

# the artery

Serving Michigan's bleeding disorders community

Winter 2019/2020



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

communication  
empowered belonging healing  
friendship educational hope children  
emotional connection liberation  
empowering sisters strength women time  
sisterhood sisters strength women time  
tribe focus powerful family validation  
learning access amazing love  
listening knowledge advocacy heard  
accepted inspirational blood compassion  
future support validated reconnecting  
connection  
powerful understanding  
community  
bloodsisters  
awesomeness

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**Above:** Attendees from HFM's Women's Conference, Being Visible: Hear our Voices shared words representing the weekend.

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Happy holidays from all of us at HFM!

## Dear HFM friends and family -

As we recognize this season of joy with family, friends, colleagues, community members, and others who impact our lives, **we join together to acknowledge and appreciate the people who make a difference.**

The many significant words listed on the cover of our newsletter represent how when we listen and learn from one another we are stronger. Though listed only once, many of the words were provided by numerous individuals who were moved by similar feelings.

In November, we had many remarkable women with hemophilia come together to share their stories. Our participants with the **2019 Being Visible: Hear Our Voices** national conference learned from one another – as well as amazing health care providers who donated their time and energy to the conference. Our presenters provided education, various perspectives, and most importantly – hope – to this special gathering. With an outstanding roster of presenters, predominantly women who are quite renowned providers, we are ever grateful to all who participated.

It was wonderful to present our Michigan State University's **Dr. Roshni Kulkarni** a special award as our community's "Fairy Godmother" ([www.hfmich.org/fairy](http://www.hfmich.org/fairy)) recognizing her support of patients in our state and internationally with a particular interest in women with hemophilia. Dr. Kulkarni is a pioneer in advocacy, recognition, and treatment for women with hemophilia.

We have had many important and valuable community gatherings this year to offer education, information and community to those served by HFM's mission. We're excited to be offering many of these same programs and events, along with some new opportunities in 2020. Our goal is to create programs and events that inspire connection, empowerment, family, learning, and much more, (similar to the words on the cover). We look forward to seeing you in 2020!

**Wishing you a beautiful season of light and love.**

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





**SERVING ALL OF MICHIGAN** HFM's community events celebrate the bleeding disorders community and families across the state, including the Upper Peninsula. We love when everyone joins us!



**Health Care Advocacy**



**Camp**



**Adoption Program**



**Butterfly Garden Dedication**



**SpringFest**



**Options for Women**

## We are Truly Inspired by You!

*By Gwyn Hulswit*

You are the reason why the Hemophilia Foundation of Michigan (HFM) has so much to celebrate in 2019. Your dedication, support, and belief in improving the lives of individuals affected by bleeding disorders is inspiring. Your stories are what bring us together as a community and for this, we are beyond grateful.

We are truly excited to welcome you to each of our events and programs throughout the year. Your participation matters in all the ways we come together as a community. You may have joined us at Lansing Days to share our need for quality and affordable healthcare access, received a rose in memory of a loved one at the rededication of our community butterfly memorial and garden, put your child on the bus for Camp Bold Eagle with trust that they would have a wonderful experience, or raised a pinwheel in celebration of the unity we find together at our Walk fundraisers – however you joined us, we are so glad that you did.

As we make plans for the coming year, HFM is excited to continue to expand our educational programming and community events. We welcome families with new diagnoses, celebrate those who reach milestones as they transition from children to young adults, and work to create supportive services for those who are growing older with a bleeding disorder.

We are asking that you continue to join us as a community member, and that you also join us as a donor to help us with these efforts.

Please consider making a donation to help the Michigan bleeding disorders community grow even stronger in the coming year. If you have already made a financial gift this year, thank you. If you have not yet made a donation, or if you can give again, we would be grateful for your support. All donations go directly to provide the many programs and services HFM offers free or with a nominal charge throughout the year.

