

the artery

Serving Michigan's bleeding disorders community

Spring/Summer 2020



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



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



TIM WICKS
Camp Director

I just wanted to let you know

Camp at Home

**Plus Online Programming During COVID-19
AND Resources for Your Well-Being**

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We are here for you.

Susan working from
home, shown here with
Chip, all around amazing
dog and HFM mascot!



Dear HFM family and friends,

My hope is that you and yours are doing well in the midst of this ongoing health crisis. **We are here for you** and our deep commitment to the bleeding disorders community remains strong. Sadly, we have made challenging decisions to adjust or cancel multiple in-person programs that typically allow us to connect, enjoy and learn from one another and various experts. Yet, we are a community that fully understands life often doesn't go as planned, and health and access to healthcare are top priorities.

HFM is proud of our heritage as the first-ever camp program for kids and teens with bleeding disorders. You can learn a bit more about **Camp at Home** on page 3.

We've uploaded online programs to HFM's YouTube (www.hfmich.org/youtube) including an excellent presentation by University of Michigan's HTC Medical Director, **Dr. Steve Pipe**, together with UM Nurse Coordinator **Jim Munn** regarding bleeding disorders/COVID-19. I anticipate we'll continue virtual programs for quite a while.

Please participate with HFM's quick **survey** (www.hfmich.org/survey2020) available via HFM's FaceBook, Constant Contact, or your mailbox (no postage required to return!); we want to understand how to best engage with you. Our commitment continues as we listen to your needs, and offer support and resources, which includes emergency financial assistance. I am privileged to work with a stellar, dedicated staff as we all navigate how to best manage this crisis and offer community education and support.

Given HFM's role as the **Federal Great Lakes Regional Core Center, United States HTC Network**, we initiated twice weekly virtual meetings with HTC colleagues in Michigan, Ohio and Indiana. I continue to be inspired by their collaboration and outreach to patients and one another.

I am grateful to each of you for your perseverance and look forward to a time we can greet one another in person. Please stay safe.

With love,

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

PAID CONSUMER OUTREACH INCLUDED IN THIS NEWSLETTER.



Join us For Camp at Home This Year

- For ages 6-17
- Scheduled at varying times (to be determined), **Monday through Friday, July 6-31**. We will communicate more information about our schedule as it becomes available.

Campers are welcome to register and participate in our **Camp at Home** program.

NOTE: Registration was **required by May 29** in order to receive the camper care-package which includes a t-shirt, art supplies, program materials, snacks and other fun stuff. If care-packages are still available, they will be sent out, yet contents and arrival dates are not guaranteed. Thank you for your understanding.

THE DECISION TO MOVE TO VIRTUAL CAMP

Hi Camp Family!

I'm happy and sad to share this news with you today. In light of COVID-19, we will be having all of our Eagle Journeys camping programs online this summer. This includes Camp Bold Eagle, Eagle Outpost, Eagle Expedition & Eagle Quest. I'm sad because this means we won't be able to be physically present with one another. Camp means so much to so many people, including myself and the rest of the staff. This will be the first time in 20 years that I won't be going to Pioneer Trails.

The reason I'm happy is because, as we talk about every year, camp is not a place. Camp is the people. Camp is the counselors, the arts & crafts director, the waterfront staff, the health center staff, the medical students, and most importantly, the campers. Camp is also the parents and families that make it possible for the campers and staff to come to camp.

The mission of Eagle Journeys is to educate and empower individuals with bleeding disorders to live a life of freedom and independence. Camp lends itself perfectly to that mission, but physical presence at a camp facility is not the only way for that mission to be fulfilled. Our staff will be working diligently to make sure all campers have a wonderful time this summer, even from the comfort of their own home.

We're not exactly sure what this new approach to camp will look like.

Here is what we are sure of:

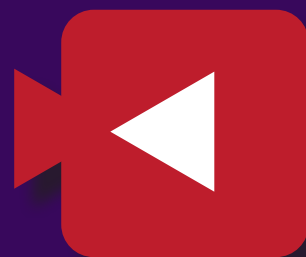


- You will still need to register if you want to participate.
- The registration deadline is Friday, May 29 in order to receive the camper care-package.
- You will still get to see many of your favorite staff members.
- We will all sing all of our favorite songs together.

We love and miss all of you!

Jim

Tim Wicks
Camp Director



Check out our videos

- www.hfmich.org/campupdate20
- www.hfmich.org/campreminder



With sincere gratitude

Thank you to our individual financial donors. This list represents contributions recorded from January 1, 2019 through December 31, 2019 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 2019 calendar year. Please consider making a donation to HFM in 2020. **Your support truly makes a difference.**

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Continued on page 5

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Up to \$100

Not listed are the many individual supporters who donated less than \$100. Thank you for your generosity; every gift makes a difference.

Please accept our apologies for any errors or omissions. Please contact **Gwyn Hulswit** at ghulswit@hfmich.org or at 734.544.0015 to correct our records.

Join us as we grow our membership!

We are so pleased that our HFM membership has grown from 11 annual members and 8 lifetime members in 2017 to our membership today which includes 101 annual members and 16 lifetime members. Each of these individuals has made a commitment to furthering the direction of HFM through their financial support and by playing an important role in voting for HFM's Board of Directors.

We are very appreciative of our 2019 annual members and are especially grateful for our lifetime members. Your support, insight, and engagement truly makes a difference. Thank you.

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COVID-19: Adjusting to the Times

By Sarah Procario

Published on May 26, please be advised that information may have evolved by the time you are reading this.

Since March, the state of Michigan has enacted several changes to mitigate the spread of COVID-19 and protect the ability of the state's healthcare system to provide for the vulnerable population.

On March 4, Governor Whitmer declared a state of emergency in Michigan. Unfortunately, in the weeks that followed, the virus continued to spread, affecting Michigan families, educational institutions, businesses, and health systems.

