. The contributions from our stakeholders were very beneficial and provided HFM with information to target 2024

advocacy priorities more effectively within the state. We were also happy to announce the creation of our Youth Advocacy Ambassador Program with those in attendance. We received valuable feedback on how to make this a successful and long-lasting program and look forward to sharing more information with the community later in 2024. ♦

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THANK YOU TO OUR PROGRAM SUPPORTER



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EAGLE STEPS IN ACTION

Have you had a chance lately to visit HFM's office in Ypsilanti? If you've stopped by recently, you may have noticed some exterior improvements, thanks to Mikey Sanger and the Holland/Sanger family. Mikey, a camper and Counselor in Training (CIT) at Camp Bold Eagle, took some great "Eagle Steps" this winter to improve our Butterfly Memorial Garden and clean up the dog run (friendly pets are always welcome to visit!) for his Eagle Project. After several site visits, discussions, and research, Mikey and his family installed a rain barrel in the Butterfly Memorial Garden, which will help water the plants during the summer season. In addition to removing branches and other debris within the dog run, Mikey and 12 local

scouts who helped with these efforts also planned for some pet-friendly plants to be placed inside that will serve to both beautify the area and to cover small gaps in the fencing.

As HFM staff members return to the office and community members begin stopping by for programs or to chat, these improvements are so appreciated in creating a welcoming environment. We hope that you will come by to visit the next time you are near the office to check out Mikey's handiwork and to enjoy the space. Thank you, Mikey, for your leadership and thoughtfulness in giving back to HFM and the community! ♦



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2023

VWD SYMPOSIUM

HFM held its Von Willebrand Symposium (VWD) virtually on Saturday, November 11, 2023. The symposium provided a comprehensive overview of VWD, including signs and symptoms, and addressing pertinent questions from the audience through large and small group sessions.

Two experienced hematologists, Dr. Jordan Shavit, from the University of Michigan Hemophilia Treatment Center, and Dr. Jill Johnsen, from the University of Washington, Seattle hosted a session called "Ask the Experts." They fielded a wide range of questions, including concerns related to diagnosis, treatment, and inheritance patterns. The dynamic exchange between doctors and the audience fostered an environment of shared learning and collaboration.

Other sessions covered diverse topics related to von Willebrand disease including tips for networking and job hunting, how to safe proof homes to reduce accidents, and discussions around managing pain. The pain session, "Dealing with Pain in Bleeding Disorders," presented by Amber Federizo, DNP provided an understanding of pain, including the different types, chronic and acute. Further discussion included treatments, medications, and alternative therapies.

The final session of the day presented tools that patients can use to track and share bleeding information with their health care providers to improve understanding of a patient's bleeding experiences and subsequent care. This session was presented by Jeanette Jones, ME.d. from the Hemophilia Federation of America. Tracking materials are available via HFA's website.

The Von Willebrand Symposium succeeded not only in disseminating crucial information but also in fostering a collaborative approach to address this complex bleeding disorder. 💧

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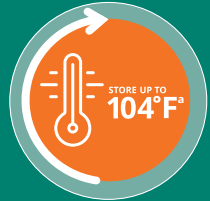



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EHL=extended half-life.

^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.

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DK-2880 Bagsværd, Denmark

For information about ESPEROCT® contact:

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800 Scudders Mill Road
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MINDFUL MOMENTS COMMUNITY NIGHT: BEING YOUR OWN BEST FRIEND

Families who attended the HFM virtual Community Night on March 8 participated in simple mindful breathing and movement activities targeted at calming stress, relaxing the mind and body, and promoting enjoyment for the whole family. Our facilitator, Julie Woodward, social worker, wellness coach, and mindful yoga teacher, started the evening by inviting participants to tune into themselves by noticing when they feel upset in their emotions, body, and mind. Julie then introduced and led the community through a variety of calming, caring activities including the seeing game, the listening game, laughter yoga, breathing exercises, and mindful movement.

We invite you to practice the listed breathing exercises to continue showing your mind, body, and emotions the care you would give to a best friend. 🩸

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MINDFUL BREATHING EXERCISES

SHARED BY FACILITATOR, JULIE WOODWARD

OCEAN BREATHING:

- Sit down in a comfortable position.
- Slowly breathe in through your nose and out through your pursed lips, as if you are blowing out through a straw.
- Notice how the slow, steady breath sounds like ocean waves, gently crashing on the shore.
- Make this sound for 2 minutes.
- What do you notice? How do you feel?