Donations can be made directly to HFM at [www.hfmich.org/donate](http://www.hfmich.org/donate) or by using the attached envelope in the newsletter. You may also make a donation to HFM in honor of someone special; we will share with them the joy this gift makes to the Michigan community.

We are grateful to be alongside all of you at HFM's many events and programs. We look forward to more times together providing support and education for one another and creating moments of celebration. Thanks to you, our engaged community members, families, and friends, we are a strong and caring community. Thank you for all that you bring to the Michigan bleeding disorders community.

We are truly inspired by you.



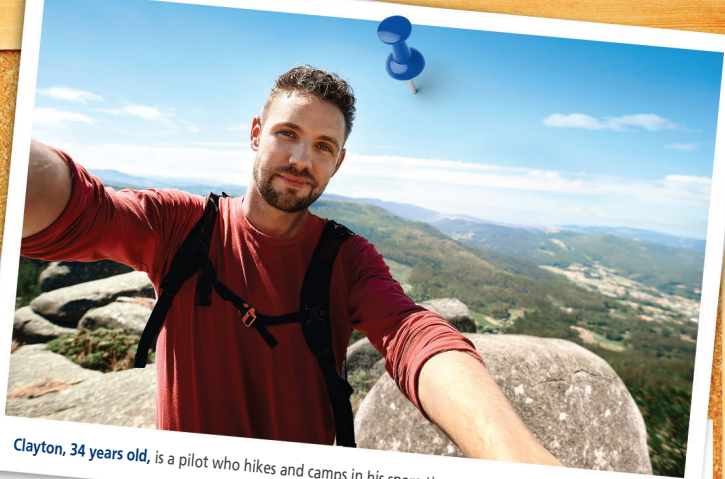
**[hfmich.org/donate](http://hfmich.org/donate)**



PAID CONSUMER OUTREACH

In hemophilia B

# TAKE CONTROL TO A HIGH LEVEL WITH REBINYN®



Clayton, 34 years old, is a pilot who hikes and camps in his spare time. Clayton lives with hemophilia B.

Rebiny® elevates factor levels above normal levels<sup>a</sup>

**+94%** Factor IX (FIX) levels achieved  
immediately after an infusion<sup>b</sup>

**17%** FIX levels sustained  
after 7 days<sup>a</sup>

With a single dose of Rebiny® 40 IU/kg in adults with  $\leq 2\%$  FIX levels<sup>a</sup>

<sup>a</sup>In two phase 3 studies, factor levels were evaluated for 1 week after the first dose of Rebiny® 40 IU/kg. The average levels after 7 days were 16.8% in 6 adults, 14.6% in 3 adolescents, 10.9% in 13 children ages 7 to 12 years, and 8.4% in 12 children up to age 6 years.

Image of hemophilia B patient shown is for illustrative purposes only.

<sup>b</sup>Based upon a 2.34% increase in factor levels per IU/kg infused in adults.

## INDICATIONS AND USAGE

### What is Rebiny® Coagulation Factor IX (Recombinant), GlycoPEGylated?

Rebiny® is an injectable medicine used to replace clotting Factor IX that is missing in patients with hemophilia B. Rebiny® is used to treat and control bleeding in people with hemophilia B. Your healthcare provider may give you Rebiny® when you have surgery. Rebiny® is not used for routine prophylaxis or for immune tolerance therapy.

## IMPORTANT SAFETY INFORMATION

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

- **Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center.** Carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing Rebiny®.

### Who should not use Rebiny®?

Do not use Rebiny® if you:

- are allergic to Factor IX or any of the other ingredients of Rebiny®.
- are allergic to hamster proteins.

### What should I tell my health care provider before using Rebiny®?

Tell your health care provider if you:

- have or have had any medical conditions.
- take any medicines, including non-prescription medicines and dietary supplements.
- are nursing, pregnant, or plan to become pregnant.
- have been told you have inhibitors to Factor IX.