In response to the widespread impact of the virus, on March 23, the Governor issued Executive Order 2020-21, ordering all people in Michigan to "stay home and stay safe." Executive Order 2020-100 has since extended the stay home, stay safe order through June 12. However, Executive Orders 2020-70, 2020-77, 2020-92, and 2020-96, have begun the process of gradually resuming in-person work and activities. Currently:

- The order "prohibits all in-person work that is not necessary to sustain or protect life."
- The order requires "all individuals currently living within the state of Michigan to stay at home or at their place of residence."
- All individuals who leave their home for essential business must maintain 6 feet of separation.

Following the current executive orders and in guidance with public health experts, HFM has adjusted our normal operations and programming to help reduce the spread of COVID-19.

The HFM office is closed to visitors and staff. Staff members are working remotely and can be contacted via telephone and email.

HFM has cancelled or moved online all in-person events through August 15, 2020 including two Days for Girls Work Days, the Butterfly Benefit, Lansing Days, the Community Night in Kalamazoo, the Community Night in Grand Rapids, Eagle Quest, and Eagle Expedition. HFM understands how important these in-person events are to the community and we were deeply saddened to cancel. Please visit www.hfmich.org/events to learn about our virtual opportunities.

We Are Here For You

HFM understands the increased challenges the bleeding disorders community is facing due to the coronavirus. HFM has been working to provide up to date information and resources for our community via hfmich.org. You may access COVID-19

resources, including emergency financial assistance, information on unemployment, and updates on the federal stimulus package.

We invite you to visit HFM's new mental health webpage (see below) where we share information and resources to support your wellbeing. As we all experience increased levels of anxiety and stress, it is more important than ever to be proactive in managing our mental health.

HFM has also been developing opportunities for online engagement and connection. Though physically separated, our community remains strong and united. Thank you to those of you who joined HFM's first Facebook Watch Party, and our other online opportunities. Please continue to follow HFM's Facebook page and website to learn about our upcoming events.

We still do not know how long this pandemic will last. We appreciate your flexibility as HFM continues to adapt to this situation.

- www.michigan.gov/coronavirus
- www.michigan.gov/whitmer/

HFM's new mental health page: www.hfmich.org/mental-health/

Mental Health

Mental health care matters. It is important to invest in our mental wellness as we would in our physical wellness. Having resources and tools to support your mental health can help you maintain your overall health.

Thank you to our speakers for sharing their unique wisdom with the bleeding disorders community.



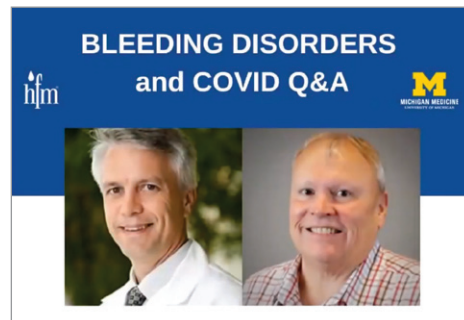
www.hfmich.org/sarahwatson

Sarah Watson, licensed counselor and sex therapist, discusses how to communicate more effectively with your partner and loved ones during times of stress and anxiety.



www.hfmich.org/jhonvelasco

Jhon Velasco, Education Manager at the National Hemophilia Foundation. Jhon guides us through a short practice to help us connect with our breath, body, and mind. *Please consult a physician before engaging in any new physical activity.*



www.hfmich.org/covid

HFM's Bleeding Disorders and COVID Q & A with **Steven Pipe**, MD, Medical Director, University of Michigan Pediatric Hemophilia & Coagulation Disorders Program (HTC), and **Jim Munn**, RN, BS, BSN, MS, Program Nurse Coordinator, University of Michigan HTC.



June Programming

Connect with your community online!

Go to www.hfmich.org/events to learn more about our upcoming events

Mon., June 1, 12pm
Women's Luncheon
Speaker: Annie Phillips, LMSW

Wed., June 3, 7pm
Advocating for Your Care in the ER with VWD
Speaker: Sue Geraghty, RN
(Sponsored by NHF)

Fri., June 5, 6pm
Family Community Night

Mon., June 15, 12pm
Women's Luncheon

Thurs., June 18, 7pm
Successful Communication
Speaker: Dr. Jeffrey Karst, PhD
(Sponsored by HFA)

Mon., June 29, 12pm
Women's Luncheon

Thanks to our sponsors who supported our online May and June events.



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What is HEMLIBRA?

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

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

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. HEMLIBRA may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

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


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

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	– stomach (abdomen) or back pain
– weakness	– nausea or vomiting
– swelling of arms and legs	– feeling sick
– yellowing of skin and eyes	– 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	– cough up blood
– pain or redness in your arms or legs	– feel faint
– shortness of breath	– headache
– chest pain or tightness	– numbness in your face
– fast heart rate	– eye pain or swelling
	– trouble seeing

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

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

What is HEMLIBRA?

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

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

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

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

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

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

How should I use HEMLIBRA?

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

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

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

What are the possible side effects of HEMLIBRA?

- See “What is the most important information I should know about HEMLIBRA?”

The most common side effects of HEMLIBRA include:

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

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

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

How should I store HEMLIBRA?

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

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

General information about the safe and effective use of HEMLIBRA.

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

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

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

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

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For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.

This Medication Guide has been approved by the U.S. Food and Drug Administration
 Revised: 10/2018



