the artery

Serving Michigan's bleeding disorders community

Spring 2019

EAGLE JOURNEYS
CAMPING PROGRAMS

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

hfm©

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

INSIDE

pages 10 & 11

HFM's Team unveils updated website!

One of HFM's brainstorming sessions for the website – where our team is fortunate to experience "people who challenge and inspire." Left to right: Laura Olson, Data Manager/Project Coordinator; Sarah Procario, Advocacy/Communications Manager; Gwyn Hulswit, Associate Director; Susan Fenters Lerch, Executive Director; Shari Luckey, Program Services Manager.

Dear friends,

It is our hope to create the kind of community Amy Poehler references in her quote. We believe that by participating in our offerings, **you'll connect with the most amazing people in our community, and be forever changed in the most wonderful ways!**

We work with inspiring people and organizations. Our volunteer leadership via HFM's Board of Directors together with Michigan's treatment center medical care providers, community participants, HFM camp volunteers and staff, Cascade Hemophilia Consortium colleagues, other bleeding disorder chapters and agencies, NHF and HFA, other rare disease/disorder organizations, industry partners - and so very many more - provide valuable wisdom and input to HFM's staff team as we continue our daily work to enhance the lives of people with bleeding disorders, their families and loved ones, through education, advocacy, and support (fun, too!!).

We work hard to provide options for learning and growth for as many people as possible. We listen and consider a variety of viewpoints - all while understanding it is not feasible to be all things to everyone and to please each individual. Yet, we always strive to offer opportunities for our bleeding disorders family to access important, relevant information, programs, services – **and most significantly, a sense of belonging**.

I'm proud of our collaborations and especially proud of HFM's staff. **We work together through trust, accountability, and caring for our community.**

Thanks for being a part of our community, our bleeding disorders family – please share your ideas and perspectives.

Warmly,

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

"Alone we can do so little; together we can do so much."
Helen Keller

With sincere gratitude

Thank you to our individual financial donors. This list represents contributions recorded from January 1, 2018 through December 31, 2018 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 2018 calendar year. Please consider making a donation to HFM in 2019. **Your support truly makes a difference.**

"If you want to lift yourself up, lift up someone else."

Booker T. Washington

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Continued on page 4

"Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it's the only thing that ever has." Margaret Mead

With gratitude to our financial donors *continued from page 3*

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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.

Your dreams.
Our dedication.

Michelle
vWD
Nevada

At Shire we are driven to help improve the lives of members of the bleeding disorders community. You inspire us. Each pioneering new product and program represents another step toward our ultimate goal: **a life full of dreams and free of bleeds.**

Shire

bleedingdisorders.com

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Dr. Deanna Mitchell & Dr. Gary Rich
Laura & Bill Sparrow
Jeanne White-Ginder & Roy Ginder

"Teamwork is the ability to work together toward a common vision."

Andrew Carnegie

Join HFM This Year as a Member!

We love seeing our community at SpringFest, camp, our walks and the many other HFM events and programs throughout the year. And yet we know that many community members want to deepen their involvement with HFM and help guide our work. Did you know that there are additional ways that you can be involved, and that you can be a member of HFM?

Membership in HFM is an important way of supporting the Michigan bleeding disorders community. HFM does not do our work alone, but in partnership with those who have bleeding disorders, family members, caregivers, medical professionals, friends, and HFM members. By making a financial commitment to the work of HFM and through their involvement, HFM members demonstrate the importance of enhancing the quality of life for all affected by bleeding disorders and highlight their desire to work in collaboration with HFM. As a membership organization, members have the responsibility of informing HFM's work by participating in the annual meeting. The annual meeting typically takes place during the SpringFest educational conference and includes a report of the activities of the Foundation and the election/reelection of Board members. Since 2018 HFM has offered a "Members Only" reception to acknowledge members and the integral role they play in our shared work.

If you wish to make a greater impact on the community and help direct the work of HFM, please join us as a member. It's easy! Please visit the Donate page at www.hfmich.org and simply make a minimum $40 donation for an annual family membership, or a $1,000 donation for a lifetime family membership. (Payments may be made in installments.) Please select the "Membership" designation when making your gift so that we appropriately welcome you as a member. This donation is separate from any other event or registration fees and goes directly to support annual programming designed to delight and educate hundreds of individuals and families each year. Your involvement, care and financial support of HFM are deeply appreciated. If you have additional questions or would like more information on how your gifts – particularly your gift of membership – make a difference, please contact HFM's Associate Director, **Gwyn Hulswit, at ghulswit@hfmich.org**.

Thank you.

NHF's Washington Days

Several Michigan community members participated with NHF's annual Washington Days legislative advocacy day, March 27-29, 2019.

How Will the Midterm Election Results Affect Healthcare in Michigan?

Sarah Procario

The 2018 midterms ushered in significant changes in legislatures across the United States. Michigan experienced a particularly significant change in representation as all 110 seats in the Michigan House were up for re-election and 24 representatives were bound by term limits (meaning they served the maximum terms allowed). All 38 seats in the Senate were also up for re-election with 26 senators term-limited.

Over all, Michigan welcomed 74 new representatives to Lansing, bringing more balance to the House and Senate. Democrats won five seats in the house, resulting in a 58 to 52 majority for Republicans. In the Senate, Democrats saw a net gain of five seats, resulting in a 22 to 16 majority for Republicans.

Michigan also welcomed a new governor, Gretchen Whitmer. Governor Whitmer campaigned on the belief that everyone in Michigan has a right to quality healthcare they can afford. She was also instrumental in developing Michigan's Medicaid expansion titled Healthy Michigan during her time in the State Senate. We feel optimistic that we will find support for the bleeding disorders community from her administration.

As the 2019 legislative cycle begins, HFM will be monitoring the introduction of bills and assessing their possible impact on the bleeding disorders community. It is HFM's goal to develop positive relationships with all the new representatives and maintain positive relationships with those continuing to serve in Lansing to ensure our community's voice is heard if/when healthcare decisions are made.