### How should I use Rebiny®?

- Rebiny® is given as an infusion into the vein.
- **Call your healthcare provider right away if your bleeding does not stop after taking Rebiny®.**
- Do not stop using Rebiny® without consulting your healthcare provider.

### What are the possible side effects of Rebiny®?

- **Common side effects include** swelling, pain, rash or redness at the location of the infusion, and itching.
- **Call your healthcare provider right away or get emergency treatment right away if you get any of the following signs of an allergic reaction:** hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.
- **Tell your healthcare provider about any side effect that bothers you or that does not go away.**
- Animals given repeat doses of Rebiny® showed Polyethylene Glycol (PEG) inside cells lining blood vessels in the choroid plexus, which makes the fluid that cushions the brain. The potential human implications of these animal tests are unknown.

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

Rebiny® is a prescription medication.

You are encouraged to report negative side effects of prescription drugs to the FDA.

Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.

**Learn more at [rebiny.com](http://rebiny.com)**



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

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**rebiny®**  
Coagulation Factor IX  
(Recombinant), GlycoPEGylated



# rebinyn®

## Coagulation Factor IX (Recombinant), GlycoPEGylated

### Brief Summary Information about: REBINYN® Coagulation Factor IX (Recombinant), GlycoPEGylated

#### Rx Only

This information is not comprehensive.

- Talk to your healthcare provider or pharmacist
- Visit [www.novo-pi.com/REBINYN.pdf](http://www.novo-pi.com/REBINYN.pdf) to obtain FDA-approved product labeling
- Call 1-844-REB-INYN

### Read the Patient Product Information and the Instructions For Use that come with REBINYN® 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 REBINYN® after reading this information, ask your healthcare provider.

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

#### 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 REBINYN® so that your treatment will work best for you.

#### What is REBINYN®?

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

REBINYN® is used to treat and control bleeding in people with hemophilia B.

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

REBINYN® is not used for routine prophylaxis or for immune tolerance therapy.

#### Who should not use REBINYN®?

You should not use REBINYN® if you

- are allergic to Factor IX or any of the other ingredients of REBINYN®
- 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 REBINYN® might not be right for you.

#### What should I tell my healthcare provider before I use REBINYN®?

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 IX.

#### How should I use REBINYN®?

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

REBINYN® is given as an infusion into the vein.

You may infuse REBINYN® 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 B learn to

infuse the medicine by themselves or with the help of a family member.

Your healthcare provider will tell you how much REBINYN® to use based on your weight, the severity of your hemophilia B, 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 REBINYN®.

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

#### Use in children

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

#### If you forget to use REBINYN®

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 REBINYN®

Do not stop using REBINYN® 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 REBINYN®?

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

#### What are the possible side effects of REBINYN®?

##### Common Side Effects Include:

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

##### Other Possible Side Effects:

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

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

You may be at an increased risk of forming blood clots in your body, especially if you have risk factors for developing blood clots. Call your healthcare provider if you have chest pain, difficulty breathing, leg tenderness or swelling.

Animals given repeat doses of REBINYN® showed Polyethylene Glycol (PEG) inside cells lining blood vessels in the choroid plexus, which makes the fluid that cushions the brain. The potential human implications of these animal tests are unknown.

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

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

Cap Color Indicator	Nominal Strength
Red	500 IU per vial
Green	1000 IU per vial
Yellow	2000 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 REBINYN®?

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

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

REBINYN® vials can be stored in the refrigerator (36-46°F [2°C-8°C]) for up to 24 months until the expiration date, or at room temperature (up to 86°F [30°C]) for a single period not more than 6 months.

If you choose to store REBINYN® at room temperature:

- Note the date that the product is removed from refrigeration on the box.
- The total time of storage at room temperature should not be more than 6 months. Do not return the product to the refrigerator.
- Do not use after 6 months from this date or the expiration date listed on the vial, whichever is earlier.