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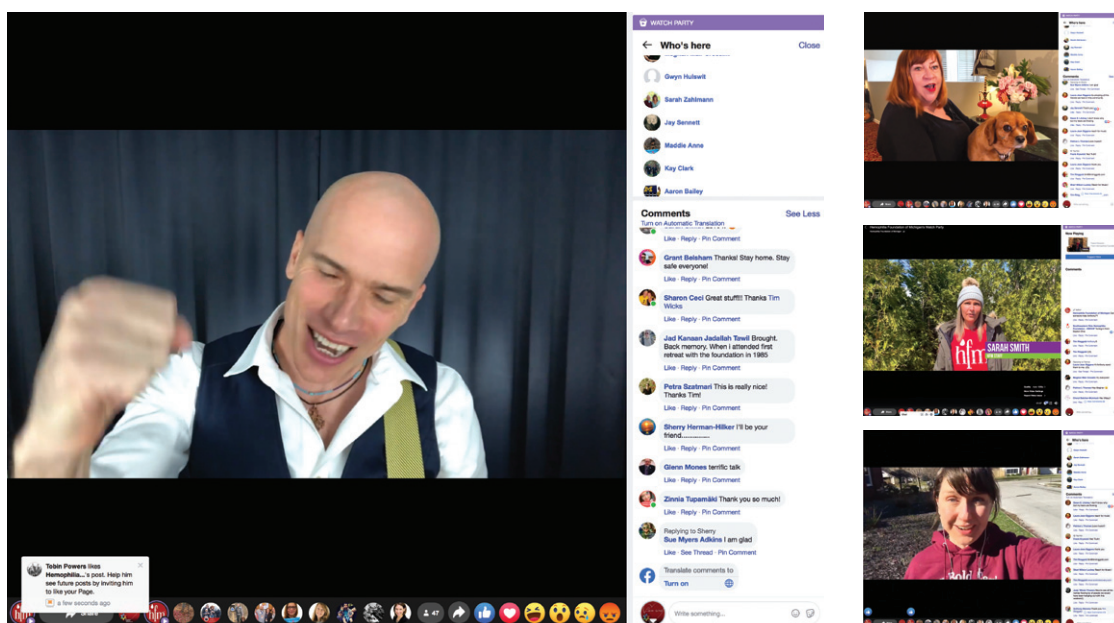
hfm WATCH PARTY

Watch the replay by visiting:
www.hfmich.org/watchpartyapril20

Also, get Tim's FREE relaxation vacation and other free gifts by registering at
www.sonicrecovery.com

After HFM made the difficult decision to not hold our April SpringFest weekend, we immediately started working to create a way to connect with community members online.

On April 4, the HFM community came together for our first online event. Through Facebook Live, Tim Ringgold, certified music therapist, showed us how to reach for music in times of stress. Participants shared thoughts, feelings, and memories as we learned how powerful music is for our mind and body. As we were all coping with the new realities of COVID-19, his gift of music was deeply welcomed.



Additional speakers included industry partners; Special Events Manager, Carrie McCulloch; Sarah Smith, RN, BSN; and a message from our Executive Director, Susan Fenters Lerch addressing how HFM and the region are responding to COVID-19.

Special thanks to our SpringFest sponsors for their ongoing support of our community.

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Special Thanks



HFM exists to enhance the quality of life for all affected by bleeding disorders • HFM (Hemophilia Foundation of Michigan) does not endorse any specific product or company.

Cascade Celebrates 25 Years of Supporting the Community

Cascade's Mission

To enhance the system of care for people with bleeding disorders and related complications, by assuring the lowest possible price for the full range of treatments, HIV and hepatitis related therapies and other medications available to treat their disease; to provide access to these medications for those without insurance or inadequate insurance coverage; to support the comprehensive hemophilia treatment centers in treating and educating consumers and their families so they may become knowledgeable and proactive in managing their own care; to fund research.

The Cascade Hemophilia Consortium pharmacy began its development in the early 1990's following the devastation of the hemophilia community from AIDS. HFM's Board of Directors collaborated with various community members and foundation staff to utilize the federal government's new 340B Drug Discount Program that was created to stretch federal funds for treatment of vulnerable populations, including people with hemophilia.

In 1994 Bill Sparrow became Cascade's first Executive Director with Cascade realizing its first insurance payment in 1995. Bill retired 10 years ago and remains deeply committed and engaged with the Consortium. Cascade's current Executive Director, Stephanie Raymond, began her career with Cascade in 1996 and was named Executive Director in 2014. She has continued and strengthened Cascade's purpose in sharing 340B savings through discounted pricing, and offering support to federally recognized



Cascade's Colleen Joiner, LMSW, Clinical Care, Education and Outreach Manager and Stephanie Raymond, Executive Director supporting HFM at a recent Butterfly Benefit.

Hemophilia Treatment Centers (HTCs) within the Great Lakes Region (Michigan, Ohio, and Indiana) in collaboration with HFM as the federal government's Regional Core Center. The dollars earned through the 340B program are put back into the community through funding for specific services and education for the bleeding disorders community.

In addition, Cascade provides contract pharmacy services to many HTCs across the region. Through that income, Cascade is able to provide even more support by offering chapter grants to support localized programs from the Hemophilia Foundation of Michigan, several Ohio chapters, and Hemophilia of Indiana.

Congratulations and appreciation to Cascade for 25 years of outstanding service and support to the bleeding disorders community. To learn more please visit www.cascadehc.org.





Exploring the science behind gene therapy research

Gene therapy research has the potential to bring an entirely new option to people with specific genetic conditions. Many gene therapies are in clinical trials to evaluate the possible risks and benefits for a range of conditions, including hemophilia. HemDifferently is here with gene therapy education, providing accurate information on the basics and beyond.

What questions do you have? Get them answered. Explore gene therapy at **HemDifferently.com**

No gene therapies for hemophilia have been approved for use or determined to be safe or effective.

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advocacy



HFM staff and advocates attending the senate health policy committee hearing.

Ending Delays in Care

The effort to pass prior authorization and step therapy reform legislation in Michigan

By Sarah Procario

Patients and providers from across disease states have joined forces to reform prior authorization and step therapy in Michigan through Health Can't Wait (HCW). HCW is “a coalition of patients, health care providers, and associations dedicated to putting Michigan patients first and ending delays in patients’ access to health care.”

Currently, prior authorization and step therapy requirements add additional and often unnecessary steps that delay (or deny) access to physician-prescribed treatment. For bleeding disorders patients, a delay in care is serious and can be life threatening. Lengthy prior authorization processes not only harm patients, but add more administrative work for physicians, leading to less time spent with patients. The coalition has worked closely with State Senator Curt VanderWall to draft legislation that would make these insurance processes clearer and more efficient so all patients can be sure they will receive their medication on time.

The draft legislation ensures that:

- PA requirements are easily understandable and accessible to physicians, providers, and patients.

