hm ARTERY FALL 2024



DEAR HFM FRIENDS & FAMILY,

With each issue of *The Artery* newsletter I hope you find joy in reviewing the many activities that take place to fulfill HFM's mission. As we share events and programs that have happened this year, as well as announcing upcoming activities, please know planning is taking place for the coming months - and even years! We hope you and yours will consider what programming works best for you and/ or your family as well as sharing ideas and support.

2024 represents the 56th summer of Camp Bold Eagle (CBE) including our virtual camp-at-home programs in 2020 and 2021. CBE continues to provide special and sometimes surprising opportunities for campers, staff, medical students, and others to experience learning and growing together. Highlighted on page 9 are the campers who earned their Butterfly Award this summer. The award is an outstanding achievement for campers and celebrated by our medical and camp staff alike! To be 6 years old and successfully self-infuse is such a thrill. Truly any camper or affected staff, regardless of age, that is able to learn self-infusion is something we celebrate. We are tremendously proud of our campers and community!

While we have been back to mostly in person programming, we are delighted to continue to get to know several community members and families who first joined us via virtual programs. Though virtual programming remains an important part of our activities

there really isn't anything quite like the chance to be together face-to-face! During our June summer kick-off at HFM's Ypsilanti headquarters and at our 2024 SpringFest, many people had their first experience joining the community in person, which is such a benefit for joyous community engagement and robust educational programming. HFM's board of directors' youth representative, Ismael Jaber, was onsite at the summer kick-off with his new food truck, Get Loaded! During SpringFest we celebrated Ismael who completed his term as our first youth representative, as well as the dedication of two additional retiring board members, Kathleen Donohoe and Patrick Monks. Kathleen and Patrick have each supported HFM's organization as outstanding and involved members of the board. President of the Board, Elliot Jones, recognized Kathleen, Patrick, and Ismael's service during the HFM membership meeting that took place at SpringFest.

Folks from Michigan's bleeding disorders community have a variety of interesting stories to share, please take a look at the articles contributed by Eliza, Claude, and Emily as they each share personal experiences. We had a chance to hear from Claude at SpringFest with Eliza and Emily both participating with the Women's Retreat in Kalamazoo. Our summer intern, Allie, shares a bit about her experience with HFM and finding the bleeding disorders community following a fairly recent diagnosis.



We're excited for Allie as she returns to Oakland University this fall to complete her Master's program.

In-person registration for HFM's October National Conference for Women and Teens with Hemophilia A or B and Other Rare Factor Deficiencies was "sold out" before we could even complete our marketing efforts! We are grateful to the conference speakers, supporters and our HFM team for the exceptional reputation this conference has garnered and the impact it continues to make for women.

There are many additional pieces of information contained in The Artery. We really hope you'll read it cover to cover! As always, heartfelt thanks to our remarkable community.

Susan Fenters Lerch HFM Executive Director

Regional Director, Great Lakes Federal

HTC Network

IN THIS ISSUE

COMMUNITY REUNION AND CAMP KICK OFF

05 WOMEN'S RETREAT 2024

07 BLOOD BUDS AND LAUNCH

8 EAGLEJOURNEYS CAMP

YPSILANTI PRIDE AND 2024 GARDEN WALK

12 WFH GLOBAL CONGRESS

SPRINGFEST 2024

16 COMMUNITY NIGHT: CRAIG'S CRUISERS

20 COMMUNITY MEMBER FEATURE: CLAUDE MOORE

21 EXPERIENCE WITH CHILD AND MEDICAL PLAY

23 STATEMENT OF BELONGING

26 BACK TO SCHOOL

27 STUDENTS WITH BLEEDING DISORDERS HAVE A RIGHT TO ACCOMMODATIONS

29 INTERN PERSPECTIVE

CELEBRATING THE REMARKABLE CAREERS OF PATRICE THOMAS AND SUE ADKINS

31 NATIONAL WOMEN'S CONFERENCE

32 2024 SCHOLARSHIP WINNERS

33 BLUE BRIDGE LIGHTING

34 BLEEDING DISORDERS AWARENESS MONTH RESOLUTION

MAKE A PLAN TO VOTE IN THE GENERAL ELECTION ON NOVEMBER 5TH

THANK YOU TO OUR CONTRIBUTING AUTHORS

HFM BOARD OF DIRECTORS

Troy Briggs, Treasurer
David Hart, Secretary
Jason Rogers, Vice President
Adrienne Jankens, PhD
Elliot Jones, President
Jim Mohnach

EX OFFICIO

Susan Fenters Lerch Gwyn Hulswit, MA

Grace Trinidad, PhD

HFM STAFF

Sharon Ceci*, Finance and Operations Director

Meghan Mair Crosslin, Marketing and Communications Director

Gwyn Hulswit, MA, Associate Director

David L. Kaumeyer*, EdD, Finance and Operations Manager

Angellica "Gelli" Kelley, BSN, RN, Associate Camp Director and Program Services Manager

Susan Fenters Lerch, Executive Director

Shari Luckey, MA, Education and Program Services Director

Carrie McCulloch, Development Director

Travis Miller, MEd, Associate Camp Director and Program Services Manager

Laura Olson*, Office Manager

Zach Ryan, MPP, Government Relations and Communications Manager

Kaite Scott, LLMSW, Program Social Worker

Tim Wicks, Camp and Youth Services Director

CONTRACTORS

Sarah Spencer*, MPA, RN, BSN, NREMT, Eagle Journeys Camp Programs

Additional Camp and Program contractors*

GREAT LAKES/V-E FEDERAL HTC NETWORK REGIONAL CORE CENTER

Saydi Davis, LLMSW, Regional Program Manager

Susan Fenters Lerch, Regional Director

Travis Tussing, JD, Regional Administrator, Federal Grants Director

Amy Shapiro*, MD, Medical Director, Chair, Regional Advisory Council

*Denotes part-time

PAID CONSUMER OUTREACH INCLUDED IN THIS NEWSLETTER

COMMUNITY REUNION & CAMP KICK OFF

On June 1st, the Hemophilia Foundation of Michigan (HFM) hosted the ALL-Community Reunion & Camp Season Kickoff at our "home," the HFM office. The event brought together community members for a day filled with education, games, activities, music, and more.