Do you have a new state representative or senator? Introduce yourself and start building a relationship.

Please contact Sarah Procario at sprocario@hfmich.org if you have any questions about getting in touch with your representative or visit our new advocacy website at www.hfmich.org/advocacy.

⇨Advocacy is in our blood

Lynn Ray Allen meeting with his state representative in 2018.

Do you have a new state representative or senator? Introduce yourself and start building a relationship. Need help? Go to **www.hfmich.org/advocacy**, or contact Sarah Procario, sprocario@hfmich.org.

PAID CONSUMER OUTREACH

Go beyond 86°F—**Novoeight®** can help you get there

A recombinant factor VIII to prevent and control bleeding in people with hemophilia A

Up to **104°F** for up to **3** months

Julian, 25 years old, lives with hemophilia A.

Please see Prescribing Information for complete product storage conditions.

PORTABILITY

Novoeight® can be stored:

Up to **104°F** for up to **3** months

Up to **86°F** for up to **12** months

Longest room temperature storage time after reconstitution—**up to 4 hours at up to 86°F**[a]

Highest storage temperature after reconstitution—**up to 104°F for up to 2 hours**[a]

[a]Compared with other recombinant FVIII products. Please see Prescribing Information for complete product storage conditions.

SAFETY

0 INHIBITORS

were confirmed in one of the largest clinical trial programs with[b]

225 previously treated patients

receiving

88,000 infusions

[b]People with previous inhibitors and those new to treatment were not included in the trial. People with hemophilia A may develop inhibitors to factor VIII.

BLEED CONTROL

89% of adults and adolescents aged 12-65

95% of children aged 0-11

Bleeds treated with 1 or 2 infusions

Indications and Usage

Novoeight® (Antihemophilic Factor [Recombinant]) is an injectable medicine used to control and prevent bleeding in people with hemophilia A. Your healthcare provider may give you Novoeight when you have surgery.

Novoeight® is not used to treat von Willebrand Disease.

Important Safety Information

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

Call your healthcare provider right away and stop treatment if you get any of the following signs of an allergic reaction: rashes or hives, difficulty breathing or swallowing, tightness of the chest, swelling of the lips and tongue, light-headedness, dizziness or loss of consciousness, pale and cold skin, fast heartbeat, or red or swollen face or hands.

Before taking Novoeight®, 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 Novoeight®, which may stop Novoeight® from working properly. Call your healthcare provider right away if your bleeding does not stop after taking Novoeight®.

Common side effects of Novoeight® include swelling or itching at the location of injection, changes in liver tests, and fever.

Please see Brief Summary of Prescribing Information on following page.

Novoeight® is a prescription medication.
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.

Visit Novoeight104.com today to learn more.

novo nordisk®

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

 Printed in the U.S.A. US18NEGT00013 June 2018

novoeight®
Antihemophilic Factor (Recombinant)

novoeight®

Antihemophilic Factor (Recombinant)

Brief Summary information about Novoeight® Antihemophilic Factor (Recombinant)

Rx Only

This information is not comprehensive.

- Talk to your healthcare provider or pharmacist
- Visit www.novo-pi.com/novoeight.pdf to obtain the FDA-approved product labeling
- Call 1-844-30-eight

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

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

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

Do not attempt to do an infusion 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 Novoeight® so that your treatment will work best for you.

What is Novoeight®?

Novoeight® 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 that prevents blood from clotting normally.

Novoeight® is used to control and prevent bleeding in people with hemophilia A.

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

Novoeight® is not used to treat von Willebrand Disease.

Who should not use Novoeight®?

You should not use Novoeight® if you

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

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

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

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 Novoeight®?

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

Novoeight® is given as an injection into the vein.

You may infuse Novoeight® 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 Novoeight® to use based on your weight, the severity of your hemophilia A, and where you are bleeding.

You may need to have blood tests done after getting Novoeight® to be sure that your blood level of factor VIII is high enough to clot your blood. This is particularly important if you are having major surgery.

Your healthcare provider will calculate your dose of Novoeight® (in international units, IU) depending on your condition and body weight.

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

Development of factor VIII inhibitors

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

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 Novoeight® or even a different product to control bleeding. Do not increase the total dose of Novoeight® to control your bleeding without consulting your healthcare provider.

Use in children

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

If you forget to use Novoeight®

Do not inject a double dose to make up for a forgotten dose. Proceed with the next injections as scheduled and continue as advised by your healthcare provider.

If you stop using Novoeight®

If you stop using Novoeight® you are not protected against bleeding. Do not stop using Novoeight® 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 Novoeight®?

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

What are the possible side effects of Novoeight®?

Common Side Effects Include:

- swelling or itching at the location of injection
- changes in liver tests
- fever

Other Possible Side Effects:

You could have an allergic reaction to coagulation factor VIII products. **Call your healthcare provider right away and stop treatment if you get any of the following signs of an allergic reaction:**

- rashes including hives
- difficulty breathing, shortness of breath or wheezing
- tightness of the chest or throat, difficulty swallowing
- swelling of the lips and tongue
- light-headedness, dizziness or loss of consciousness
- pale and cold skin, fast heart beat which may be signs of low blood pressure
- red or swollen face or hands

These are not all of the possible side effects from Novoeight®. 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 Novoeight® dosage strengths?

Novoeight comes in six 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 six different strengths are as follows:

Dosage strength of approximately 250 IU per vial
Dosage strength of approximately 500 IU per vial
Dosage strength of approximately 1000 IU per vial
Dosage strength of approximately 1500 IU per vial
Dosage strength of approximately 2000 IU per vial
Dosage strength of approximately 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 doctor.

How should I store Novoeight®?

Prior to Reconstitution:

Store in original package in order to protect from light. Do not freeze Novoeight®.

Novoeight® vials can be stored in the refrigerator (36°F to 46°F [2°C to 8°C]) for up to 30 months or up to the expiration date. During the 30 month shelf life, the product may be kept at room temperature up to 86°F (30°C) for no longer than 12 months, **or** up to 104°F (40°C) for no longer than 3 months.