- Adverse determinations and appeals must be made by an expert reviewer who is a physician/provider in the specialty of the service in question.
- Step therapy protocols can be overridden if a physician determines it is in the best interest of the patient.
- Urgent PA requests be acted upon within 24 hours of submission.
- Standard PA requests be acted upon within 48 hours of submission.

On January 30, 2020, HFM staff and members of the bleeding disorders community attended the Senate Health Policy Committee hearing in Lansing to show our support for Senate Bill 612. Committee members listened to harrowing stories from patients and providers on the detrimental effects of prior authorization and step therapy practices.

HFM will continue to keep the community up to date as we continue to advocate for SB 612. The health of our community should come before cost considerations.

Prior authorization (PA):

a requirement that your health care provider obtain approval from your health insurance before the provider can prescribe a specific medication or procedure.

Step therapy (ST):

often called “fail first,” is a process used by health insurance companies that requires patients to try some (generally less expensive) drug/treatment, before they cover other (generally more expensive) drugs/treatments that treat your condition.

DEDICATION and PERSONAL SUPPORT

Your Pfizer Patient Affairs Liaison is a professional dedicated to serving you and the hemophilia community by connecting patients and caregivers with Pfizer Hemophilia tools and resources. We are committed to continuing Pfizer's more than 20 years of listening to the hemophilia community and working to meet its needs.



Chris Liddell

Southern OH, MI, KY, IN

"I've worked in rare disease for 15 years, and I have experience collaborating with and advocating for different members of this community."



PATIENT
AFFAIRS
LIAISONS



248-660-7384 chris.liddell@pfizer.com

MY WORK IS GUIDED BY:

Compassion

Listening to your needs and addressing questions and concerns that you may have

Commitment

Educating you about Pfizer's tools and resources, including the Pfizer Community Connections Program, the HemMobile® app for logging bleeds and infusions, B2B materials, and more

Connection

Connecting you with hemophilia advocacy groups and programs like Leading Edge, the National Hemophilia Foundation, the Coalition for Hemophilia B, and others

Did You Say Dentist?

Responses from a U of M Dental School survey on dental habits and experiences

By Lisa Clothier

We understand that the bleeding disorders community can face unique challenges while engaging in dental health care. To better understand how we might support the bleeding disorders community, the Hemophilia Foundation of Michigan partnered with the University of Michigan Dental Hygiene Program to support a dental health survey developed to explore dental health habits and experiences. You may have even participated in this survey. If so, thank you so much for sharing your dental health care experiences! This survey is part of an overall HFM program to support dental health and improve health outcomes.

A snapshot of the survey results is shared below.

98

community members
responded to the survey

79.5%

of participants have a
bleeding disorder

86.7%

indicated that they
have dental coverage
or insurance

71.4%

believe dental health is important

Have you ever avoided seeing the dentist?

68.4%

participants said they have not
avoided the dentist

31.6%

said they have avoided the dentist

The top five reasons for avoiding the dentist are:

1. Cost/no insurance
2. Bad experience at the dentist
3. Afraid of having dental work done
4. Mouth sensitivity
5. Time

Tips to Improve Your Dental Experience

Contact your HTC or hematologist to discuss your dental appointment with them to determine if you will need any pre-treatment planning – often the first appointment includes teeth cleaning and x-rays.



Be the teacher – take information with you from your HTC or hematologist. Let the dentist know what bleeding disorder you have, how you treat it, and possible complications. Ask the HTC or your hematologist's office for educational materials to provide to your dentist's office.

Provide your HTC's or hematologist's office contact information to your dentist so that he/she can contact the HTC or hematologist directly if they require more information. Ask the dentist to explain any upcoming dental procedures so that you can discuss your treatment plan with your HTC or hematologist. Do not wait until the day of the procedure!

**Tips provided by Karen Ridley, MSDH*

Protect yourself by learning more about the connection between your dental health and overall health. Visit www.hfmich.org/dental-health/ for more information.

PAID CONSUMER OUTREACH




Explore HEAD-TO-HEAD

Pharmacokinetic (PK) Study Data

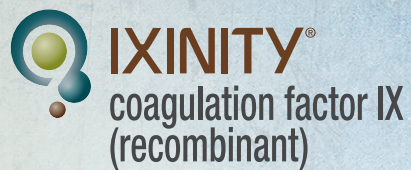
See half-life, clearance and other PK data from the crossover study comparing **Jivi®** and **Eloctate®**.
Visit PKStudies.com to find out more.

► **Pharmacokinetics** is the study of the activity of drugs in the body over a period of time.



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(Recombinant)

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HFM's 2019 national conference could not have been possible without the support of our sponsors.

We are grateful to each of them, most especially to our **lead sponsors**, **Indiana Hemophilia & Thrombosis Center, Inc.** and **Novo Nordisk**.



2019 National Conference Being Visible: Hear Our Voices Women with Hemophilia

November 1-3, 2019

Westin Hotel, Detroit Metropolitan Airport

Regional Sponsor



Presenting Sponsor



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

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



2020 National Conference for Women with Hemophilia **Hear Our Voices: Continuing to Grow**

October 9-11, 2020

Westin Hotel, Detroit Metropolitan Airport

*Stay tuned to learn if this
conference will become virtual*

Application Process Opens July 2020



We're celebrating another
**Women with Hemophilia,
Being Visible Conference**
success story!

My Journey to Prophylaxis

By Rachel Neyland

After HFM's Women's Hemophilia Conference in Michigan, I started keeping a pain journal. About four weeks ago I had an appointment at my Hemophilia Treatment Center (HTC) and I brought my pain journal and factor log. This was the first time I met with this hematologist. She looked at my log and said, "Wow, you have a lot of bleeds!" I said I know! She said I should be on prophylaxis to see if that helps. So I am now on two times a week prophylaxis.

I'm so grateful for the Women's Conference and hearing others' stories and hearing about the importance of logging our bleeds. Of course I've logged my boy's bleeds, but I put my own needs on the back burner. After the Women's Conference I felt empowered. And after my HTC appointment I felt validated & empowered. I pray every woman with hemophilia can get the proper treatment!