HEART BREATH:

- Sit or stand in a comfortable position.
- Place your hand on your heart and feel your breath, feel the touch of your hand.
- What do you notice? How do you feel?
- Can you be your own best friend by listening to your breath, noticing your heartbeat, and taking care of yourself?

HFM IS JOINING THE EFFORT TO IMPROVE ACCESS TO MENTAL HEALTH AND SUBSTANCE USE DISORDER TREATMENT FOR INDIVIDUALS WITH BLEEDING DISORDERS

People with bleeding disorders are struggling to get access to the mental health and substance use disorder treatment they need, and the Hemophilia Foundation of Michigan (HFM) is working to change that. Teaming up with the Munson Medical Center Northern Regional Bleeding Disorders Center, HFM joined the Bleeding Disorder Substance Use and Mental Health Access Coalition (BD SUMHAC) to improve access in Michigan.

BD SUMHAC, a multi-stakeholder coalition that includes the Hemophilia Federation of America, the National Bleeding Disorders Foundation, hemophilia treatment centers, local bleeding disorders chapters, and the bleeding disorders community, was born out of tragedy. In late 2021, Derick, a young man with hemophilia in Massachusetts, asked his hemophilia treatment center (HTC) for help finding a residential treatment facility for his substance use disorder. Although the nurse called many residential substance use disorder facilities, none would take a patient with a bleeding disorder. Without access to appropriate treatment, he unfortunately overdosed and died.

The BD SUMHAC advocates wanted to understand whether Derick's denials were a terrible but unusual experience or whether it was indicative

of a larger problem facing the community. They conducted a national survey and found that a staggering 83% of HTC providers surveyed faced denials when attempting to get a placement for their patients at an inpatient or residential mental health or substance use treatment facility. This was true in 21 different states, including Michigan. The primary reasons for denial were related to the use of infusion or injection medications, or fear that the treatment facilities couldn't handle the "medical complexity" of a person with a stable, well-managed bleeding disorder. It was clear that this was a critical health equity issue for the community.

In late 2023, BD SUMHAC, with the support of the Hemophilia Alliance Foundation, launched a State Advocacy Program to improve access in specific states where people with bleeding disorders have been previously denied access because of their condition. Zach Ryan, HFM's Government Relations & Communications Manager; Kaite Scott, HFM's Program Services social worker; and Dave Rushlow, a social worker with Munson Medical Center Northern Regional Bleeding Disorders Center, applied as a team and became one of five states engaged in this important work. The goals of the program are to:

- 01 identify champions in state government who can help facilitate access to mental health or substance use facilities for a person with a bleeding disorder in Michigan
- 02 map the regulatory landscape so that we know whether there are any regulatory barriers that prevent people from using infusion or injection medications in behavioral health facilities
- 03 identify next steps for advocacy, such as educating local behavioral health facilities about bleeding disorders

The Michigan team is making progress! They have already met with staff at the Michigan Department of Health and Human Services who offered to partner with the team to improve access.

Through collaboration and teamwork with state government, local providers, and other advocates across the nation, HFM is breaking down barriers to behavioral health access. We are committed to bridging gaps for the bleeding disorder community in Michigan and beyond.

To learn more about BD SUMHAC or to support their advocacy efforts, please visit their website at bdsumhac.org. 🩸



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HFM SPOOKTACULAR VIRTUAL COMMUNITY NIGHT

As October 2023 concluded, our community came together for a virtual celebration that blended the festive spirit of Halloween with valuable insights into dental care. The virtual Halloween Pumpkin Decorating and Dental Care event, held on Friday, October 27, proved to be a delightful and educational experience for participants of all ages. The fifty-five children who were registered from thirty-two homes were sent boxes with all the materials needed to decorate a plastic pumpkin, as well as a toothbrush and toothpaste, a reminder of the dental instruction!

The virtual gathering kicked off with a burst of creativity as participants unleashed their artistic talents on the pumpkins. From spooky jack-o'-lanterns to whimsical designs, the virtual gallery showcased a kaleidoscope of Halloween-inspired masterpieces.