If you choose to store Novoeight® at room temperature:

- Note the date that the product is removed from refrigeration on the box.
- Do not return the product to the refrigerator.
- Do not use after 12 months if stored up to 86°F (30°C) **or** after 3 months if stored up to 104°F (40°C) **or** the expiration date listed on the vial, whichever is earlier.

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

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

The reconstituted Novoeight® should appear clear to slightly unclear without particles.

The reconstituted Novoeight® should be used immediately.

If you cannot use the Novoeight® immediately after it is mixed, it must be used within 4 hours when stored at ≤ 86°F (30°C) or within 2 hours when stored between 86°F (30°C) to 104°F (40°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 Novoeight® and hemophilia A?

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

For more information about Novoeight®, please call Novo Nordisk at 1-844-30-EIGHT.

Revised: 05/2018

Novoeight® is a registered trademark of Novo Nordisk Health Care AG.

Patent Information: http://novonordisk-us.com/patients/products/product-patents.html

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

More detailed information is available upon request.

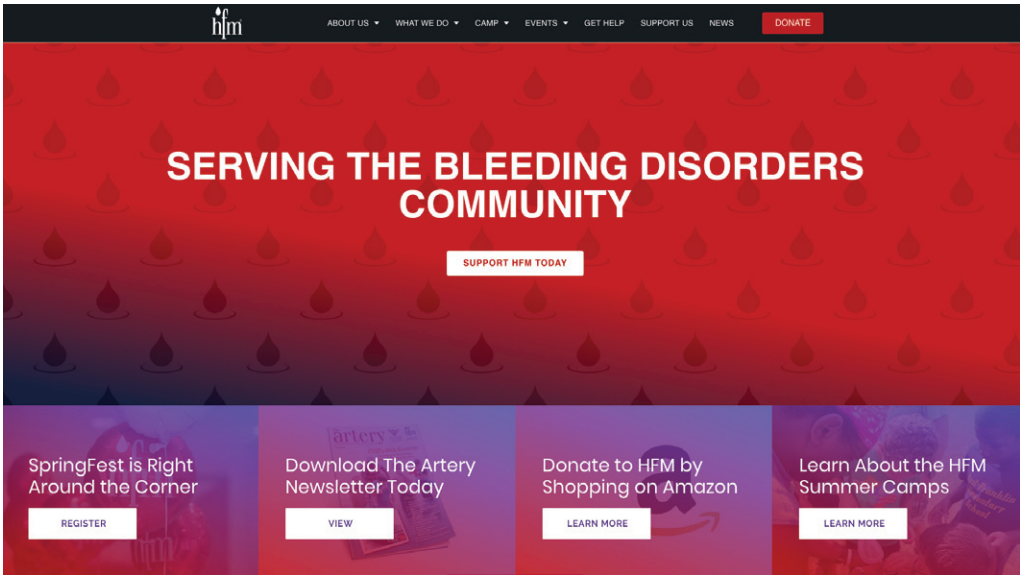
Available by prescription only.

For information about Novoeight® contact:
Novo Nordisk Inc.
800 Scudders Mill Road
Plainsboro, NJ 08536, USA