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

#### After Reconstitution:

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

The reconstituted REBINYN® should be used immediately.

If you cannot use the reconstituted REBINYN® immediately, it should be used within 4 hours when stored at or below 86°F (30°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 REBINYN® and hemophilia B?

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

#### More detailed information is available upon request.

Available by prescription only.

For more information about REBINYN®, please call Novo Nordisk at 1-844-REB-INYN.

Revised: 11/2017

REBINYN® 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

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For information about REBINYN® contact:  
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To view women's conference photos, go to  
[www.hfmich.org/beingvisible19](http://www.hfmich.org/beingvisible19)

# 2019 National Conference

## Being Visible: Hear our Voices

### Women with Hemophilia

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

*By Patrice Thomas*

#### States represented:

Alabama, Alaska, Arizona,  
Arkansas, California,  
Colorado, Connecticut,  
Florida, Georgia, Idaho,  
Illinois, Indiana, Iowa,  
Kansas, Kentucky,  
Louisiana, Maine, Maryland,  
Massachusetts, Michigan,  
Minnesota, Missouri,  
Montana, Nebraska,  
Nevada, New Hampshire,  
New Jersey, New Mexico,  
New York, Ohio, Oklahoma,  
Oregon, South Carolina,  
Tennessee, Texas,  
Virginia, Washington  
and Washington DC.

HFM hosted the 2nd annual National Conference for Women with Hemophilia at the Westin Detroit Metropolitan Airport hotel. We were so grateful to be able to increase attendance from 2018 by nearly 50%, with a total of 150 affected women attending! Attendees represented 37 states and the District of Columbia (listed to the left) and ranged in age from 14 to 74.

HFM's National Conference, Being Visible: Hear our Voices was developed to provide needed education and resources to an overlooked and underserved population of women in the bleeding disorders community—those with hemophilia. While many participants have been aware they are hemophilia carriers, only now are some being recognized as having hemophilia. HFM's hope is to build a community of trust, empowerment, and understanding for women as they share symptoms and experiences, and further their understanding and management of their disorders.

To help close the gap between patients' experiences and treatment, HFM brought

together an expert group of faculty to support women seeking to learn more about their disorder, from diagnosis to treatment, and to listen to the women's personal experiences. Hematologists and gynecologists spoke to the group about managing heavy periods, planning for high-risk pregnancies, and addressing potential health conditions such as muscle and joint bleeds and anemia. Breakout sessions on Saturday afternoon included topics about identifying and addressing joint issues, quality of life, depression and other psychosocial issues that may impact one's health.

At the final session, Shellye Horowitz, attendee, speaker, and bleeding disorders advocate, discussed the impact of attending the 2018 conference and the modifications she was empowered to make in her healthcare. After sharing her own post-conference actions, she invited other attendees to share action steps they can take in their own lives.

*See next page.*

**HFM's national conference could not have happened without the support of our sponsors.**

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**CSL Behring**



Special Thanks



HFM does not endorse any specific product or company.

Special thanks as well to Skinnytees for donating camisoles and gift bags





## Being Visible: Hear our Voices Women with Hemophilia

Go to the links below to view a short video from some of our attendees.



[www.hfmich.org/w19a](http://www.hfmich.org/w19a)



[www.hfmich.org/w19b](http://www.hfmich.org/w19b)



[www.hfmich.org/w19c](http://www.hfmich.org/w19c)



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[www.hfmich.org/w19s](http://www.hfmich.org/w19s)

“This conference means the world to me. It means I’m being heard and validated. Thanks for listening.”

~Conference Attendee

### ATTENDEES’ PLANS FOR AFTER THE CONFERENCE:

“I am going to track my bleeds.”

“Share the knowledge.”

“I want to advocate at the state level to ensure protections and coverage for women with hemophilia.”

“Work with my local chapter!”

“Give myself permission to feel exactly how I feel.”