Following the pumpkin decorating festivities, our special guest, Jill Foley RDH, RN, BSN, from Michigan State University's Center for Bleeding and Clotting Disorders, took the virtual stage to share valuable insights into dental care. With a focus on maintaining healthy smiles, Jill engaged participants in an interactive presentation. Children and adults alike learned about proper oral hygiene practices, the importance of regular dental check-ups, and practical tips for keeping their teeth in top-notch condition.

What made this event truly special was the sense of community it fostered in a virtual setting. Families and

individuals connected over shared creative endeavors, exchanged dental care experiences, and left the event not only with beautifully decorated pumpkins but also with a wealth of knowledge about maintaining optimal oral health.

HFM expresses our gratitude to Jill Foley for spearheading the educational portion of our event. 🍁

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COMMUNITY NIGHT: INCREDIBLE MO'S



The November 2023 Community Night in Traverse City hosted at Incredible Mo's was an absolute delight. Bria Massaway, certified personal trainer and owner of the Massaway Method, joined us to discuss simple ways for participants to improve their strength, conditioning, and joint health. Stronger muscles and joints have been proven to help protect the body from injury and reduce bleeding, particularly in the event of an accidental fall. Bria encouraged folks to get creative by using a gallon of water, which is 8.3 pounds, for squatting exercises or cans you'd find in the pantry for bicep curls. She emphasized that individuals don't need to buy special equipment to strengthen their bodies. Thanks to Bria for joining us and sharing her valuable insights! After the presentation, everyone enjoyed Incredible Mo's pizza and breadsticks and had fun bowling. One family had such a blast we asked Jennifer Weber to share her thoughts about the program:

WHY DO YOU ATTEND THE COMMUNITY NIGHT?

"So my boys and I can meet other families and people in the bleeding disorders community."

WHAT WAS THE BENEFIT FOR YOUR FAMILY TO MEET OTHERS WITH BLEEDING DISORDERS?

"That my sons got to meet and talk with other kids and adults that are dealing with and living with bleeding disorders... And how they don't let their bleeding disorder define who they are and how they live."

WHAT DO YOUR CHILDREN THINK ABOUT THIS EVENT?

"Both my boys love the event! We are able to make it to the bowling event. And that has sparked their interest in taking up bowling now. They are always looking forward to the next event."



WHAT WOULD YOU TELL SOMEONE ELSE ABOUT COMMUNITY NIGHTS?

"It's a great event to meet and talk with other people in the bleeding disorders community that are going through similar things that your family may be going through... And there so many activities at the event for your family and friends."

Thank you to the families who joined us and our sponsors. Also, a big thanks to the Munson HTC staff who joined us, Dave Rushlow and Kathi Sheldon! 💧

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For more than 20 years CSL Behring has hosted the Gettin' in the Game Junior National Championship—a weekend for children and teens in the bleeding disorders community, along with a parent or guardian, to come together for education, sports training, and friendship. In 2023 participants could choose to spend the weekend building skills in basketball, golf, baseball, or swimming. HFM was excited to send two Michigan families for a weekend of connection with other bleeding disorders community members from across the country while learning about the importance of physical activity and having fun.



GETTIN' IN THE GAME 2023



with severe bleeding disorders and are just as active in sports as Gavin is. As a parent, I don't often get the chance to have these types of conversations. The staff that run the program were very encouraging and inspirational. It was obvious that they cared so much for the kids and building their self-esteem. We felt truly blessed to be able to have this opportunity."

Would you like to participate in the 2024 Gettin' in the Game program? We encourage all interested and eligible participants to apply. HFM will share details on social media later this summer. 💧

THANK YOU TO CSL BEHRING FOR OFFERING THESE OPPORTUNITIES FOR THE MICHIGAN COMMUNITY.

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The mother of one of Michigan's youth attendees, Diane Sassak, shared, "The Gettin' in the Game Program was a wonderful experience for both Gavin and I. We got our first chance to meet others in the bleeding disorders community from all over the United States. This gave us the opportunity to learn about how bleeding disorders are treated in different areas. We also loved hearing from others who live



NBDF: NATIONAL RESEARCH BLUEPRINT

CONTRIBUTED BY THE NATIONAL BLEEDING DISORDERS FOUNDATION

Based on the product of the 2021 State of the Science initiative to evaluate the current state of scientific research in bleeding disorders, the National Bleeding Disorders Foundation is creating the National Research Blueprint. The blueprint is a comprehensive, collaborative, and community-driven national research strategy that prioritizes patient and caregivers—Lived Experience Experts (LEE)—throughout the full spectrum of research. This is called community based participatory research which incorporates everyone into the process of research. NBDF hosted the National Research Blueprint Summit January 25-27 in Arlington, VA to announce the final draft of the Blueprint.