After a warm welcome from Executive Director Susan Lerch, attendees enjoyed a variety of engaging activities, including games, face paint, and temporary tattoo stations. New camp families were able to chat with those who have been to camp before, and campers had a chance to meet their counselors and cabin mates before the official start of the camp season.

Guests were treated to a tour of the HFM office, offering a glimpse into our daily operations and the heart of our mission. A memory area and timeline were featured, allowing attendees to reflect on the rich history and milestones of our community.

HFM Program Social Worker Kaite Scott gave an informative presentation on sun safety, ensuring attendees were well-versed in protecting themselves from the sun's harmful rays. Camp Director Tim Wicks and Associate Camp Director Gelli Kelley presented packing "dos and dont's" for campers.

One of the highlights of the day was the debut of community member, Ismael Jaber's "Get Loaded" Food Truck. The food was a hit! It was delicious and fresh, and many attendees had a difficult time choosing between the food options. They were all so appetizing!

The ALL-Community Reunion & Camp Season Kick-off was a special event at our office, and we sincerely hope that we can see our community members whenever they are in the area. We so enjoyed having everyone in our community "home." Please stop by to peruse the lending library, visit the memorial garden, or to just say "hello" the next time you are in Ypsilanti!

THANK YOU TO OUR SPONSORS

SOARING EAGLE SPONSOR:



HAPPY CAMPER SPONSORS:





FRIENDS OF HFM SPONSORS:









HFM does not endorse any specific product or company.





SPIRIT OF WELLNESS

The Raddison Hotel in Kalamazoo provided the perfect backdrop for an inspiring women's retreat dedicated to bleeding disorders patients and caregivers. The retreat spanned two days of empowering activities, educational sessions, and meaningful connections. This year's theme, "Spirit of Wellness," encapsulated the offerings of the event. It allowed participants an opportunity to step away from the demands of daily life and immerse themselves in a community of understanding and support.

Education was a cornerstone of the retreat; several speakers imparted their wisdom on topics related to bleeding disorders and mental health. Samantha Carlson, MSW, LMSW, from the National Bleeding Disorders Foundation, presented a compelling session on mental health and burnout. Kaite Scott, LLMSW, HFM's Program Social Worker, shared a presentation on adult attachment styles and discussed navigating relationships.

Dr. Katie M. Scott, Hematologist & Jennifer Luitje, BSN, RN, Nurse Coordinator, from the local HTC, together delivered an informative presentation on comprehensive care for bleeding disorders patients. Maria Rohan, BSN, RN from Takeda shared insight on nutrition and encouraged the participants to prioritize themselves. Lastly, Shari Luckey facilitated the popular and requested activity, Sisterhood Symphony. In the evening, there were activities like decoupage on glass vases, custom candle making with Kalamazoo Candle Company, beading, swimming, and hot tubbing!

A very special thank you to Patrice Thomas as this event marked the end of her career with HFM! Attendees honored her contributions to the community with heartfelt tributes and gratitude.

Look out for information about the 2025 Women's Retreat in Muskegon!



THANK YOU TO OUR SPONSORS

BUTTERFLY KISS SPONSOR:



SOARING EAGLE SPONSOR:



HAPPY CAMPER SPONSORS:







Optum

FRIENDS OF HFM SPONSORS:







CHAPTER EDUCATION SUPPORTER:



HFM does not endorse any specific product or company.





Tara Dryer

Regional Account Manager Serves IN, KY and MI

"I am committed to being a resource for the bleeding disorders community via trust and educational partnerships."

- ✓ Tara.Dryer@hemabio.com
- **248.376.8483**











BLOOD BUDS

Living with a bleeding disorder can be painful and pose an obstacle to participating in community events. Understanding that this experience can be challenging and isolating, Blood Buds provides accessible events for men with bleeding disorders ages 18+. We hold virtual events every month, including game nights, like trivia and Jeopardy. We also offer in-person events such as escape rooms, trivia, and card nights. New members are always welcome! Join us by signing up at hfmich.org/events.

LAUNGH

The Hemophilia Foundation of Michigan's LAUNCH Vocational Job Training Assistance Program provides education, vocational, and professional assistance to post-high school-aged individuals within the bleeding disorders community. We help individuals find jobs that accommodate their needs by offering support in obtaining certifications in select fields such as healthcare and information technology,

as well as providing resume and cover letter reviews and mock interview skills coaching. We help individuals find jobs that accommodate bleeding disorders. In partnership with the hemophilia treatment centers in Michigan, HFM works to improve the quality of life for all members of the Michigan bleeding disorders community. If you would like more information, contact Travis Miller at tmiller@hfmich.org.

THANK YOU TO OUR SPONSOR

Genentech

A Member of the Roche Group

HFM does not endorse any specific product or company.

THANK YOU TO OUR CHAPTER EDUCATION SUPPORTER







CAMP CONNECTIONS

Families joined us on May 6 for a virtual dinner chat where we discussed what makes Eagle Journeys special and explored the various camping adventures available to our community. We sang songs, shared pictures from our camps, and introduced attendees to Camp Bold Eagle, Eagle Outpost, Eagle Quest, Eagle Expedition, and Eagles Nest Family Camp. What a great way to start the 2024 camp season!







EAGLES NEST FAMILY CAMP

Eagles Nest Family camp is for first-time campers and their families to experience the magic of Camp Bold Eagle! This was a great opportunity for new campers to see the various activities offered at camp, including a much-anticipated kickball tournament and boat rides around Big Blue Lake. New campers and their families got a firsthand glimpse into the daily adventures that make Camp Bold Eagle so special!

CAMP BOLD EAGLE (CBE)

Camp Bold Eagle is our annual residential summer camp for kids with bleeding disorders. Session 1 is for ages 6-9 and session 2 is for ages 10-12. A camp day is filled with program area rotations of nature, arts and crafts, health education (Hi-C), waterfront, and archery. We sing songs and dance before every meal! This summer campers enjoyed exciting evening programs such as the Mario Kart Relay Race, Bold Eagle Idol, and Square Dance night. Session 2 campers participated in a cabin lake swim and camped out in tents for a night. Camp is a great place for creating lasting friendships and cherished memories. We hope to see you next year at Camp Bold Eagle!