“This conference has given me the knowledge and confidence to speak up and ask doctors for the test and treatment I need.”

“Request that MASAC appoints a female hemophilia representative.”

“I am motivated to look at my genetic results from the My Life Our Future study.”

“I am armed with the knowledge that I deserve treatment!”

“The conference last year allowed me to approach my clinic in a new way. I went to a new clinic, armed with the knowledge I learned at the conference last year.”

“I want to build a relationship with my HTC to create a proper treatment plan.”

“I want to thank and appreciate those who support us as women with hemophilia.”

“I am going to communicate more often and document my bleeds.”

“After making changes as a result of last year’s conference, I am getting things back in my life that feed my soul. I am healthier. I am not in pain all the time.”

“I will start monitoring my bleeds. I am going to do that for myself and tell my sister to do that too.”

“With conferences like this we are going to partner with physicians to change the paradigm that only men have hemophilia.”

“Ask for prophylaxis! It’s worth fighting for and improved my life.”

“I dealt with a severe joint bleed this year that caught my attention. I can now identify other bleeds across my life that were more subtle.”

“I’ve learned that physicians want to help.”

“My HTC told me, ‘We agree. You shouldn’t be bleeding this often. We want you to start a prophylaxis trial.’ All of this couldn’t have happened without the information I learned at last year’s conference.”

“Both my daughter and I are going to set up appointments with our treatment center and get a care plan.”

**We look forward to gathering this empowered group of women again in 2020.**





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By Anthony Stevens

Old friendships renewed and new friendships formed, Old Beagle 2019 was the incubator for both. Pioneer Trails came back alive with the sounds of children playing, splashing, and enjoying nature. Bold Eagle alumni spanning several decades joined together this year and exchanged many fond memories of the past. Fish were caught, canoe trips were taken, and two beautiful sunsets were witnessed. The weekend started out with a scavenger hunt around the campgrounds and ended with a last minute dip in Big Blue Lake to finish off a wonderful weekend.

September 13-15, 2019

# Old Beagle Weekend

PAID CONSUMER OUTREACH

**NUWIQ®**

Antihemophilic Factor  
(Recombinant)



**For more information, contact your  
Octapharma Representative:**

**Chad Andersen**

Phone | 210.394.7694

E-mail | [Chad.Andersen@octapharma.com](mailto:Chad.Andersen@octapharma.com)

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Date of preparation: 4/2019. NUW-0212-CAD

**octapharma**  
For the safe and optimal use of human proteins



# Bleeder and a Buddy Teen Retreat

October 11-13, 2019

*By Anthony Stevens*

HFM's Bleeder and a Buddy welcomed the teens back to the Fifth Third Ballpark to assist in the Unite for Bleeding Disorders Walk in Grand Rapids. The teens enjoyed an opportunity to give back while sharing the experience and what life's like for people with bleeding disorders – with their closest friends. Their time at the ballpark was both fun and rewarding and their Saturday night activity was no different. This year the teens had the task of memorizing a dessert pie recipe in 10 minutes. That may seem challenging enough, but they had one more curve ball thrown their way, they would also be wearing blindfolds while making the desserts. Needless to say, the adult participants enjoyed the ensuing mayhem. The pies turned out exactly as you would imagine.

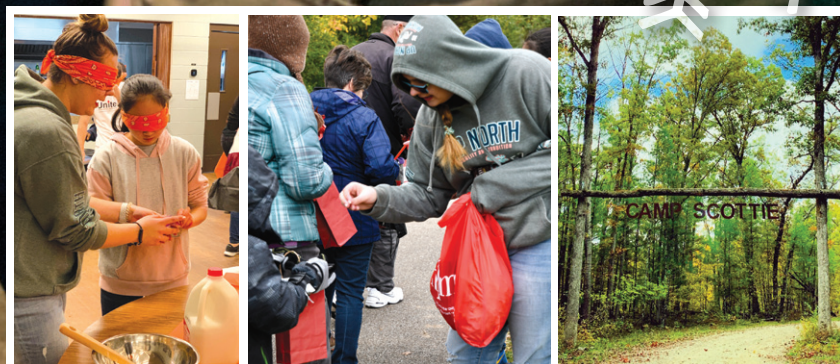
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AND A BUDDY SPONSORS