Thank you again for putting the Women's Conference together. It is by far the best conference I have ever been to! Thank you.

Real world meets virtual world at Spring 2020 Teen Retreat

By Anthony Stevens

At HFM's **Spring 2020 Teen Retreat** March 3-5, the teens played games and activities that related to bleeding disorders awareness, including creating their own logic puzzles that had to be bleeding disorder related. Saturday night included an opportunity to strap on the virtual reality headsets and experience walking planks and swinging lightsabers!

SPECIAL THANKS TO OUR TEEN RETREAT SPONSORS

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Register to Walk Today



Unite with your community!

Unite Walk SE Michigan
August 23, 2020
Register at
www.hfmich.org/unitedetroit

Unite Walk Grand Rapids
September 19, 2020
Register at
www.hfmich.org/unitegrandrapids

Unite
for Bleeding Disorders

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Welcome home Trey
and welcome to the
hemophilia community.

Trey Has Found His Forever Family

By Shari Luckey

The staff of HFM and the hemophilia adoption community would like to congratulate the Poynter family, **2019 Luke and Jack's Together Forever Adoption Grant recipients**. It has been a whirlwind year for parents Josh and Monica as they "chased paper" over the past many months, preparing to expand their family from three to four.

Finally, in January all their hard work paid off and they were able to travel to China with their youngest son to bring big brother Trey home. After eleven days in China and a very long trip around the world, they arrived home mid-January.

Monica reports that Trey is adjusting well and has already begun treatment with a subcutaneous product to prevent bleeding. The two brothers share the same diagnosis and medication and will get to do their treatments together! Trey has been having a lot of fun in his new home in the country and delights in standing on the big front porch. He and his little brother enjoy playing outside together in their very own dirt pile. The brothers work together with toy trucks, shovels, and wheelbarrows to move the dirt from one location to another. It is so wonderful that they can grow up together and support each other in their hemophilia and in life.

did you know?

In 2010 the adoption of a child with hemophilia from China was unprecedented. Now 10 years later, due to the efforts of HFM's Hemophilia Adoption Program (HAP), Pam Thomas and other adoption agencies, Melissa Penn and other parent advocates, and so many social media hemophilia adoption families, more than 50 families have adopted children with bleeding disorders.

**HAP records indicate China - 43;
Domestic - 4; Bulgaria - 3; Philippines - 1.**

The focus of HAP in 2020 is to expand relationships with US adoption agencies that advocate for other countries to assess the situation for children with hemophilia in need of forever families. We understand that with the current COVID-19 situation that international adoption travel is on hold, however, it is a good time to research and possibly apply for a home study.

www.hfmich.org/what-we-do-adoption/

Learn more about hemophilia adoption & **Luke and Jack's Together Forever Adoption Grant**

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When it comes to your hemophilia A treatment

Move beyond the threshold^a

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



Extend half-life beyond the standard

22-hour average half-life in adults^c

High factor levels in adults and adolescents

At or above 3% for 100% of the time^{a,d}

At or above 5% for 90% of the time^{a,e}

Flexible on the go^c

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

^aTrough level goal is 1% for prophylaxis.

^bCompared with standard half-life products.

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

^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 PK modeling.

^fFor up to 3 months.

What is Esperoct[®]?

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

- Esperoct[®] is not used to treat von Willebrand Disease

IMPORTANT SAFETY INFORMATION

Who should not use Esperoct[®]?

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

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

- Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center
- Call your healthcare provider right away or get emergency treatment right away if you get any signs of an allergic reaction, such as: hives, chest tightness, wheezing, dizziness, difficulty breathing, and/or swelling of the face

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

- Before taking Esperoct[®], you should tell your healthcare provider if you have or have had any medical conditions, take any medicines (including non-prescription medicines and dietary supplements), are nursing, pregnant or planning to become pregnant, or have been told that you have inhibitors to factor VIII
- Your body can make antibodies called “inhibitors” against Esperoct[®], which may stop Esperoct[®] from working properly. **Call your healthcare provider right away if your bleeding does not stop after taking Esperoct[®]**

What are the possible side effects of Esperoct[®]?

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

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

Discover more at [Esperoct.com](https://www.esperoct.com).



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

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esperoct[®]
*antihemophilic factor (recombinant),
glycopegylated-exei*

esperoct®

antihemophilic factor (recombinant), glycopegylated-exei

Brief Summary information about ESPEROCT® [antihemophilic Factor (recombinant), glycopegylated-exei]

This information is not comprehensive.

- Talk to your healthcare provider or pharmacist
- Visit www.novo-pi.com/esperoct.pdf to obtain FDA-approved product labeling
- Call 1-800-727-6500

Patient Information

ESPEROCT®

[antihemophilic factor (recombinant), glycopegylated-exei]

Read the Patient Information and the Instructions For Use that come with ESPEROCT® before you start taking this medicine and each time you get a refill. There may be new information.

This Patient Information does not take the place of talking with your healthcare provider about your medical condition or treatment. If you have questions about ESPEROCT® after reading this information, ask your healthcare provider.

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

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

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

What is ESPEROCT®?

ESPEROCT® is an injectable medicine used to replace clotting Factor VIII that is missing in patients with hemophilia A. Hemophilia A is an inherited bleeding disorder in all age groups that prevents blood from clotting normally.

ESPEROCT® is used to treat and prevent or reduce the number of bleeding episodes in people with hemophilia A.

Your healthcare provider may give you ESPEROCT® when you have surgery.

Who should not use ESPEROCT®?

You should not use ESPEROCT® if you

- are allergic to Factor VIII or any of the other ingredients of ESPEROCT®
- if you are allergic to hamster proteins

If you are not sure, talk to your healthcare provider before using this medicine.

Tell your healthcare provider if you are pregnant or nursing because ESPEROCT® might not be right for you.

What should I tell my healthcare provider before I use ESPEROCT®?

You should tell your healthcare provider if you:

- Have or have had any medical conditions.
- Take any medicines, including non-prescription medicines and dietary supplements.
- Are nursing.
- Are pregnant or planning to become pregnant.
- Have been told that you have inhibitors to Factor VIII.