TEEN CAMP

Our Teen Camp is for ages 13-17 and gives campers more choice during their program area rotations. Campers enjoyed a fun "drive-in" movie night and went rafting on the White River! They also learned useful skills like changing a tire, taking care of their hair, and cooking simple meals. Teen Camp is a fantastic opportunity for teens to discover more about themselves and step out of their comfort zone!







EAGLE OUTPOST

Eagle Outpost is our leadership camp for teens ages 14-15. Our teens kicked off their adventure at Covenant Hills Campground by participating in activities like ziplining, high ropes courses, and various team-building exercises. Each day, a cooking crew headed to the store to prepare a full day of meals. Participants learned leadership skills and took Eagle Steps throughout the week. The week closed with an adventure to Mackinac Island!

EAGLE EXPEDITION

Eagle Expedition is an adventurous opportunity for community members 16 and up. Participants white water rafted and kayaked on the American River and sea kayaked out of the San Francisco Bay. Potential destinations for sea kayaking included Angel Island State Park, Tomales Bay State Park, and Point Reyes National Seashore. This was a great chance to learn some new skills and gain some thrilling new experiences!

EAGLE QUEST

Eagle Quest is our adult backpacking trip through rustic settings. This year participants hiked through the Manistee River Trail, carrying with them everything they needed for five days. This included all the food they cooked and ate, all the clothes they wore, and all the equipment for water and hygiene as well as medical treatments. It was a great opportunity to step outside of comfort zones and experience sights such as waterfalls, beautiful overlooks of the Manistee River. and the 245-foot-long Manistee River Little Mac suspension bridge.

THANK YOU TO OUR SPONSORS

BIG BLUE LAKE SPONSORS:



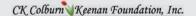






CAMPFIRE SPONSORS:







POLAR BEAR SPONSORS:





ARTS AND CRAFTS SPONSORS:

THE ALLSTATE FOUNDATION - GRIFOLS - MEIJER - PFIZER STERLING HEIGHTS KIWANIS CLUB - YOUTH FOUNDATION OF AMERICA

HFM does not endorse any specific product or company.

CHAPTER EDUCATION SUPPORTER:



BUTTERFLY AWARD RECIPIENTS

These campers learned to self infuse their own factor while at camp, earning them a coveted "Butterfly Award."

Congratulations to all **Butterfly Award recipients!**

EAGLES NEST FAMILY CAMP Joseph Maywood

CBE SESSION ONE Hunter Rurka

CBE SESSION TWO Graham Carlson TEEN CAMP Maxwell Perkins Liam Schau Brooklynn Shuman Avery Smith

COUNSELOR IN TRAINING Josh Bye





Esperoct® is a registered trademark of Novo Nordisk Health Care AG. Novo Nordisk is a registered trademark of Novo Nordisk A/S. © 2020 Novo Nordisk Printed in the U.S.A. US19ESP00186 February 2020



HFM had a wonderful time tabling at Ypsilanti Pride on June 7th! It was a great opportunity to show our support for the LGBTQIA+ community. We spread awareness about bleeding disorders and educated attendees on the bleeding disorders history and the HIV/AIDS crisis.



ANN ARBOR FARM AND GARDEN'S 2024 GARDEN WALK

HFM's Associate Director, Gwyn Hulswit and HFM's Education and Program Services Director, Shari Luckey were delighted to volunteer for the annual Ann Arbor Garden Walk on June 8, 2024. Featured this year were seven beautiful, and very different, home gardens and one organic farm. Throughout the day, hundreds of gardeners and admirers explored diverse and beautiful outdoor spaces, many never open to the public.



Founded to promote and support local gardens and farms, the Garden Walk is a fundraiser for Ann Arbor Farm and Garden's (AAFG) annual grant and scholarship program.

HFM was selected earlier this year as a recipient of a 2024 grant from AAFG to help beautify the Memorial Garden at the HFM office. Members from AAFG have also provided expert assistance in

helping us assess our immediate needs and how we can obtain assistance from a master gardener. We are grateful for the support of AAFG as a first-time grant recipient, and we hope that you plan a visit to the HFM office soon to see the improvements we have been able to make.



Hi there! My name is Eliza, and I am writing to share my experience at the World Federation of Hemophilia (WFH) 2024 Global Congress in Madrid, Spain. I had the honor of attending this year's Congress thanks to the Susan Skinner Memorial Fund, which cultivates leadership and promotes the engagement of women in the global bleeding disorders community through education, training, and networking. I was introduced to this opportunity during my participation with the National Youth Leadership Institute (NYLI) program at the National Bleeding Disorders Foundation (NBDF).

Through my involvement with the Hemophilia Foundation of Michigan (HFM) and attending the annual Lansing Days, I thought I was familiar with issues facing patients

with bleeding disorders. Nothing could prepare me, however, for the accounts I heard from patients all around the world who don't have access to prophylactic care and have challenges getting a diagnosis. As a patient diagnosed with Glanzmann's Thrombasthenia (GT), it was so meaningful to meet other GT patients from around the world — and also to see some familiar faces from Michigan, like Dr. Roshni Kulkarni!

The most impactful sessions I attended were those focused on women and girls with bleeding disorders. It is so encouraging to see these topics getting more attention! I also learned about psychosocial aspects of having a bleeding disorder, humanitarian aid efforts, the latest treatment options available, and aging with a bleeding disorder.

I am very grateful to WFH for selecting me for this scholarship, and NBDF and HFM for their support. The deep friendships and medical connections I now have with people from all over the world are invaluable, and I look forward to applying what I learned here at home!





OUR VISION: A WORLD WHERE NO LIFE IS LIMITED BY GENETIC DISEASE

At Spark® Therapeutics, we are committed to discovering, developing and delivering gene therapies.

We believe investigational gene therapy has the potential to be transformative in the treatment of hemophilia and we understand the importance of developing gene therapies that meet the needs of the hemophilia community. Our priority is the safety and well-being of clinical trial participants.



Learn about gene therapy research for hemophilia.





Interested in enrolling in a Spark-sponsored hemophilia gene therapy clinical trial?

Discover more about gene therapy research



Want to know more about gene therapy clinical trials?





SPRINGFEST 2024

In April, the warm weather brought the Hemophilia Foundation of Michigan's SpringFest 2024: Community Spirit, to the Ann Arbor Sheraton Hotel. The weekend was filled with connection, education, and activities for more than 350 attendees.