At the Summit, each working group—Research & Development, Workforce, Infrastructure, Policy, Community Engagement, Lived Experience Experts, and Health Equity, Diversity,

and Inclusion (HEDI)—highlighted the priorities on how to coordinate effective collaboration to improve research in the bleeding disorder community. The steering committee combined the recommendations into one large, structured plan, incorporating HEDI & LEE principles throughout the entire structure. Historically, LEEs have only been involved as participants in clinical trials. Through this initiative, LEEs will be part of the entire process including identifying research priorities through developing clinical trial design, participant recruitment through a LEE Ambassador program, and sharing the findings in non-scientific language accessible to all.

So what does this mean? NBDF will continue to work with key stakeholders to move forward into the next phases of development. Later this year, NBDF will be announcing the opportunity for

people living with bleeding disorders to participate through a LEE Research Ambassador program. For more information on the National Research Blueprint, please visit the NBDF website or review the below resource: <https://www.hemophilia.org/research/national-research-blueprint/what-is-the-national-research-blueprint> 📌



WHAT IS THE NATIONAL RESEARCH BLUEPRINT?

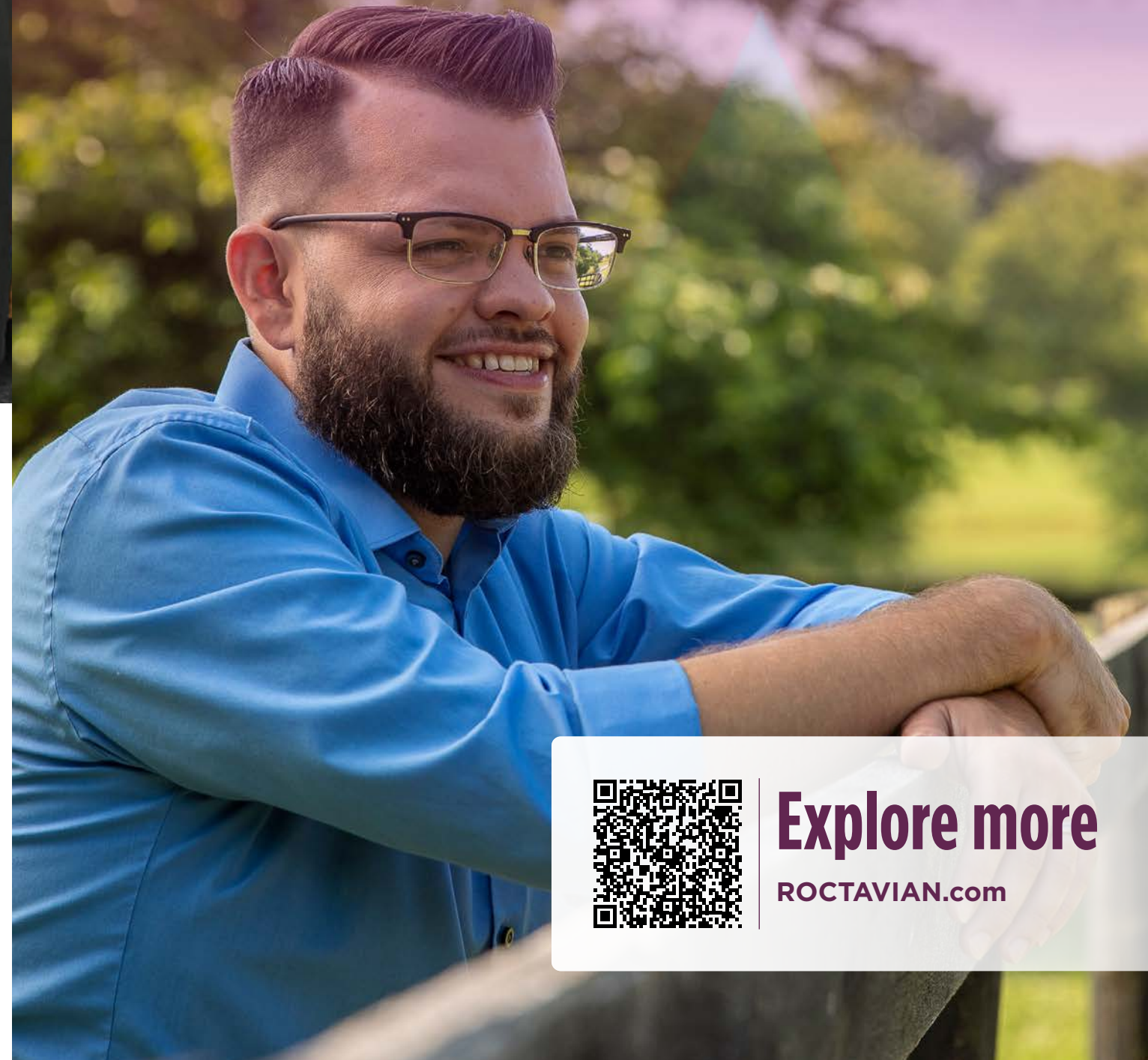
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WATCH THE NATIONAL RESEARCH BLUEPRINT FOR PUBLIC COMMENT VIDEO