How should I use ESPEROCT®?

Treatment with ESPEROCT® should be started by a healthcare provider who is experienced in the care of patients with hemophilia A.

ESPEROCT® is given as an infusion into the vein.

You may infuse ESPEROCT® at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your hemophilia treatment center or healthcare provider. Many people with hemophilia A learn to infuse the medicine by themselves or with the help of a family member.

Your healthcare provider will tell you how much ESPEROCT® to use based on your weight, the severity of your hemophilia A, and where you are bleeding. Your dose will be calculated in international units, IU.

Call your healthcare provider right away if your bleeding does not stop after taking ESPEROCT®.

If your bleeding is not adequately controlled, it could be due to the development of Factor VIII inhibitors. This should be checked by your healthcare provider. You might need a higher dose of ESPEROCT® or even a different product to control bleeding. Do not increase the total dose of ESPEROCT® to control your bleeding without consulting your healthcare provider.

Use in children

ESPEROCT® can be used in children. Your healthcare provider will decide the dose of ESPEROCT® you will receive.

If you forget to use ESPEROCT®

If you forget a dose, infuse the missed dose when you discover the mistake. Do not infuse a double dose to make up for a forgotten dose. Proceed with the next infusions as scheduled and continue as advised by your healthcare provider.

If you stop using ESPEROCT®

Do not stop using ESPEROCT® without consulting your healthcare provider.

If you have any further questions on the use of this product, ask your healthcare provider.

What if I take too much ESPEROCT®?

Always take ESPEROCT® exactly as your healthcare provider has told you. You should check with your healthcare provider if you are not sure. If you infuse more ESPEROCT® than recommended, tell your healthcare provider as soon as possible.

What are the possible side effects of ESPEROCT®?

Common Side Effects Include:

- rash or itching
- swelling, pain, rash or redness at the location of infusion

Other Possible Side Effects:

You could have an allergic reaction to coagulation Factor VIII products. **Call your healthcare provider right away or get emergency treatment right away if you get any signs of an allergic reaction, such as:** hives, chest tightness, wheezing, dizziness, difficulty breathing, and/or swelling of the face.

Your body can also make antibodies called "inhibitors" against ESPEROCT®, which may stop ESPEROCT® from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

These are not all of the possible side effects from ESPEROCT®. Ask your healthcare provider for more information. You are encouraged to report side effects to FDA at 1-800-FDA-1088.

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

What are the ESPEROCT® dosage strengths?

ESPEROCT® comes in five different dosage strengths. The actual number of international units (IU) of Factor VIII in the vial will be imprinted on the label and on the box. The five different strengths are as follows:

Cap Color Indicator	Nominal Strength
Red	500 IU per vial
Green	1000 IU per vial
Gray	1500 IU per vial
Yellow	2000 IU per vial
Black	3000 IU per vial

Always check the actual dosage strength printed on the label to make sure you are using the strength prescribed by your healthcare provider.

How should I store ESPEROCT®?

Prior to Reconstitution (mixing the dry powder in the vial with the diluent):

Protect from light. Do not freeze ESPEROCT®.

ESPEROCT® can be stored in refrigeration at 36°F to 46°F (2°C to 8°C) for up to 30 months from the date of manufacture until the expiration date stated on the label.

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

Do not use this medicine after the expiration date which is on the outer carton and the vial. The expiration date refers to the last day of that month.

After Reconstitution:

The reconstituted (the final product once the powder is mixed with the diluent) ESPEROCT® should appear clear and colorless without visible particles.

The reconstituted ESPEROCT® should be used immediately.

If you cannot use the reconstituted ESPEROCT® immediately, it must be used within 4 hours when stored at or below 86°F (30°C) or within 24 hours when stored in a refrigerator at 36°F to 46°F (2°C to 8°C). Store the reconstituted product in the vial.

Keep this medicine out of the sight and out of reach of children.

What else should I know about ESPEROCT® and hemophilia A?

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

Revised: 02/2019

ESPEROCT® is a trademark of Novo Nordisk A/S.

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

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

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

For information about ESPEROCT® contact:

Novo Nordisk Inc.
800 Scudders Mill Road
Plainsboro, NJ 08536, USA
1-800-727-6500

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US19ESP00010 August 2019





Ypsilanti MI Days for Girls

By Shari Luckey

In January, HFM's Ypsilanti MI Days for Girls' Team was joined by local Girl Scout Troop 40091. Before their day of volunteering, HFM shared an overview of the Days for Girls International Program and our motivation to support females in bleeding disorder communities in developing countries. We educated them about the signs and symptoms of bleeding disorders in girls and women and prompted them to imagine experiencing a period with no sanitary supplies. We further encouraged them to envision attempting to accomplish daily tasks when bleeding heavier than normal without essentials needed to manage their flow.

It is hard to imagine such a situation, but according to UNICEF and the World Health Organization's 2015 report, 500 million females around the world lack adequate facilities to manage their periods. Menstruators without access to sanitary menstrual supplies and facilities are forced to miss school/work during their cycle. Due to the struggle to keep up with school work, many quit shortly after their cycle begins. Without an education and the ability to hold a job, they are unable to fully interact and contribute within their communities.

The scouts realized the impact a DfG reusable menstrual hygiene kit can have on the lives of women and girls around the world. With these supplies, women are empowered to attend school/work, complete daily activities, and even play a sport without stigma. Thank you troop 40091!

We will continue to work diligently to create kits for distribution around the globe. If you would like to join us, please visit www.hfmich.org/events/ to learn more about our upcoming meetings.

Here is what our DfG Team can make with 1 1/2 yards of fabric:

- 2 feminine hygiene shields
- 8 liner pads
- 1 cute kit carrying tote bag
- 1 waterproof transport bag (to carry soiled liners & to soak or wash liners)

Then we add these items to complete a kit:

- 2 panties
- 1 small bar of soap
- 1 wash cloth





Left to right: Rosanne Ososki, MSN, APRN; Shonethia Perkins, Data Manager; Asif Alavi, MD; Jennifer Hoenicke, RN; Suzanne Rogers, LMSW

Center of Care: Doin' It In the "D"

By Suzanne Rogers, LMSW

"Detroit: Cars and rock 'n' roll.
Not a bad combo."