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*A Member of the Roche Group*

**SANOFI GENZYME** 

**Pfizer Hemophilia**

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HFM is grateful to the following companies who partially sponsored  
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HAPPY CAMPER



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## Health, Wellness, and Connection Between Women

By Shari Luckey

On a beautiful weekend in September, 24 women soaked in some comfort at The H Hotel in Midland. We spent the weekend focusing on overall health, wellness, and connection.

On Saturday, HFM's YpsilantiMI Days for Girls Team shared a presentation about the important work the team is doing for woman in bleeding disorders communities around the world. The creation of reusable menstrual hygiene products in Michigan is truly making an impact for women around the world. Afterwards, we all enjoyed participating in the session *The Science of Connection* and we came away with great information. We rounded out our Saturday creating special cases out of cigar boxes and then dinner at the local favorite restaurant, Annabelle's Own.

Sunday was another packed day as we learned how dental hygiene can affect our overall health, followed by an overview of joint health through the lifecycle. Our cherry on top of the weekend was a guided tour of the Whiting Forest Canopy Walk, the largest elevated canopy walk in the US. We could not have asked for better weather or a more superior tour guide. We learned, laughed, connected, and enjoyed the great outdoors.

We thank our sponsors that helped to make this weekend possible. We look forward to seeing everyone again next year along with some new faces.

To view women's retreat photos, go to  
[www.hfmich.org/womensretreatphotos19](http://www.hfmich.org/womensretreatphotos19)

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**LET'S GO**





# What is Yoga and Why Do People Keep Telling You to Try It?

By Sarah Procario, RYT 200

## What does yoga mean to you? How would you define it? What comes to mind?

It may be challenging for many of us to form a concise definition of yoga. In fact, there is no ONE definition of yoga; rather there are several widely used definitions and understandings of the practice. The Sanskrit word yoga is literally translated as to “yoke” or “unite,” often interpreted as the union of the self with one’s higher (better) self. Patanjali, the author of the Yoga Sutras, defined yoga as “the cessation of the fluctuations of the mind”— i.e. calming our minds. Others define yoga as any practice that allows one to bring greater awareness to the self.

But how do these definitions relate to the yoga we see practiced in the US today? Since the beginnings of yoga were developed in India over 5,000 years ago, it is no surprise that we have seen large transformations in how it is practiced and which aspects of the practice are emphasized. However, as the teachings have been passed from teacher to student, a focus on spiritual development practices and mental fitness has remained. These practices work to train the body and mind to self observe and become aware of our own nature; typically involving philosophy and

readings, postures, breath control, concentration, and meditation. In simpler words, yoga is a mind-body practice.

Today, many different types of yoga are practiced around the world, including bhakti yoga (yoga of devotion), karma yoga (yoga through action), and jnana yoga (yoga of self study)-none of which are physical practices. In the west, most individuals practice hatha yoga, which focuses on asana (postures) to build strength and stamina to prepare the body for long periods of meditation. Hatha yoga has been further broken down into styles such as Vinyasa, Power, Bikram, and more!

**So, why do people keep telling you to do it?** Because people have experienced a variety of physical and mental benefits!

For individuals affected by bleeding disorders who deal with pain, joint issues, and stress associated with living with a chronic disorder, yoga may provide an alternative or additional way to find relief. Hatha yoga offers benefits such as increased flexibility, muscle tone, balance, and improved respiration. For

individuals in the bleeding disorders community, yoga may help strengthen muscles to support joints and improve mobility. Yoga’s emphasis on mindfulness, breath control, and self-study can lead to reduced stress, improved mood, and a better body image. New research is even showing the ability for yoga to relieve chronic pain.