The first morning began with welcoming comments from Susan Fenters Lerch, Executive Director of the Hemophilia Foundation of Michigan (HFM), Regional Director of the Great Lakes Federal HTC Network.





The atmosphere turned electric with the opening Community Spirit Kickoff led by Michael Jay Garner of Beyond Recreation, who engaged attendees with an interactive, musical, and fun introduction, fostering a sense of excitement that lasted throughout the weekend. Other mainstage presentations throughout the weekend included local and national advocacy and policy updates and a community pep rally!



The conference breakout sessions covered a wide range of topics tailored to various life stages and specific needs. These included navigating new diagnoses, bridging gaps between HTCs and schools, achieving success in college, and preparing for aging. There were also sessions addressing issues specific to men, women, VWD, and ultra-rare factor deficiencies. Topics spanned joint pathology and management, dental health, gene therapy, and mental health. Additionally, activity sessions included offerings such as creative art expressions, journaling, yoga, tai chi, and karate.





SpringFest provided education, community bonding, and empowerment for individuals and families navigating life with bleeding disorders. From practical health management strategies to community-building activities, the event underscored HFM's commitment to supporting and enriching the lives of those affected by these conditions. The sense of camaraderie and community was deeply felt, and we are profoundly grateful for our shared experiences; learning from one another and embracing our community together.















Mark your calendars for SpringFest 2025, taking place from April 25 to 27 in Troy! ♦



SOARING EAGLE SPONSORS



HAPPY CAMPER SPONSORS

BIOMARIN CSL Behring















SPRINGFEST DISPLAY SPONSORS

ACCREDO • BAYER • CVS SPECIALTY • KEDRION BIOPHARMA • PROMPTCARE

SPRINGFEST PROGRAM SUPPORT



CHAPTER EDUCATION SUPPORTER







NEW AT 2024 SPRINGFEST!

- New bingo game encouraged interaction with sponsors and
- An exciting debut of the first ever community crafted raffle.
- The new quiet room offered a space for prayer, meditation, and
- The memory swap collected community members' photos and items for preservation.
- Kids got to visit the Wide Ann Arbor Hands on Museum! Teens learned about the clotting cascade through an interactive activity and discussed mental health and wellness.
- Attendees enjoyed a performance from the Eastern Michigan University dance team and had a visit from EMU's

COMMUNITY NIGHT:





CRUISING INTO FUN

Craig's Cruisers in Grand Rapids recently played host to an exciting evening for our HFM community, offering thrills, laughter, and camaraderie in equal measure. From a pizza buffet and an educational program to arcade adventures and zipping through the sky, attendees experienced a night filled with games and solidarity.

For those craving speed, the go-kart track provided the ultimate adrenaline rush. Racing around twists and turns, participants reveled in the exhilaration of friendly rivalry while making lasting memories. Several daring souls soared through the air on the zip line, feeling the wind rush past as they embraced the thrill of flight — rumor has it the zip line was both exciting and scary! Mini golf enthusiasts enjoyed a leisurely round, navigating through hilly obstacles and challenging their friends to friendly matches.

Amidst the excitement, an educational session about sunscreen emphasized the importance of sun protection, ensuring everyone stayed safe while enjoying the outdoor attractions. UV stickers were provided to all attendees so they could remember to reapply 30+ SPF broad-spectrum sunscreen to get the most protection.

As the night concluded, winners proudly claimed their prizes at the ticket counter, but the true victory lay in the bonds formed and the memories shared. Craig's Cruisers had once again proven to be more than just an entertainment center — it was a place where education, joy, and inclusion intersected.

THANK YOU TO OUR SPONSORS

SOARING EAGLE SPONSOR:

sanofi

HAPPY CAMPER SPONSORS:





FRIENDS OF HFM SPONSORS:







BAYER • PFIZER • PROMPTCARE

HFM does not endorse any specific product or company.

CHAPTER EDUCATION SUPPORTER





MICHIGAN ASSOCIATION OF SCHOOL NURSES

Associate Camp Director Angellica "Gelli" Kelley and Camp Health Officer Sarah Spencer took a trip to Grand Haven for the Michigan Association of School Nurses (MASN) conference this spring. Staff from the MSU Center for Bleeding and Clotting Disorders were also there to

educate and spread awareness about bleeding disorders. We are excited about these steps to partner with school nurses across Michigan to ensure students with bleeding disorders have a safe and inclusive school experience.





Learn about the next step on HEMGENIX.COM

WHY WAIT TO SEE IF YOU'RE ELIGIBLE? SCHEDULE TESTING WITH YOUR DOCTOR TODAY!

HEMGENIX is manufactured by uniQure Inc. and distributed by CSL Behring LLC. HEMGENIX® is a registered trademark of CSL Behring LLC.

© 2024 CSL Behring LLC 1020 First Avenue, PO Box 61501, King of Prussia, PA 19406-0901 USA www.CSLBehring.com www.HEMGENIX.com USA-HGX-0623-FEB24

FACTOR UP with ALTUVIIIO **TOR UP with ALTUVIIIO***



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



HIGHER FACTOR LEVELS FOR LONGER

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



HOUR HALF-LIFE IN ADULTS

In a Phase 3 study,† ALTUVIIIO offered adults the longest half-life of any Factor VIII therapy. 0.7

BLEEDS PER YEAR‡

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

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

*Average trough levels were 18% for adults 18 years and older, 9% for adolescents aged 12 years to under 18 years, 10% for children aged 6 years to under 12 years, and 7% for children aged 1 year to under 6 years.

†159 adults and adolescents with severe hemophilia (aged 12 years and older) were enrolled in the XTEND-1 study; 133 people were in Group 1 and switched to ALTUVIIIO prophylaxis from prior prophylaxis therapy. Efficacy of prophylaxis was evaluated in 128 of these patients.



CONNECT WITH YOUR CORE TODAY

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



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

INDICATION

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

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

IMPORTANT SAFETY INFORMATION

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

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

Who should not use ALTUVIIIO?

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

What should I tell my healthcare provider before using ALTUVIIIO?

Tell your healthcare provider if you have had any medical problems, take any medications, including prescription and non-prescription medicines, supplements, or herbal medicines, are breastfeeding, or are pregnant or planning to become pregnant.