US18NEGT00039 6/2018

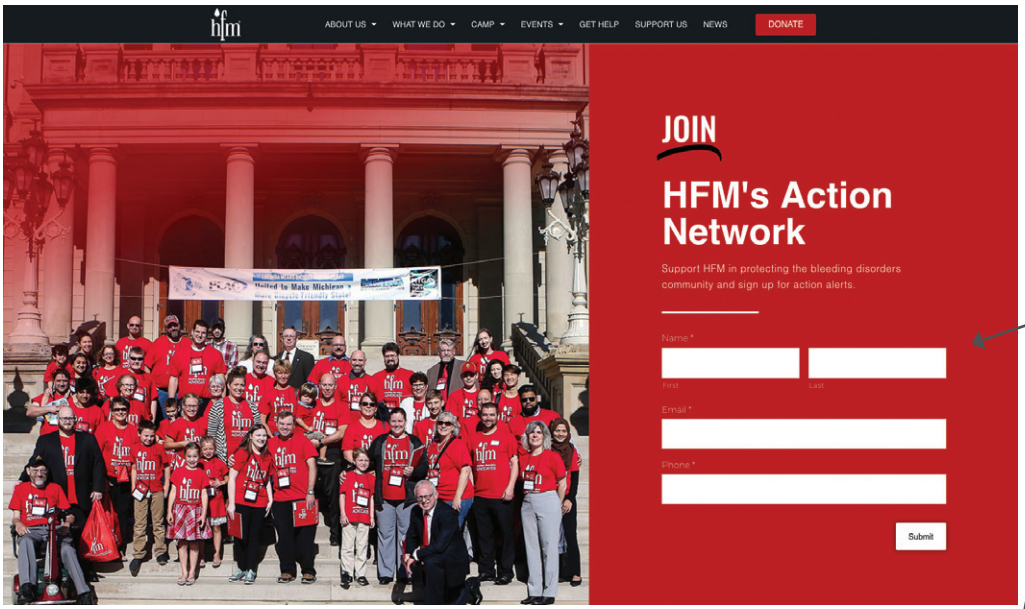
novo nordisk®

Take a Tour of HFM's New Website



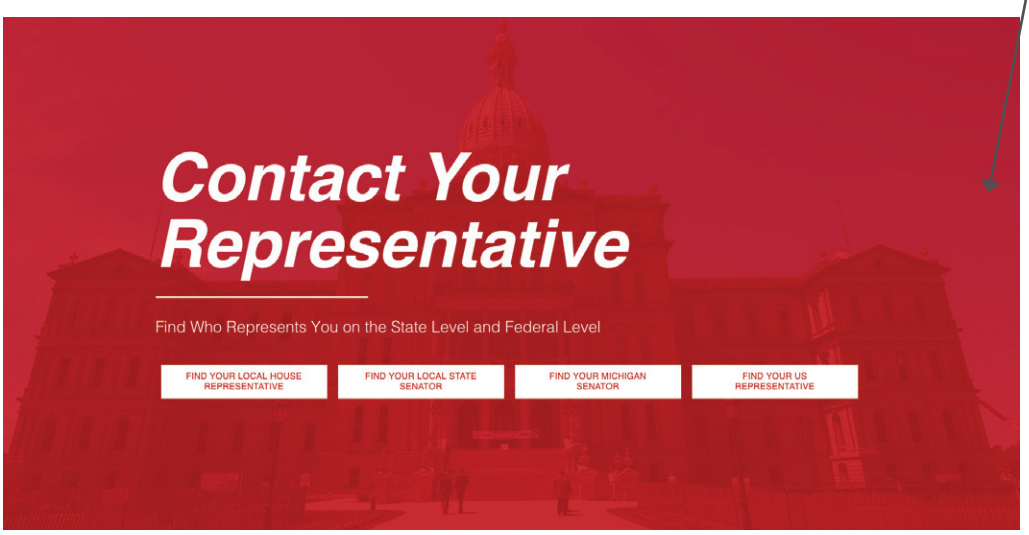
Homepage

HFM's new website includes a re-organized menu. Hover over ABOUT US, WHAT WE DO, CAMP, and EVENTS to see the dropdown options. Can't find what you are looking for? Use the search tool at the very bottom of the page. When you want to go back to the homepage, just click on the HFM logo.



Advocacy

Hfmich.org has an entirely new advocacy section. You can sign up to be a part of HFM's Action Network, a group of advocates trained to respond to threats to care, review issues impacting the bleeding disorders community, use the contact your representative and voter registration tools, and register for Lansing Days 2019.



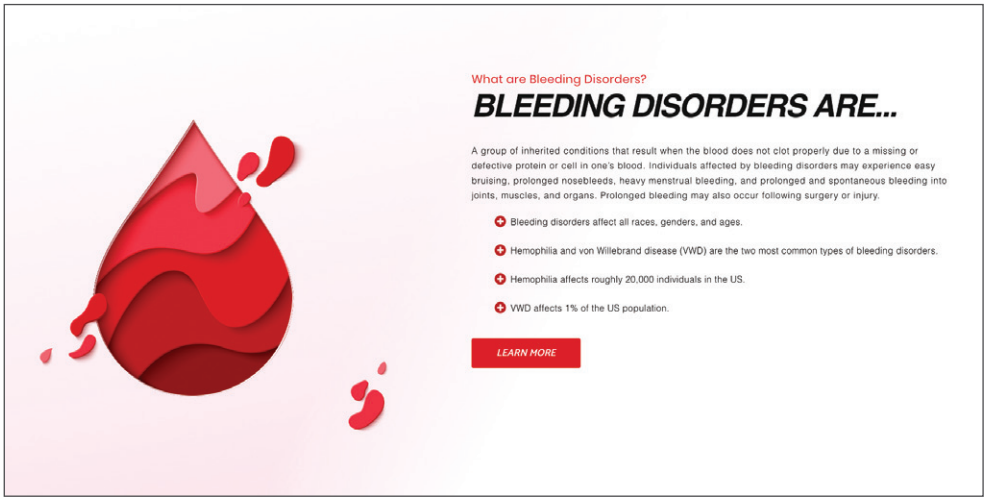
This site was made possible in part through a grant from Pfizer

Pfizer Hemophilia

It is HFM's pleasure to formally announce our newest update to HFMICH.org. Over the past two years, HFM staff has dedicated countless hours to create a more usable and friendly online space for all members of the Michigan bleeding disorders community. Special thanks to Jeff Fansler of Fanzoo Technology and the GiveCamp crew for bringing our website into the 21st century! And more recently, thank you to Andrew Sieloff, of Park Ryan Marketing, LLC, for bringing to life all our website visions. It is our sincere hope that you find support, education, and connection on **hfmich.org**.

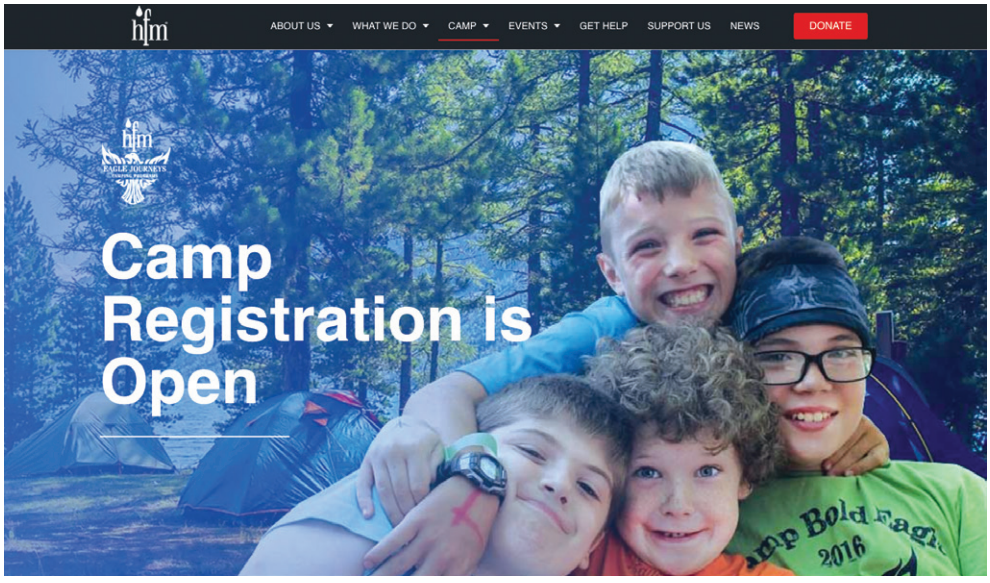
News

We created this section to share more information with our community members. Follow bleeding disorders news as it happens or learn more about a topic of interest. Use the sharing tools to post articles to your social media platforms.