~ Kid Rock

Cars, rock 'n' roll and world class medical care—an even greater Motown mix! The Comprehensive Center for Bleeding Disorders and Thrombosis, a Karmanos Cancer Center clinic is located in the Detroit Medical Center's University Health Center, serving adults primarily living in the metro-Detroit tri-county areas of Wayne, Oakland, and Macomb. We also welcome patients from as far as Monroe, Oscoda, and St. Clair counties. Near or far, our patients recognize that great health care is available in the heart of the city of Detroit. Patients with bleeding disorders benefit from Karmanos' commitment to transformative care, research, and education through courage, commitment, and compassion.

"Detroit is big enough to matter in the world and small enough for you to matter in it."

~ Jeanette Pierce, Director, The City Institute

We like to think the same could be said of our clinic. Attracting renowned physicians, the comprehensive cancer institute is proud of its cutting-edge research in bone marrow and stem cell transplant which has far reaching implications for advancing care for

patients with bleeding disorders. Yet we pride ourselves in providing the personal touch. Asif Alavi, MD notes the importance of getting to know his patient's values when setting a treatment course. "My goal is to focus on what's important to them: family, work. Knowing their values helps us to make treatment decisions together."

We go the distance for our patients. Literally. Dr. Indryas Woldie is particularly proud of our twinning project with Ethiopia. Dr. Woldie and nurse practitioner, Rosanne Ososki recently completed medical staff training there through a World Hemophilia grant establishing the second HTC in the country.

"Detroit is a city that works hard, gets tired, gets dirty, gets defeated, and picks itself up every day and keeps going with a tenacity that amazes anyone who is paying attention."

~ Aaron Foley, Journalist, Author

Sounds a lot like our bleeding disorders community, right? Nursing care provided by Rosanne Ososki, MSN APRN and Jennifer Hoenicke, RN shares that same tenacity. Partnering with patients, Jennifer is our newest team member. Eager to put her research background to work, Jennifer has already taken a

leadership role with our latest Quality Improvement project.

"Nowhere on earth has more soul than Detroit."

~ Mayer Hawthorne, Singer

Data Manager, Shonethia Perkins knows this first hand. To her, our patients are so much more than numbers and statistics. Promoted from the ranks of Patient Access Representative, Shonethia was often the first face our patients met and their stories stay with her in her current role as she shares her own brand of humor, encouragement, and yes, soul with each and every patient encounter.

"The city of Detroit as a metaphor for our patients is apt," says social worker, Suzanne Rogers. "They're tough. They keep fighting. They rise back up." Here's to our champions! Our patients, our team, our community!

**The Comprehensive Center for
Bleeding Disorders and Thrombosis
Karmanos Cancer Center Clinic
Detroit Medical Center
University Health Center
4201 St. Antoine 7B UHC
Detroit, MI 48201
Phone: 313.745.7690**

LIFE HAPPENS

AND ADVATE WILL BE THERE WHEN IT DOES

***In clinical trials, ADVATE demonstrated the ability to help prevent bleeding episodes using a prophylaxis regimen. Not an actual patient.**

ADVATE has over 15 years of treatment experience in the real world and provides clinically proven bleed protection* for patients with hemophilia A.¹



[Antihemophilic Factor (Recombinant)]

REAL LIFE. REAL BLEED PROTECTION.*

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Prophylaxis with ADVATE prevented bleeds¹

- ADVATE was proven in a pivotal clinical trial to prevent or reduce the number of bleeding episodes in children and adults when used regularly (prophylaxis)
- The efficacy of ADVATE was studied in a multicenter, open-label, prospective, randomized, 2-arm controlled trial of 53 previously treated patients with severe to moderately severe hemophilia A. Two different ADVATE prophylaxis regimens (standard, 20–40 IU/kg every 48 hours, or pharmacokinetic-driven, 20–80 IU/kg every 72 hours) were compared with on-demand treatment. Patients underwent 6 months of on-demand treatment before 12 months of prophylaxis
 - 98% reduction in median annualized bleeding rate (ABR) from 44 to 1 when 53 patients in the clinical study switched from on-demand to prophylaxis
 - 0 bleeds in 42% (22/53) of patients during 1 year on prophylaxis

ADVATE Important Information

What is ADVATE?

- ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called “classic” hemophilia).
- ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A. Your healthcare provider (HCP) may give you ADVATE when you have surgery.
- ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADVATE?

Do not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

Tell your HCP if you are pregnant or breastfeeding because ADVATE may not be right for you.

What should I tell my HCP before using ADVATE?

Tell your HCP if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADVATE passes into your milk and if it can harm your baby.

What should I tell my HCP before using ADVATE? (continued)

- Are or become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What important information do I need to know about ADVATE?

- You can have an allergic reaction to ADVATE. Call your HCP right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.
- Do not attempt to infuse yourself with ADVATE unless you have been taught by your HCP or hemophilia center.

What else should I know about ADVATE and Hemophilia A?

- Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADVATE from working properly. Talk with your HCP to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

What are possible side effects of ADVATE?

- Side effects that have been reported with ADVATE include: cough, headache, joint swelling/aching, sore throat, fever, itching, unusual taste, dizziness, hematoma, abdominal pain, hot flashes, swelling of legs, diarrhea, chills, runny nose/congestion, nausea/vomiting, sweating, and rash. Tell your HCP about any side effects that bother you or do not go away or if your bleeding does not stop after taking ADVATE.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see Important Facts about ADVATE on the following page and discuss with your HCP.

For Full Prescribing Information, visit www.ADVATE.com.

Reference: 1. ADVATE Prescribing Information.

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[Antihemophilic Factor(Recombinant)]

Important facts about

ADVATE [Antihemophilic Factor (Recombinant)]

This leaflet summarizes important information about ADVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADVATE. If you have any questions after reading this, ask your healthcare provider.