What are the possible side effects of ALTUVIIIO?

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

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

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

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

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



Patient Information

Rx Only

ALTUVIIIO™ (al too'vee oh)

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

Single-dose vial

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

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

Do not attempt to give yourself an injection unless you have been taught how by your healthcare provider or hemophilia center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for injecting ALTUVIIIO so that your treatment will work best for you.

What is ALTUVIIIO?

ALTUVIIIO is an injectable medicine that is used to control and reduce the number of bleeding episodes in people with Hemophilia A (congenital Factor VIII deficiency).

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

Who should not use ALTUVIIIO?

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

What should I tell my healthcare provider before using ALTUVIIIO? Talk to your healthcare provider about:

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

How should I use ALTUVIIIO?

You get ALTUVIIIO as an injection into your vein. Your healthcare provider will instruct you on how to do injections on your own, and may watch you give yourself the first dose of ALTUVIIIO.

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

What are the possible side effects of ALTUVIIIO?

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

Your body can also make antibodies called "inhibitors" against ALTUVIIIO. This can stop ALTUVIIIO from working properly. Your healthcare provider may give you blood tests to check for inhibitors. The common side effects of ALTUVIIIO are headache, joint pain, and back pain.

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

What are the ALTUVIIIO dosage strengths?

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

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

(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 ALTUVIIIO?**

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

After mixing with the diluent:

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

What else should I know about ALTUVIIIO?

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

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

©2023 Bioverativ Therapeutics Inc. All rights reserved.

ALTUVIIIO™ is a trademark of Bioverativ Therapeutics Inc.

AHF-PPI-SL-FEB23



PLEASE PROVIDE A BRIEF OVERVIEW OF WHO YOU ARE AND HOW AND WHY YOU ARE INVOLVED IN THE HFM COMMUNITY.

My name is Claude Preston Moore, and I'm here to fulfill my purpose. I was born and raised in Detroit, Michigan. I'm an A&P mechanic and I have severe hemophilia A with inhibitor. If I'm blessed to live long enough, I'm going to change the world, or at the very least make the world a better place. I'm involved with the HFM community to help people with hemophilia and other bleeding disorders live better lives and to prevent what happened to me from happening to anyone else.

A COUPLE OF YEARS AGO YOU WROTE A BOOK, "MY LIFE WITH HEMOPHILIA." WHAT COMPELLED YOU TO WRITE THIS BOOK AND WHAT DID YOU WANT TO SHARE MOST WITH YOUR READERS THROUGH YOUR PERSONAL STORY? After an incident, which almost cost me my life, I realized my purpose. I asked my wife if I should write a book and she said, "You have an inspiring story to tell." I just knew it was what I needed to do. It was only the beginning stages of my plan. My book is my testimony and I want people to know to never give up and to let them know that they're not alone and that there's no excuse for failure.

THROUGH YOUR BOOK SALES YOU HAVE DONATED MUCH OF THE PROCEEDS TO HFM. WHY DO YOU THINK IT'S IMPORTANT TO DONATE TO HFM?

I donate because I want to make sure that HFM has the tools they need to help people with the bleeding disorder that I have, so that people with this disorder can have a better and more fulfilling life, and so that nobody else on earth has to endure what I've had to deal with. I don't wish what I went through on anybody.

WHAT IS YOUR FAVORITE ACTIVITY OR PROGRAM THAT HFM OFFERS?

Camp Bold Eagle is the best program.

YOU ARE ON TO SOME NEW CREATIVE AND INSPIRING ADVENTURES, INCLUDING WORKING TOWARD BREAKING A WORLD RECORD! CAN YOU TELL US MORE ABOUT WHAT YOU ARE CURRENTLY WORKING ON?

I'm working on breaking the world record for the largest Rubber Band Ball. I chose to break this record because I said I would. When I say I am going do something, I do it. I plan on offering to donate it to downtown Detroit as a token of my appreciation and as a glimpse of what I plan to do for the city. After I break the world record, I plan to.... Well, you'll just have to wait and see.





Learn more about Claude's work to break the world record.



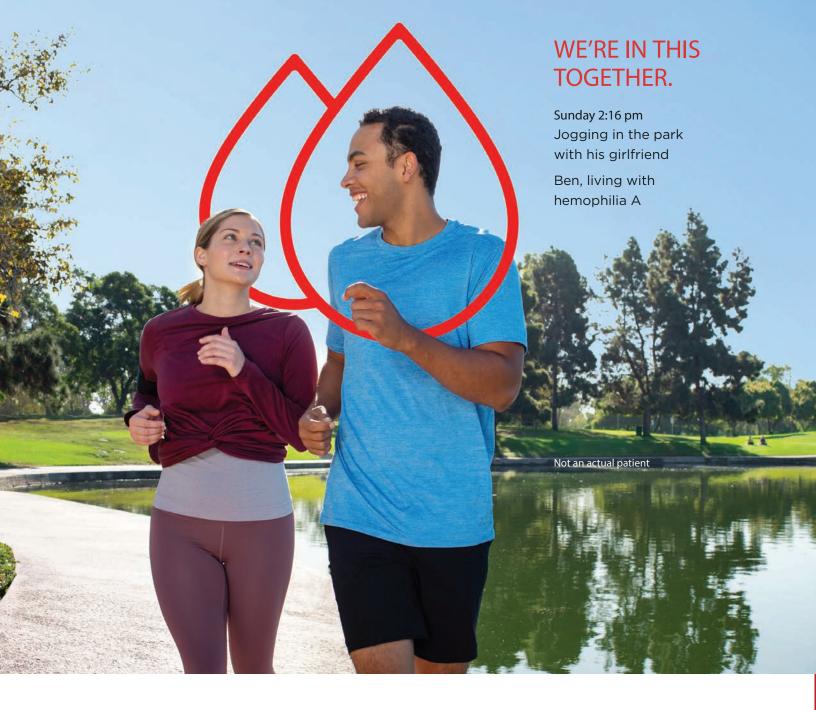
Getting a toddler to do anything is hard. Eat lunch? Hard. Go to sleep? Hard. Put shoes on? An impossible feat. So, finding out that every single week we needed to infuse our independent, wiggly, "no-no-no" son Atlas was... not ideal. On top of having a steady routine (same day, same place, lidocaine no matter what, YouTube video, etc.), we wanted to get him comfortable with the process and not just distract him.