Bleeding Disorders

Now use HFM's website as a resource. Direct friends, family, and others to **hfmich.org** where they can learn the basics of bleeding disorders.



Camp

Browse HFM's new camp page. Learn about each camp, get to know the camp team, and review important information about sending your child to camp. The entire parent handbook is now online!

Days for Girls Winter Work Day and Potluck: Supporting Global Women's Health

Shari Luckey

Once inside the cozy atmosphere of the Ypsilanti HFM offices we didn't notice the frigid 11-degree temperature outside. Between the irons, crockpots, oven, and sincere comradery, we were warm and cozy as we began making bags to hold our next 100 menstrual hygiene kits for Days for Girls (DFG).

DFG aims to increase access to menstrual products and education for women and girls around the world through the creation and distribution of reusable menstrual kits. With access to these products, women and girls will no longer miss school and work, or be separated from family and friends, during their menstrual cycle.

With nine women working on this project, we made excellent progress. As we talked, we realized that some in our community might assume this is a women only working group. We decided we should set the record straight. We thankfully welcome anyone who has a heart for global women's health. Our DFG group is focused on sending kits to women that are recognized to have a bleeding disorder, related to someone with a bleeding disorder, or may have an undiagnosed bleeding disorder. A woman with a bleeding disorder that does not have access to feminine hygiene products may bleed heavier and longer than a typical menstrual cycle. Without access to these reusable products they may be at a higher risk of missing work, school, or being ostracized from family and friends.

Support HFM's Days for Girls Work Group by purchasing something from our wish list online at **www.hfmich.org/dfgwishlist**.

If ordering online through Amazon, go to Smile.Amazon.com and designate the Hemophilia Foundation of Michigan as your charity and HFM will receive 0.5% of the purchase price of eligible items.

Donations can be sent to Shari Luckey at HFM, 1921 W Michigan Ave., Ypsilanti, MI 48197 or contact Shari at **sluckey@hfmich.org** to make other arrangements.

Megan is currently a Ph.D. candidate in the department of Microbiology and Immunology at the University of Michigan Medical School. In addition to her thesis work studying viruses, she is passionate about science in general and enjoys sharing it with others via educational programs and outreach.

On-Demand, Prophy, Gene Therapy, Gene Editing: **What is the difference?**

Megan Procario

There are many treatment options for patients with hemophilia, with even more being developed in scientific laboratories. I'd like to use an analogy to outline the broad principles of some of these therapies.

I'd like you to picture a neighborhood full of houses. Normally, all of these houses would be well-lit once evening falls. These houses are lit because they have power supplied by the local electric company. Within this neighborhood, however, there is one house that is unlike the others. This house can't utilize the power from the electric company due to faulty wiring connecting the house to the power cables. Once the residents of the house identified the cause of their power deficit, they were able to talk with some engineers who specialized in this sort of problem. This group of engineers presented the following list of options to the homeowners.

- Don't do anything. Accept that the house doesn't have electricity and all of the complications that come with that problem.
- Purchase a short-term power source to temporarily supply electricity to the house. These power sources usually last about 3-4 days before running out. There is both an option to buy these power sources as needed or to have them delivered on a regular schedule, twice a week.
- Purchase a large generator to supply electricity to the house. This isn't exactly the same as the other houses in the neighborhood but is functionally very similar.
- Hire technicians to come to the house and repair the faulty wiring connecting it to the cables from the electric company. This should allow the house to finally (and permanently) utilize the power supplied by the electric company.

As you may have guessed, this story is an analogy for the different treatment options currently (or potentially) available to patients with hemophilia A or B. The power/electricity is the missing clotting factor, while the faulty wiring represents the mutation in the gene for the factor. The missing clotting factor can be temporarily supplemented via infusions, either on demand or on a prophylactic schedule, just like the short-term power source in the analogy. A more recent therapy that is in trial for patients with hemophilia is gene therapy. Very simply, this consists of adding a functional version of the gene for the missing clotting factor to the body. This doesn't replace the mutated gene, which is still there, but instead allows the body to make factor using the additional gene. Just like in the analogy, where the generator didn't change the faulty wiring, it performs its function in a slightly different way. The final therapy that this analogy refers to is not yet available for hemophilia patients but is currently being researched in the laboratory. This therapy is called 'gene-editing' and is precisely what it sounds like. Just like a technician fixing faulty wiring, this therapy allows scientists/doctors to change a patient's mutated clotting factor gene to restore its function.

While there are MANY more details about these therapeutic options than I have discussed here, hopefully this will establish a good foundation. As always, if you have questions about your current hemophilia treatment, please reach out to your treatment team at your Hemophilia Treatment Center.

...this story is an analogy for the different treatment options currently (or potentially) available to patients with hemophilia A or B.

PAID CONSUMER OUTREACH

GO SEEK. GO EXPLORE.
GO AHEAD.

Discover your sense of go. Discover HEMLIBRA®.

HEMLIBRA.com

What is HEMLIBRA?

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

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

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

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

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

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

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

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

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

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

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

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

What is HEMLIBRA?

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

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

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

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

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

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

How should I use HEMLIBRA?

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

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

What are the possible side effects of HEMLIBRA?

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

The most common side effects of HEMLIBRA include:

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

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

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

How should I store HEMLIBRA?

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

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

General information about the safe and effective use of HEMLIBRA.

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

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

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

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

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

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

Genentech
A Member of the Roche Group

Center of Care

Elizabeth Sandon-Kleiboer RN, BA
Pediatric Coagulation Program Manager, Helen DeVos Children's Hospital

Helen DeVos Children's Coagulation Disorders Program was founded in 1990 by Dr. James Fahner, Division Chief of Pediatric Hematology/Oncology. Julie Webb, RN, was the first Nurse Coordinator, and saw patients in the tiny waiting room on the Pediatric floor at Butterworth Hospital. This new Hemophilia Treatment Center was supported by federal funding through the Hemophilia Foundation of Michigan, and through the very special and direct advocacy and support by the late United States Representative Paul Henry.