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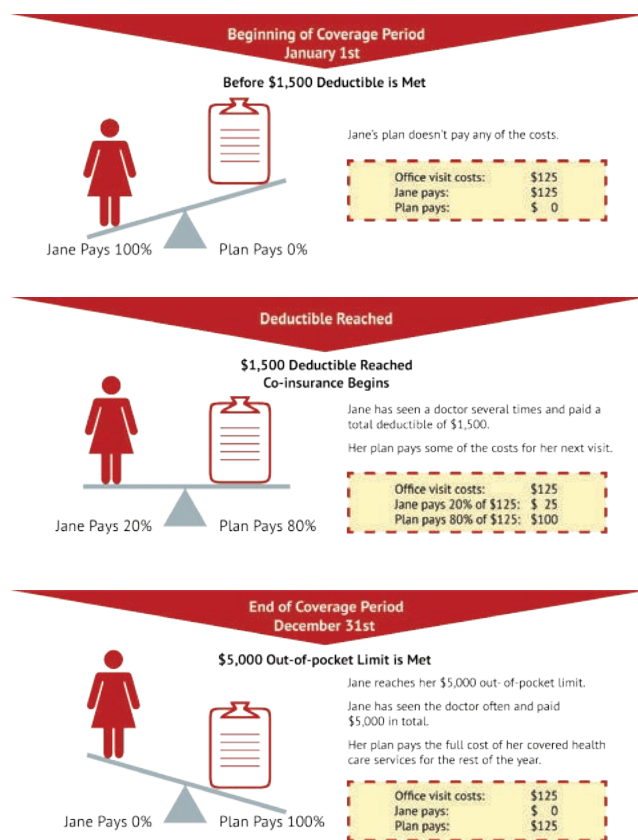
THANK YOU TO SANOFI FOR THEIR LEADERSHIP AND SUPPORT OF HFM'S 2023 NATIONAL CONFERENCE FOR WOMEN AND TEENS WITH HEMOPHILIA AND RARE FACTOR DEFICIENCIES



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GET TO KNOW YOUR INSURANCE (SO THAT IT WORKS THE BEST FOR YOU!)



On Thursday, December 14, HFM was joined by Cascade Hemophilia Consortium's Colleen Joiner and Stephanie Sibrel, and Henry Ford Health System's Ellen Kachalsky to give patients the opportunity to hear some of the most common insurance questions and to feel more comfortable engaging with insurance plans.

Thank you to Colleen, Stephanie, and Ellen for volunteering their time to answer questions and explain many of the complexities of insurance plans.

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HFM IS GRATEFUL TO OUR ADVOCACY WEBINAR PARTNERS FOR SUPPORTING THESE VALUABLE PROGRAMMING OPPORTUNITIES.



On Tuesday, March 19 and Wednesday, March 20, 2024, forty-eight Michigan bleeding disorders advocates joined the Hemophilia Foundation of Michigan (HFM) for our legislative advocacy event, Lansing Days. On Tuesday evening at the Kellogg Hotel and Conference Center, HFM staff provided legislative advocacy training, discussed our asks, and introduced a new "Mad-Libs" style training tool to help advocates hone their stories for their legislative meetings. We were also thrilled to welcome Representative Jason Morgan who discussed his path to the Michigan Legislature as well as the importance of being a patient advocate. Representative Morgan helped our advocates understand the importance of establishing a Rare Disease Advisory Council, one of our legislative asks this year. Representative Morgan's personal journey with a rare disorder, which motivated him to propose this bill, resonated deeply with our attendees and his comprehensive overview proved invaluable.