One day, Atlas got a "play" doctor set. To his surprise, there was a plastic toy syringe included. I saw him pick it up, inspect it, put it where his port was, and slowly push. This kid had been paying attention after all. I let him practice taking a temperature under

his little brother's arm and try sticking band-aids all over. When doing his infusion, he now wants to pick out his own mask, wear his own set of gloves, and hold the gauze on the site afterwards. We let him be as involved as he can be without pushing him to do anything. We don't make a big show of it, just as if we were brushing our teeth.

Atlas loves that it's one of the rare times he gets to watch a video, but he also loves being able to help. Things change and there will be new obstacles yet to come. However, for now, we have a toddler that won't keep a hat on but is very proud that he helps give his medicine!





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.





STATEMENT OF BELONGING

HFM is committed to supporting the unique needs of our community. We strive to foster an inclusive environment that welcomes people of all ages, races, religious beliefs, gender identity, sexual orientation, socioeconomic status, ability, and ethnicity. Together, we create a culture of belonging where all are valued and heard, shaping a brighter future for the bleeding disorders community.





When we say at HFM that people of all ages belong, we really mean it. In these photos, campers during Camp Bold Eagle session 2 share during their Hi-C period their own ideas on belonging. First, they participated in an activity where the whole group connected finding commonalities until each person was linked together. Then, the campers answered questions ranging from what it feels like to belong, how they know when they belong, and how they help others to belong. Cabin groups then crafted posters with their themes, drawings, and words that encapsulated belonging to them. With all the unique ideas, each group agreed, we all belong together at Camp Bold Eagle.



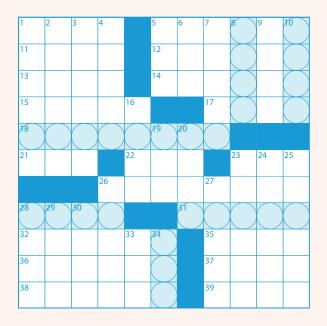












ACROSS

- 1. Wine barrel
- 5. Deep fissures
- **11.** Mideast gulf port
- 12. District
- 13. Ripped
- 14. Familiar with
- **15.** Mean
- **17.** Roost
- **18.** The #1 prescribed prophylaxis for people with hemophilia A without factor VIII inhibitors*

*According to IQVIA claims data (various insurance plan types) from September 2021–August 2022 (refreshed November 2022), accounting for prophylaxis use in the US.

- 21. Calendar divs.
- 22. Regret
- **23.** Banquet hosts (abbr.)
- 26. International travel necessity
- **28.** Check out the _____ treated bleeds data with HEMLIBRA
- **31.** Number of dosing options HEMLIBRA offers

- 32. Small hole in lace cloth
- 35. Central Plains tribe
- **36.** Melodic
- 37. Towering
- 38. Reduce
- **39.** Spanish cheers

DOWN

- 1. Memorable, as an earworm
- 2. Devotee
- 3. Medical fluids
- 4. Prepare to propose, perhaps
- 5. PC's "brain"
- 6. Owns
- 7. Concert venue
- **8.** See Medication Guide or talk to your doctor about potential _____ effects
- 9. Winter hrs. in Denver and El Paso
- **10.** HEMLIBRA is the only prophylactic treatment offered this way under the skin

- 16. Pre-Euro currency in Italy
- 19. Subway alternative
- **20.** Relax
- **23.** Human
- 24. New Orleans cuisine
- 25. Mentally prepares
- 26. Collared shirts
- **27.** Instagram post
- 28. Ardent enthusiasm
- **29.** Brontë heroine Jane
- **30.** Old Portuguese coins **33.** Opposite of WNW
- **34.** More than _____ thousand patients have been treated with HEMLIBRA worldwide¹
 - [†]Number of people with hemophilia A treated as of October 2021.

SOLUTIONS

Across: 1, cask, 5, chasms, 11. Aden, 12. parish, 13. totel, 14. used to, 15, cruel, 17. neet, 13. totel, 17. neet, 18. totel to, 18. totel, 17. neet, 18. totel, 18. totel, 18. totel, 18. totel, 18. totel, 28. oyelet, 28. cato, 31. three, 32. oyelet, 28. cato, 31. three, 32. oyelet, 28. cato, 37. three, 36. Oto, 6, sac, 32. oro, 37. oyelet, 18. totel, 32. oro, 37. totel, 37. totel,

Discover more at HEMLIBRA.com/answers

INDICATION & IMPORTANT SAFETY INFORMATION

What is HEMLIBRA?

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

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

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

These serious side effects include:

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

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



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

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

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

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

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

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

Your body may make antibodies against HEMLIBRA, which may stop HEMLIBRA from working properly. Contact your healthcare provider immediately if you notice that HEMLIBRA has stopped working for you (eg, increase in bleeds).

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

What is HEMLIBRA?

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

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

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

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

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

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

How should I use HEMLIBRA?

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

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

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

What are the possible side effects of HEMLIBRA?

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

The most common side effects of HEMLIBRA include:

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

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

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

How should I store HEMLIBRA?

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

Keep HEMLIBRA and all medicines out of the reach of children. General information about the safe and effective use of HEMLIBRA.

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

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

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

Manufactured by: Genentech, Inc., A Member of the Roche Group,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048
HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan
©2021 Genentech, Inc. All rights reserved.
For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.

This Medication Guide has been approved by the U.S. Food and Drug Administration Revised: 03/2023



HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan. The HEMLIBRA logo is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan. The Genentech logo is a registered trademark of Genentech, Inc. All other trademarks are the property of their respective owners ©2023 Genentech USA, Inc. All rights reserved. M-US-00011998(v3.0) 08/23





Whether this is their first day or their senior year, every child needs some preparation for the return to school. The American Association of Pediatrics (AAP), through their online magazine, *Healthy Children*, have provided several tips to help your child transition from vacation back to the classroom. They suggest having your child visit the school before school starts and attend any orientations available. This can help reduce anxiety about a new teacher, classroom, or school. They may also meet some other kids who will be in their class. The AAP also suggests reestablishing a sleep routine at least a week or two before school resumes. If your child will be taking the bus, know the bus stops and the bus schedule, and review the rules and expectations of riding the bus, with an emphasis on safety.