Helen DeVos Children's Hospital started as an entity within Butterworth Hospital in 1993. Butterworth joined with Blodgett Hospital in 1997 to become Spectrum Health. The Helen DeVos Children's Hospital (HDVCH) built a new, free-standing 14 story building on the campus of Spectrum-Butterworth in 2011. This beautiful campus is located on the "Medical Mile" on Michigan Street in downtown Grand Rapids.

In the years since its inception, the Pediatric Coagulation Disorders Program has grown from seeing a handful of children with hemophilia to a program providing care and services to over 600 children and young adults per year with bleeding and clotting disorders. We serve patients from all over West and Northern Michigan and the Upper Peninsula. We have a close association with Munson Hemophilia Treatment Center in Traverse City, for which Dr. Deanna Mitchell is the Pediatric Hematologist. We participate in one Pediatric Comprehensive Clinic each year with the Munson team.

Since 1995, Dr. Mitchell has served as the Medical Director of the HDVCH Coagulation Disorders Program. Dr. Jessica Foley also provides care to our patients with hemophilia and other bleeding disorders. Dr. Chi Braunreiter leads our Neonatal and Pediatric Thrombosis Program. Eight additional physician partners and two fellows in Pediatric Hematology/Oncology share in the care of these patients. Two nurses, Sherry Hubble and Mandy Kinker, who provided years of care and service to our patients, have recently transitioned to new roles in their lives.

The current Coagulation Disorders Program staff also includes:

Beth Sandon-Kleiboer RN, BA, Program Manager
Barb Milzarski, RN, Clinical Nurse
Kristen Veenstra, RN, BSN, Clinical Nurse
Erika Leep, RN, BSN, Clinical Nurse
Allison Postma, RN, BSN, Clinical Nurse
Lynn Vanderwal, LMSW, Social Worker
Melissa Laustroer, BA, Data Manager/ Pharmacy Coordinator
Roxanne Hull, Administrative Assistant
Krista DeLong, PA, Physician Assistant-Hemophilia
Rebecca Shreur, Pharmacy Technician
Denise May, Physical Therapist
Christy Clark, Dental Hygienist
Steve Pastyrnak, PhD, Psychologist

We are lucky to be able to provide care for our patients from birth through their early 20s. Patients transition to adult care when they and their care team agree that they are ready. Our patients most often transition to other HTCs in Michigan, including Michigan State University (in conjunction with a local Hematologist), West Michigan HTC in Kalamazoo, and Munson HTC in Traverse City. We are also happy to assist in transitioning to treatment centers far and wide, depending on where the patient is going to "land" in their adulthood.

We work closely with the Hemophilia Foundation of Michigan to provide opportunities for learning and fun for our families, including SpringFest and camp programs as well as annual fundraisers including the Butterfly Benefit and the Walks. As a treatment center, we also provide learning and recreational events, including parent dinners, family movie days, a holiday party, medical school panels, and one-on-one support for new families.

The HTC team members at Helen DeVos Children's Hospital are truly inspired by the patients and families for whom we provide services. We love to participate in their lives as these children grow into healthy, active, independent young adults! We are grateful to have very supportive team members who work closely together to provide timely coordination of care. The safety, health, and happiness of our patients are our primary goals.

Thank you to all of our families for inviting us into your lives and allowing us to walk through these years with you!

Join HFM for an unforgettable evening of transformation.

Butterfly BENEFIT

benefiting HFM &
HFM's Eagle Journeys
Camping Programs

Music, Dinner, Auction & more!

Make a night of it with your friends and help Michigan children with bleeding disorders experience the magic of HFM's summer camps. **Purchase tickets or make a donation: www.hfmich.org/benefit-tickets**
Limited Seating - starts at $40

For more information contact Carrie McCulloch, HFM Special Events Manager West Michigan Office cmcculloch@hfmich.org 734.544.0015 ext. 503

Thursday, May 23, 2019 I 5:30-9pm I Grand Rapids Art Museum **I hfmich.org/benefit-tickets**

PAID CONSUMER OUTREACH

DON'T STAND ON THE SIDELINES

Indications for RIXUBIS [Coagulation Factor IX (Recombinant)]

RIXUBIS is an injectable medicine used to replace clotting factor IX that is missing in adults and children with hemophilia B (also called congenital factor IX deficiency or Christmas disease).

RIXUBIS is used to control and prevent bleeding in people with hemophilia B. Your healthcare provider may give you RIXUBIS when you have surgery. RIXUBIS can reduce the number of bleeding episodes when used regularly (prophylaxis).

Detailed Important Risk Information

You should not use RIXUBIS if you are allergic to hamsters or any ingredients in RIXUBIS.

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 hamsters, are nursing, are pregnant or planning to become pregnant, or have been told that you have inhibitors to factor IX.

Allergic reactions have been reported with RIXUBIS. Call your healthcare provider or get emergency treatment right away if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea, or fainting.

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

If you have risk factors for developing blood clots, the use of factor IX products may increase the risk of abnormal blood clots.

Common side effects that have been reported with RIXUBIS include: unusual taste in the mouth, limb pain, and atypical blood test results.

Call your healthcare provider right away about any side effects that bother you or if your bleeding does not stop after taking RIXUBIS.

Please see following page for RIXUBIS Important Facts.

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.

Shire

RIXUBIS
[COAGULATION FACTOR IX (RECOMBINANT)]
MOVING FORWARD

RIXUBIS
[COAGULATION FACTOR IX (RECOMBINANT)]

Important facts about

RIXUBIS [Coagulation Factor IX (Recombinant)]

This leaflet summarizes important information about RIXUBIS. 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 RIXUBIS. If you have any questions after reading this, ask your healthcare provider.

What is RIXUBIS?