In the end, yoga is a practice that can be modified, altered, and transformed into the practice that best supports you and your life. And if yoga is not the practice for you, there are many other practices, activities, and philosophies that may enhance your wellbeing and quality of life.

“Yoga does not adhere to any particular religion, belief system or community; it has always been approached as a technology for inner wellbeing.”

~Dr. Ishwar V. Basavaraddi

**Check with your physician to make sure yoga is right for you.**



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**Sunday, 2:15 pm**

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Marcy, von Willebrand disease



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[bleedingdisorders.com](http://bleedingdisorders.com)

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

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# Advocacy and Health Policy Summit: Looking Forward

By Sarah Procario

On November 25, 2019 HFM was pleased to host our fourth annual Advocacy Summit in Ann Arbor, Michigan. The Summit is intended to gather a variety of stakeholders familiar with legislative, health, and advocacy policy, who can lend their voice to local and national issues impacting the bleeding disorders community. The information gathered is used to target advocacy priorities for the coming year.

Over the past four years, HFM has dedicated time and resources to expand our advocacy program throughout the state and is happy to see the growth in our Summit, which has become a strong and valuable aspect of HFM's advocacy program.

This year, HFM was joined by representatives from the National Hemophilia Foundation, The Bonnell Foundation, the Health Can't Wait Coalition, the Hemophilia Alliance, staff from several of our local Hemophilia Treatment centers, industry government affairs specialists, and two of our lead community advocates.

The event focused on identifying current health policy that may impact the bleeding disorders community. Topics included Medicaid policy trends, cost management strategies introduced by insurance companies, and the coverage of emerging high-cost therapies.

The variety of attendees who participate in HFM's Summit allows for important information sharing and discussion. When we work as one voice, as one community, we are able to make a much larger impact. Thank you to our attendees for lending their voice and a very special thank you to our event sponsor, Genentech. We look forward to hosting our fifth annual Summit again in November 2020.

**SPECIAL THANKS TO OUR ADVOCACY AND HEALTH POLICY SUMMIT SPONSOR**

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to join our  
advocacy efforts!**

If you are interested  
in participating with  
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efforts on a higher  
level, please contact  
Sarah Procario at  
[sprocario@hfmich.org](mailto:sprocario@hfmich.org).

## SpringFest 2020

**April 3-5, 2020 Amway Grand Hotel** | Grand Rapids, Michigan

SpringFest is HFM's largest annual family educational conference. It is open to Michigan individuals with a bleeding disorder and their immediate family. This amazing weekend includes educational sessions, networking opportunities, children's programming, infant care, and opportunities for fun and celebration!

This year marks our first-ever west side SpringFest! Join us **April 3-5, 2020 at the Amway Grand Hotel. Registration opens February 5, 2020.** Stay tuned to [www.hfmich.org/springfest2020](http://www.hfmich.org/springfest2020) as more information about the weekend becomes available.

Interested in **volunteering** for SpringFest? Please reach out to Carrie McCulloch at: 734.544.0015 ext. 503 (Grand Rapids Office) or at [cmcculloch@hfmich.org](mailto:cmcculloch@hfmich.org).

**NEW LOCATION!**

Registration opens  
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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**.



**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)
– weakness	– or back pain
– swelling of arms and legs	– nausea or vomiting
– yellowing of skin and eyes	– 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	– 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.