The AAP and *Healthy Children* also provide guidelines for cell phone usage and screen times. For younger children, they suggest using screens together, selecting educational and non-violent programming, and making sure to incorporate other activities for overall health.

For tweens and teens, keep an open dialogue about what they might see or hear from social media, websites, and online gaming. Parents should not feel pressured into giving their children electronic devices before they are ready, and it will be important to set limits, regardless of age. Children should not have their devices in their rooms with them at night, and it is recommended that screen usage ends one hour before bedtime.

Regarding your child's health, it is highly recommended that you start the Individualized Education Program (IEP) or 504 process as soon as possible. These are plans that provide legal protection for your child's education and medical needs while they are at school. This can be particularly important if your child will have to have medications and treatments at school or during school-related events. If you have questions about how the IEP and 504 process works, please reach out to your HTC social worker and your school social worker for more information.

Have a wonderful school year!

Adapted from Healthy Children and the American Association of Pediatrics.

This is not a substitute for medical advice. Please contact your pediatrician or Hemophilia Treatment Center for more information.

STUDENTS WITH BLEEDING DISORDERS HAVE A RIGHT TO ACCOMMODATIONS

VANESSA LONG, BSN, RN, SCHOOL OUTREACH NURSE

Students with bleeding disorders may qualify for Section 504 of the 1973 Rehabilitation Act. Section 504 is a federal law that makes discrimination against anyone with disabilities illegal and requires school districts to provide accommodations for students with a physical or mental impairment. Section 504 is meant to provide equal opportunities for students with major life impairments, such as those with chronic health conditions like a bleeding disorder.

THE GOAL OF A 504 PLAN IS TO SUPPORT ALL STUDENTS AND PROTECT THEIR RIGHTS TO AN EDUCATION.

It is important to be proactive and request a 504 plan **before** a student begins to struggle in school. Anticipating a student's needs is key because this process takes time! Initiation begins with either a staff referral or parent request to the school's 504 coordinator. Schools should respond in a timely manner. A diagnosis of a bleeding disorder does not automatically determine eligibility; each student must go through an evaluation process. A collaborative team will meet to determine eligibility and accommodations.

ALL 504S SHOULD BE UNIQUE AND TAILORED FOR INDIVIDUAL STUDENTS.

Good communication between the hemophilia treatment center (HTC), families, and schools may assist in the development of 504 plans with appropriate accommodations. A 504 plan is a fluid document that should be reviewed and modified as needed. Families of students diagnosed with bleeding disorders should work with their HTC, school, and school nurse to identify and support needs. Through this collaboration, students with bleeding disorders will receive the support required for positive educational outcomes.



SAMPLE ACCOMMODATIONS TO CONSIDER

SECTION 504 TOOLKIT FOR EDUCATORS, ADMINISTRATORS, FAMILIES, AND SCHOOL STAFF







Contact your Octapharma Representative:

Bri McLaughlin

Phone: 551.502.7007

Email: briana.mclaughlin@octapharma.com



NUWIQ®

Antihemophilic Factor (Recombinant)

www.NUWIQUSA.com



von Willebrand Factor/Coagulation Factor VIII Complex (Human)

www.wilateusa.com





Wealth of resources for patients and caregivers to help navigate care

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

factormyway.com

855-498-4260







Becoming an intern for the Hemophilia Foundation of Michigan (HFM) has provided me with a valuable and unique experience that benefits me both academically and as a community member. Recently being diagnosed with Factor 7 deficiency has been challenging and isolating, especially since I initially knew nothing about the bleeding disorders community. Working at HFM has prompted me to engage with this community in a different capacity. I have learned many meaningful things, such as the butterfly symbol representing our community. I have also had the chance to connect with and listen to community members' stories, whether tragic or triumphant.

A particular conversation with a community member that left a lasting impression on me was when they explained how in the 1980s and 1990s, the HIV/AIDS epidemic had a devastating impact on the bleeding disorders community, referring to the people lost during that time as "the lost generation." My heart sank, knowing these community members never got the chance to fulfill their dreams or live normal lives. This is why I love that the butterfly is our symbol. When I sit in HFM's Butterfly Memorial Garden, I imagine that the lives lost are sitting with me, too. It is peaceful, healing, and gives me hope that maybe one day our community won't always have to struggle.

As an intern at HFM, I am driven to push the narrative forward. We must become more visible and continue to march on in the face of adversity. The challenges I've faced with my own diagnosis have been met with the support of a community that understands and shares my struggles. The experiences at HFM have solidified my dedication to this community and inspire me to continue advocating for a better future for all of us. •

CELEBRATING THE REMARKABLE CAREERS OF PATRICE THOMAS AND SUE ADKINS: RETIRING FROM THE HEMOPHILIA FOUNDATION OF MICHIGAN

We celebrate the retirement of two extraordinary professionals, Patrice Thomas, MSW, MS and Sue Adkins, BSN, RN whose careers in social work and nursing have profoundly impacted countless lives. Their dedication and excellence at the Hemophilia Foundation of Michigan have set a high standard for those who follow in their footsteps.



COMPASSIONATE SOCIAL WORK Throughout Patrice Thomas's career, she has

been a beacon of hope and support for many. Known for her empathy and advocacy, Patrice has helped individuals and families navigate social

services, ensuring they receive necessary care and resources. Her work at the Hemophilia Foundation of Michigan, the University of Michigan, and the National Bleeding Disorders Foundation has been particularly impactful. Patrice's efforts in establishing community outreach programs, furthering education and connection for those with VWD, promoting opportunities for women in the bleeding disorders community, and mentoring young social workers reflect her unwavering commitment to the well-being of others.



SUE ADKINS: EXCELLENCE IN NURSING AND LEADERSHIP Sue Adkins' nursing career began as a registered nurse and culminated in her role as a regional manager. At the Hemophilia

Foundation of Michigan, Sue advanced care for

those affected by bleeding disorders and HIV/AIDS. Her previous work at Michigan State University and her many years with Camp Bold Eagle demonstrated her dedication to improving healthcare delivery and fostering supportive environments for children with bleeding disorders. Sue's leadership, characterized by empathy and innovation, has left a lasting mark on the efforts she has led.