RIXUBIS is a medicine used to replace clotting factor (Factor IX) that is missing in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Hemophilia B is an inherited bleeding disorder that prevents blood from clotting normally. RIXUBIS is used to prevent and control bleeding in people with hemophilia B. Your healthcare provider may give you RIXUBIS when you have surgery. RIXUBIS can reduce the number of bleeding episodes when used regularly (prophylaxis).

Who should not use RIXUBIS?

You should not use RIXUBIS if you

- are allergic to hamsters
- are allergic to any ingredients in RIXUBIS.

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

What should I tell my healthcare provider before using RIXUBIS?

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 hamsters
- are breastfeeding. It is not known if RIXUBIS passes into your milk and if it can harm your baby
- are pregnant or planning to become pregnant. It is not known if RIXUBIS may harm your unborn baby
- have been told that you have inhibitors to factor IX (because RIXUBIS may not work for you).

How should I infuse RIXUBIS?

RIXUBIS is given directly into the bloodstream. RIXUBIS should be administered as ordered by your healthcare provider. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia B learn to infuse their RIXUBIS by themselves or with the help of a family member.

Your healthcare provider will tell you how much RIXUBIS to use based on your weight, the severity of your hemophilia B, and where you are bleeding. You may have to have blood tests done after getting RIXUBIS to be sure that your blood level of factor IX is high enough to clot your blood. Call your healthcare provider right away if your bleeding does not stop after taking RIXUBIS.

What are the possible side effects of RIXUBIS?

Allergic reactions may occur with RIXUBIS. Call your healthcare provider or get emergency treatment right away if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting. Some common side effects of RIXUBIS were unusual taste in the mouth and limb pain. Tell your healthcare provider about any side effects that bother you or do not go away. These are not all the side effects possible with RIXUBIS. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about RIXUBIS?

Your body may form inhibitors to factor IX. An inhibitor is part of the body's defense system. If you form inhibitors, it may stop RIXUBIS 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 IX.

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

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.

The risk information provided here is not comprehensive. To learn more, talk about RIXUBIS with your healthcare provider or pharmacist. The FDA-approved product labeling can be found at http://www.shirecontent.com/PI/PDFs/RIXUBIS_USA_ENG.pdf or by calling 1-800-FDA-1088.

Issued 03/2016

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S27967 02/17

Shire

Dental Facts: Did You Know?

Jennifer Kerns, BS, RDH

Dental pain and infection prevent 4% -7% of students from doing their required homework and attending school, which makes it difficult for little ones with cavities to achieve literacy. If your child misses multiple days of school from dental problems, talk to your hematologist about making a dental appointment to improve your child's oral health – and their future.

Fluoride is a naturally occurring mineral in the earth and has been used to prevent cavities in the US since the 1940s. Gaining tremendous popularity now, SDF is a non-invasive liquid that can be used to treat small cavities easily without pain or trauma. Ask a dental professional if SDF would be a good treatment option for your family.

Advances in dentistry and the discovery of fluoride have made it possible for people to keep their teeth longer. On average, only 24% of seniors are now missing their teeth, compared to 47% just a few decades ago. Preventing dental problems is a lot less expensive than fixing them.

For years, researchers have been studying the effects of oral bacteria in our blood stream. These dangerous oral pathogens have been linked to heart disease, stroke, diabetes, atherosclerosis, premature birth, aspiration pneumonia, COPD, and chronic bronchitis. In more recent years, new studies have shown that periodontal bacterium is also linked to Alzhiemer's Disease. This new research confirms how important dental care is throughout our lifetime.

Don't wait, talk to your HTC and dental provider today.
Allow several weeks for the HTC to develop a safe & appropriate treatment plan with your provider and for you to obtain prescribed coagulation medications prior to your procedure. The information provided is for guidance only, not to be replaced by medical recommendations.

Jennifer Kerns, BS, RDH is a practicing clinician, educator, speaker, and writer. She is an adjunct clinical faculty member at the University of Michigan, Dental Hygienist for the Northern Regional Bleeding Disorder Center at Munson Healthcare, Dental Outreach Coordinator at NMHSI.org, and Dental Consultant for various national and community projects. Contact Jennifer at (231) 632-2238 or Hijenist1@gmail.com

HFM's national ground-breaking conference could not have happened without the support of our sponsors. We remain utterly grateful to each of them, most especially to our **founding sponsor, Bioverativ, A Sanofi Company, now known as Sanofi Genzyme**.

2018 National Conference
Being Visible: Women with Hemophilia

November 9-11, 2018 | Amway Grand Hotel | Grand Rapids, MI

Founding Sponsor

Bioverativ A SANOFI COMPANY NOW KNOWN AS SANOFI GENZYME

Regional Sponsor

INDIANA HEMOPHILIA & THROMBOSIS CENTER, INC.

Community Sponsor

CSL Behring

Local Sponsor

SPECTRUM HEALTH Helen DeVos children's hospital

Special thanks as well to Skinnytees for donating camisoles and gift bags to all our attendees!

Created & Hosted By

hfm

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

2019 National Conference for Women with Hemophilia & Symptomatic Carriers: Hear Our Voices

November 1-3, 2019
Westin Hotel, Detroit Metropolitan Airport

Application Opens July 2019

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

HFM's Teen Retreat

At this year's Teen Retreat, the teens enjoyed a weekend of fun and education geared towards understanding their own boundaries and the boundaries of others. Friday night the group participated in several activities designed to help them better understand their own physical and mental boundary limits. This included a game of 52 pick-up with 52 note cards, each containing a different activity or challenge each teen could either choose to try or not to try based on their level of comfort. Saturday morning the group actively engaged in a presentation and group discussion on consent and what it means in today's world. Saturday night ended with several games of laser tag that demonstrated literal boundaries and a whole lot of team work!

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

Special thanks to our sponsor Genentech, A Member of the Roche Group

In 2018 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!