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

Do not attempt to do an infusion to yourself 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 infusing ADVATE so that your treatment will work best for you.

What is ADVATE?

ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia). The product does not contain plasma or albumin. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A.

Your healthcare provider may give you ADVATE when you have surgery. ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

Who should not use ADVATE?

You should not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

Tell your healthcare provider if you are pregnant or breastfeeding because ADVATE may not be right for you.

How should I use ADVATE?

ADVATE is given directly into the bloodstream.

You may infuse ADVATE 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 healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADVATE to use based on your weight, the severity of your hemophilia A, and where you are bleeding.

You may have to have blood tests done after getting ADVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

Call your healthcare provider right away if your bleeding does not stop after taking ADVATE.

What should I tell my healthcare provider before I use ADVATE?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What are the possible side effects of ADVATE?

You can have an allergic reaction to ADVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Side effects that have been reported with ADVATE include:

cough	headache	joint swelling/aching
sore throat	fever	itching
unusual taste	dizziness	hematoma
abdominal pain	hot flashes	swelling of legs
diarrhea	chills	runny nose/congestion
nausea/vomiting	sweating	rash

Tell your healthcare provider about any side effects that bother you or do not go away

These are not all the possible side effects with ADVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADVATE and Hemophilia A?

Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

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

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADVATE. The FDA-approved product labeling can be found at www.ADVATE.com or 1-877-825-3327.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

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Congratulations to HFM's Academic Scholarship Recipients

We are happy to announce HFM's 2020 Academic Scholarship recipients, Kenydee Otto and Ashley Holland. Thank you to our scholarship committee members: Laura Olson, James Semiski, and Lynn Allen. Lynn was a recipient of the same award many years ago and "now enjoys the opportunity to pay this generosity forward to another generation."



Ashley

I am so glad to be a part of the hemophilia family and I feel honored to inform all of those who don't know much about it. Thank you again for all that your organization does!

This scholarship is going to allow me to pursue my life-long dream of going into the Veterinarian field as well as enter my freshman year of college debt-free. To be a part of the hemophilia family for me is seen as a blessing and after overcoming and learning through my family's struggles of battling the disorder, I hope to give back as much as the HFM gave to us.



Kenydee

Receiving this scholarship goes far beyond monetary value. It has been a rewarding experience being able to advocate for something that I am so passionate about. Being an older sister of two hemophiliacs, I am desperate to be the change in hemophilia awareness. This scholarship aids these efforts while I also pursue my dream of becoming a first-generation college graduate. I thank HFM for that.

I will be a 3rd year student at Trine University in the fall. I am majoring in Exercise Science while on the 3+3 Pre-Physical Therapy Track. I am also involved in modeling and pageantry. I am currently holding the title of 2019 National American Miss Indiana Teen. Through this title, I have been able to advocate for hemophilia through various events HFM hosts including Lansing Days and the Health Can't Wait Campaign.

Again, thank you so much for aiding my education journey!

Special thanks to these event sponsors!



Replay: www.hfmich.org/shiftingperspectives

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Event Sponsors



Happy Camper



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

In 2019 HFM was able to serve the community in so many ways through outreach, education, and celebration. And it is because of YOU, our donors and community members, that we were able to provide the following events and programs. Thank you!

- **233** campers and staff with bleeding disorders participated in 7 weeks of summer camps as we celebrated Camp Bold Eagle's 50th anniversary
- **60** advocates attended 40 scheduled meetings with their elected officials at Lansing Days
- **850** walkers joined HFM at the Unite Walks in Detroit and Grand Rapids
- **180** community members attended one of HFM's community nights across the state
- **771** medical ID tags were provided to community members
- HFM supported **122** community members to obtain dental insurance
- **2,118** people "like" HFM on Facebook, **161** new "likes" in 2019
- HFM delivered **130** feminine hygiene kits to the Philippines, Kenya, and Uganda
- **550** community members attended HFM's SpringFest
- **150** women from **37** states attended the National Conference for Women with Hemophilia in Detroit
- **17** kids received swim lessons through HFM's Swim Program in collaboration with Children's Hospital of Michigan's HTC
- **120** individuals supported HFM's camps through the Butterfly Benefit
- HFM's Hemophilia Adoption Program assisted one child find their forever family and are in the process of helping another child find theirs

2019

2020 HFM

Events/Activities

www.hfmich.org/events

June 1, 12pm

Women's Luncheon

Speaker: Annie Phillips, LMSW

June 3, 7pm

**Advocating for Your Care
in the ER with VWD**

Speaker: Sue Geraghty, RN
(Sponsored by NHF)

June 5, 6pm

Family Trivia Night

June 13, 8-9pm

Virtual Prom for HS Juniors & Seniors

Hosted by New York City Chapter
<https://bit.ly/BDCVirtualProm>

June 15, 12pm

Women's Luncheon

June 18, 7pm

Successful Communication

Speaker: Dr. Jeffrey Karst, PhD
(Sponsored by HFA)

June 29, 12pm

Women's Luncheon

July 13, 12pm

Women's Luncheon

July 27, 12pm

Women's Luncheon

August 23

**Unite for Bleeding Disorders
Walk-Detroit**

Detroit Zoo, Royal Oak

September 12-13

Women's Retreat

Dearborn-Detroit

September 19

**Unite for Bleeding Disorders
Walk-Grand Rapids**

Robinette's Cider Mill, Grand Rapids

October 2

Community Night, Craig's Cruisers

Grand Rapids

Fall TBD

Bleeder & a Buddy

Location TBD

October 9-11

**National Conference for
Women with Hemophilia**

Westin, Detroit Metropolitan Airport

October 23

Community Night, Incredible Mo's

Traverse City

November 6

Community Night, Dave & Buster's

Livonia

November TBD

Advocacy Summit

SE Michigan

December TBD

**End of the Year Community
Gathering (aka holiday party)**



734. 544.0015

www.hfmich.org


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HFM has cancelled all
in-person gatherings
through **August 15, 2020.**

Please view each event
page to learn if events will
be virtual or in-person.