On Wednesday, bleeding disorders advocates traveled in small groups to the capital to visit fifty-five state legislator offices to share bleeding disorders education and discuss issues important to the community.

Advocates asked legislators to continue funding Children's Special Health Care

Services (CSHCS), a program within the Michigan Department of Health and Human Services that provides coverage for bleeding disorders treatment when all else fails.

Constituents also shared information on copay accumulator adjustment programs and the financial impact they have on Michigan patients who rely on copay assistance to access their necessary medications. Our advocates met with the sponsor of House Bill 4719 along with many of the cosponsors and offered their thanks for supporting this legislation. We also asked that they continue to advocate for a hearing on this bill in the House Insurance and Financial Services Committee.

Our advocates were also able to show their support for House Bill 5339, legislation to modify step therapy coverage. Advocates shared how crucial this legislation would be to removing barriers to access critical medication.

We were also excited to discuss our support for House Bill 4167, legislation to establish a Rare Disease Advisory Council. We're very happy that the bill was passed out of the Senate Health Policy Committee. We look forward to continuing our work with Representative Morgan as the legislation moves through the Senate and back to the House before being signed by the Governor.

Lansing Days 2024 was an incredible success. We are so thankful to the support of our sponsors and the participation and passion of our community advocates.

Together, we are making a difference!

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SPRING TEEN RETREAT 2024

The annual weekend getaway, Teen Retreat, was held at Camp Henry this year with HFM's Associate Camp Directors, Gelli Kelley and Travis Miller. Nine teens joined together for fun, laughter, and growth. Between games of archery and laser tag, our program services social worker, Kaite Scott, facilitated a dialogue with teens about the importance of developing an emotional vocabulary. During the conversation, teens discussed comfortable emotions, uncomfortable emotions and made connections to their own experiences and feelings. HFM's Government Relations and Communications Manager, Zach Ryan, helped the teens recognize how they have advocated for themselves throughout their lives and empowered them to continue using these skills to advocate for their community. We wrapped up our time together with a movie night before having to say goodbye 'til next time. 🩸



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HFM does not endorse any specific product or company.



Growing up with a bleeding disorder can be an isolating experience, especially as most of your friends may not fully understand what a bleeding disorder is, let alone what it is like to live with one. HFM's Bleeder and a Buddy, a weekend retreat for teens 13-17 and their 'buddy,' was created to help teens with bleeding disorders educate their friends about bleeding disorders, share more about their unique experience, and introduce them to the wonderful and inclusive HFM community.

Last fall, sixteen bleeders and their buddies gathered at Camp Copneconic for this annual weekend retreat focused on education and connection. Through games and trivia, teens taught their friends about bleeding disorders. The weekend was also filled with escape rooms, a cider mill, a corn maze, and a movie night for more opportunities for connection and sharing! We all had a blast, and we hope you join us next year! 🩸

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Thank you!

HFA's programming is sponsored by:



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UPCOMING 2024 EVENTS

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



May 18-19
Women's Retreat   
 Radisson Plaza Hotel,
 Kalamazoo, MI

June 1
**All Community Reunion
 and Camp Season
 Kickoff** 
 HFM Office
 Ypsilanti, MI

June 7
**Community Night:
 Craig's Cruisers** 
 Wyoming, MI


June 8-14
Eagle Quest  
 North Manitou Island
 in Lake Michigan

June 26-29
**Eagles Nest
 Family Camp** 
 Pioneer Trails, Holton, MI


Camp Bold Eagle 
 Pioneer Trails, Holton, MI
June 30-July 6
Teen Camp (ages 13-17)
July 14-18
 Session 1 (ages 6-9)
July 20-26
 Session 2 (ages 10-12)

August 4-10
Eagle Outpost 
(ages 14-15)
 Various Michigan
 state parks

August 9-17
Eagle Expedition
(ages 16+) 
 Northern California

August 23
**Community Night:
 Revel and Roll West** 
 Kalamazoo, MI

August 24
**Back to School
 Gathering** 
 Byron Center, MI

September 13-15
Old Beagle
**(open to adults and
 their families)** 
 Pioneer Trails, Holton, M

 Virtual
 In-person
 18 and older

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