A FOND FAREWELL AND LASTING LEGACY

As Patrice and Sue embark on their well-deserved retirements, we celebrate their remarkable careers and lasting legacies. Their contributions to social work and nursing have touched countless lives and will continue to inspire future generations of professionals. We wish them joy, relaxation, and fulfillment in their new adventures, knowing their impact will be felt for years to come.

Here's to Patrice Thomas and Sue Adkins, two remarkable women who have made our world a better place through their tireless efforts and unwavering commitment to helping others.

4355 / S

SAVE THE DATE!

2024 NATIONAL CONFERENCE FOR WOMEN AND TEENS

EMPOWERMENT, EDUCATION, POLICY: HEAR OUR VOICES

OCTOBER 4-6
HOSTED IN-PERSON & ONLINE
THE WESTIN
DETROIT METROPOLITAN AIRPORT



THANK YOU TO OUR SPONSORS

PRESENTING SPONSOR:

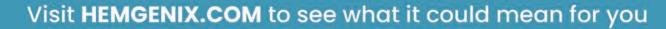
sanofi

COMMUNITY LEAD SPONSOR:





WHAT WOULD YOUR LIFE LOOK LIKE WITH HEMGENIX?





HEMGENIX is manufactured by uniQure Inc. and distributed by CSL Behring LLC. HEMGENIX® is a registered trademark of CSL Behring LLC.

© 2024 CSL Behring LLC 1020 First Avenue, PO Box 61501, King of Prussia, PA 19406-0901 USA www.CSLBehring.com www.HEMGENIX.com USA-HGX-0623-FEB24

CSL Behring



2024 SCHOLARSHIP WINNERS

Allie McComber and Brooke Thomas were announced as the recipients of the HFM Annual Scholarship at SpringFest 2024: Community Spirit, marking not only a significant achievement in their academic journeys but also a testament to their dedication and potential in their respective fields.

Allie McComber, poised to complete her master's degree in public administration with a concentration in nonprofit management in December 2024, embodies a commitment to service and community advancement. HFM was excited to welcome Allie as an intern after the scholarship nomination and selection process. Throughout her academic career, Allie has exhibited a passion for leveraging administrative skills to drive positive change within nonprofit organizations, such as Habitat for Humanity.

Brooke Thomas embarks on a new chapter in her academic journey as she prepares to begin Optometry school in the fall of 2024. Brooke's passion for vision care and her unwavering dedication to improving the lives of others through optometric practices distinguished her as a deserving recipient of the HFM Annual Scholarship.

In recognizing Brooke and Allie as scholarship winners, HFM celebrates their academic achievements and their potential to effect positive change in their respective fields. As they continue their paths of academic and professional growth, they both serve as inspiring examples of dedication, passion, and promise for the future.



BLUE BRIDGE LIGHTING

This past March, Grand Rapids witnessed a gesture of support and solidarity as the iconic Blue Bridge was illuminated in red for 5 days to mark Bleeding Disorders Awareness Month. This bridge, located in the heart of downtown Grand Rapids, is crossed by countless pedestrians each day and is a famous landmark in the city. It was amazing to see a well-known West side staple lit up red, and to know that it was done just for our community.

We want to continue this tradition in 2025 and turn this into a true celebration! On March 25, 2025, the Blue Bridge will once again go red, and we will see it happen from the ballroom overlooking the bridge in the Eberhardt Center of Grand Valley State University. This location boasts a gorgeous view of the rushing river and the full bridge just below where we will eat, socialize, and celebrate everything that makes us unique and wonderful. Please mark your calendars to join us. We can't wait!

BLEEDING DISORDERS AWARENESS MONTH RESOLUTION

Throughout the first quarter of 2024, HFM staff worked with State Senator Jeff Irwin of Ann Arbor and his staff to pass a Senate Resolution declaring March 2024 as Bleeding Disorders Awareness Month. We were delighted to be presented with the Resolution during Lansing Days on Wednesday, March 20. Bleeding Disorders Awareness Month aims to increase awareness of inheritable bleeding disorders among the public, as well as bring issues affecting the community to the attention of policymakers, public authorities, industry representatives, scientists, and health professionals.



© Brian Sevald Photograph



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.



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

PAID CONSUMER OUTREACH

MAKE A PLAN TO VOTE IN THE GENERAL ELECTION ON NOVEMBER 5TH!

GENERAL ELECTION DAY IS TUESDAY,
NOVEMBER 5. DETAILS ON VOTING IN
PERSON BEFORE ELECTION DAY OR ON
ELECTION DAY MAY BE FOUND ON THE
MICHIGAN DEPARTMENT OF STATE'S
ELECTION WEBSITE USING THE PROVIDED
QR CODE. REGISTERED VOTERS CAN
REQUEST AND COMPLETE A BALLOT AT
THEIR DESIGNATED POLLING PLACE ON
ELECTION DAY BETWEEN 7 A.M. AND 8 P.M.
LOCAL TIME. YOU CAN STILL CAST YOUR
BALLOT IF YOU ARE IN LINE TO VOTE AT
YOUR POLLING PLACE WHEN IT CLOSES
AT 8 P.M.



Michigan voters are encouraged to register to vote as early as possible before an election. Methods and requirements for voter registration depend on the following deadlines:

- If there are 15+ days before an election, voters can register online, by mail, or in person.
- Within 14 days of an election, and on Election Day, voters may only register by visiting their local clerk's office to register in person with proof of residency documentation.

You can check your voter registration status and look up your local clerk's information using the QR code. Registered voters can request and return an absentee ballot by visiting their local clerk's office beginning 40 days before Election Day and ending at 4 p.m. on the Monday before Election Day.

REMEMBER: Communities can offer up to 28 days of early voting; you may vote in person at your local early voting office location. Please use the QR code to find your early voting location.

Don't know who is on the November ballot? The Michigan Department of State has a webpage for that! Each candidate has their own website, and you can find out more information about them there.

REMEMBER: Voting is perhaps the most important action we citizens can take to shape how we want our governments to function. Please do your civic duty! And thank you for doing so!

If you would like to become more involved in HFM's advocacy work, please contact Zach Ryan at **zryan@hfmich.org**. Your voice makes a difference!

