2018

- **228** campers and staff with bleeding disorders participated in **7** weeks of summer camps
- **80** advocates attended **40** scheduled meetings with their elected officials at Lansing Days
- **880** walkers and volunteers joined HFM at the Unite Walks in Detroit and Grand Rapids
- **650** community members attended HFM's annual conference, SpringFest, and heard from over **50** speakers
- **500** medical ID tags were provided to community members
- **1956** people 'like' HFM on Facebook, **212** new 'likes' in 2018
- HFM provided financial assistance to **41** families and individuals
- HFM delivered **70** menstrual hygiene kits to women and girls in Nigeria through the Days for Girls Program
- **190** community members joined HFM at one of **4** Community Night events
- **103** women from **32** states congregated in Grand Rapids for the first ever National Conference for Women with Hemophilia
- HFM hosted **5** retreats throughout the year for women, teens, the HIV+ community, and community members in the Upper Peninsula
- **12** kids received swimming lessons through HFM's Swim Program in collaboration with Children's Hospital of Michigan's Hemophilia Treatment Center
- **110** friends from the west side supported HFM's camps via the Butterfly Benefit
- HFM's Hemophilia Adoption Program supported **5** children joining their forever families in the US
- **108** golfers supported HFM camping programs during our Swinging for Smiles Golf Outing

2019 HFM Events/Activities

May 21-22
Lansing Days
Kellogg Center, East Lansing
sprocario@hfmich.org

May 23
Butterfly Benefit
Grand Rapids Art Museum (GRAM)
cmcculloch@hfmich.org

June 3
Swinging for Smiles Charity Golf Outing
The Polo Fields-Washtenaw, Ypsilanti
cmcculloch@hfmich.org

June 7
Community Night
Craig's Cruisers, Grand Rapids
cmcculloch@hfmich.org

June 22
Butterfly Memorial & Garden Dedication
HFM, Butterfly Courtyard,Ypsilanti
sluckey@hfmich.org

August 25
UNITE for Bleeding Disorders Walk
(Walkin' on the Wild Side)
Detroit Zoo, Royal Oak
cmcculloch@hfmich.org

September 14-15
Women's Retreat
The H Hotel, Midland
sluckey@hfmich.org

September 27
Community Night
Lucky Jack's, Traverse City
cmcculloch@hfmich.org

October 11-13
Bleeder and a Buddy
Camp Roger
twicks@hfmich.org

October 12
UNITE for Bleeding Disorders Walk
(Walkin' on the West Side)
Fifth Third Ballpark, Grand Rapids
cmcculloch@hfmich.org

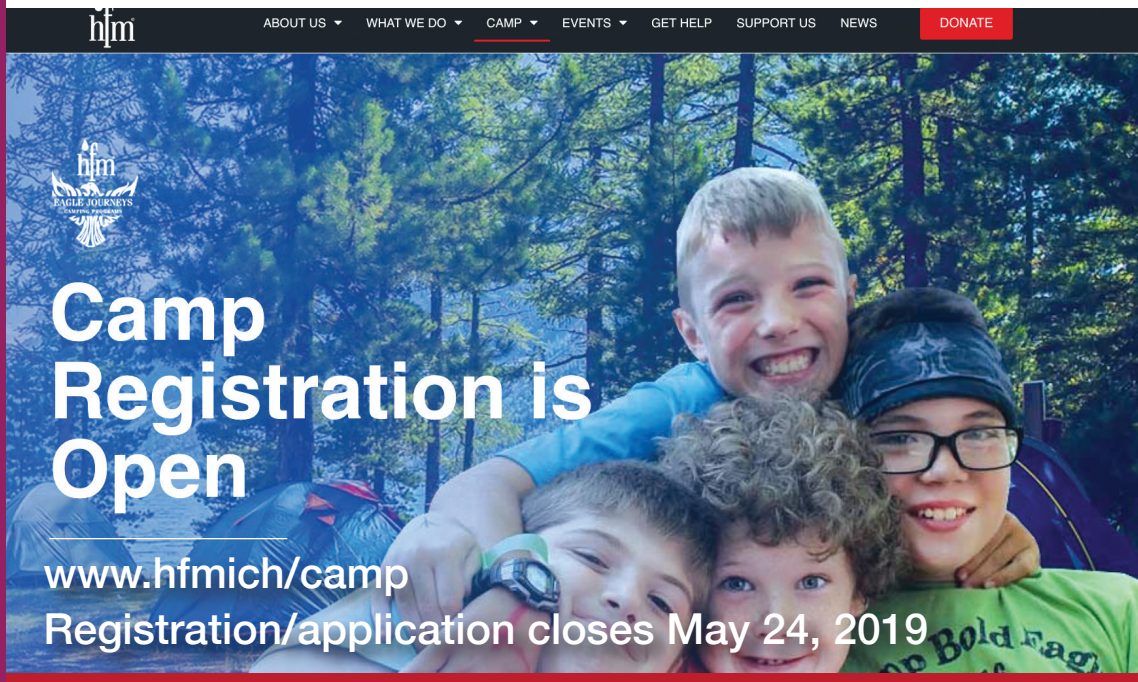
November 1-3
HFM's 2019 National Conference for Women with Hemophilia
Westin Hotel, Detroit Airport
pthomas@hfmich.org

November 8
Community Night
Spare Time Entertainment Center, Lansing
cmcculloch@hfmich.org

November 18
Advocacy Summit
Location TBA
sprocario@hfmich.org

December TBA
End of the Year Community Gathering (Holiday Party), Troy
cmcculloch@hfmich.org

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



June 8-14
Eagle Quest
(Ages 18+)

June 30-July 6
CBE Teen Camp
(Ages 13-17)

July 6-7
Camp Alumni Days at CBE

July 8-27
CIT Program

July 10-13
Camp Staff Development

July 14-18
CBE Session One
(Ages 6-9)

July 20-26
CBE Session Two
(Ages 10-12)

July 30-Aug 7
Eagle Expedition
(Ages 16+)

August 4-10
Eagle Outpost
(Ages 14-15)

September 13-15
Camp Old Beagle
(Ages 18+)

December 14
Camp Holiday Party
twicks@hfmich.org

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