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For more information, go to [www.HEMLIBRA.com](http://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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*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*

# Dental Facts: Did You Know?

*By Jennifer Kerns, BS, RDH*

Mouth guards are an important part of injury prevention during physical activity. When kids fall, get hit, or bump their mouth, we worry about permanent damage to the smile—teeth can get pushed in, knocked out, chipped, or cracked. But for those with bleeding disorders, we also worry about bleeds. To prevent unnecessary bleeds and dental office visits, think about purchasing a mouth guard. For a few hundred dollars, you can have one made at a dental office or you can get one at your local pharmacy/sports store; the difference between the two is fit. A professionally fit mouth guard is custom made to protect the jaw joint (it will need to be re-made as the teeth grow and the mouth changes size and shape). For a less expensive option, over the counter mouth guards can be boiled to become pliable and then cooled in the mouth for proper fit, but will need to be thrown out when it's no longer accurate. Until children's mouths become permanently shaped, store bought mouth guards generally provide adequate protection. Once they are older the custom made guards are recommended to help keep the bite in proper alignment to protect from improper stress on the jaw joint.

To determine the best mouth guard for you or your child, see your dental professional.

## HFM Community Nights

HFM is grateful to the following companies who partially sponsored HFM's Community Nights in Traverse City

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HFM is grateful to the following companies who partially sponsored HFM's Community Nights in Lansing

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There was no shortage of fun and education at the Traverse City and Lansing Community nights this year! Community members joined us at the top of the mitten and the middle for a chance to socialize, connect, and enjoy some time together. These nights were meaningful, and we are so grateful to everyone that came. Thank you!



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**Photo from left to right:**  
David Rushlow, LMSW, Program Manager and Social Worker; Stephanie Roessler, Research Coordinator and Program Manager; Kathi Sheldon, RN-C, Nurse Coordinator; Rebecca Asper, RN Research Nurse; Not pictured: Medical Director, Kristian Koller, DO; Susan Wischman, Data Entry Tech

# Center of Care

## The Northern Regional Bleeding Disorder Center

### Where is your HTC located?

The Northern Regional Bleeding Disorder Center is located at Munson Medical Center in Traverse City, MI.

### What is your catchment area?

We serve 26 counties including providing services in St. Ignace.

### Do you serve pediatric or adult patients or are you a lifespan center?

Lifespan. We manage pediatric patients in collaboration with Helen DeVos Children's Hospital. Dr. Deanna Mitchell is our pediatric medical director. There is no set age when patients transfer to our adult hematologist, though most transition after college. Every young adult is different and it depends on the level of medical needs they require.

### How long has your HTC operated or when did it open?

Our center formally opened in 1986, however Michigan State University began a field clinic at our hospital several years before we opened. We are thankful for their passion and commitment in obtaining funding to establish our HTC. (Sue Adkins, BSN, RN, HFM Regional Core Center Specialist, used to be the nurse here for the field clinics!)

### Do you have any specialty clinics, outreach clinics, or programs that you would like to highlight?

We have monthly adult comprehensive clinics, biweekly clinics with our

hematologist, and a yearly pediatric clinic with hematologists who travel to Traverse City to see the kids who live in our region. We attempt to have a few family fun days each year; we've visited a corn maze, attended a baseball game, and played putt putt. We hope to have a "Movie Saturday" this coming winter at a local theater.

### Do you have any new staff members?

Dr. Kristian Koller has served as the HTC's Medical Director for more than one year. He is Board Certified in hematology and oncology. He completed his fellowship at Penn State and rotated through Penn's Hemophilia Treatment Center which inspired his interest in Traverse City's HTC.

Kathi Sheldon is our nurse coordinator and has been with our program for two years. She has over thirty years experience working in Ob/Maternity. Kathi came to an educational dinner on bleeding disorders and when the speaker asked if anyone was interested in knowing more about Camp Bold Eagle, Kathi raised her hand and ended up volunteering. Kathi states for some reason she can't explain, she felt drawn to bleeding disorders and is now our coordinator. She brings passion and enthusiasm to her new role and has quickly become an integral part of our team.

### What do you see as your biggest strength as a center?

We are a smaller center serving the lifespan, which has given us the privilege to work with many of our patients for over 27 years. We have incredibly skilled nurses who can infuse patients like no one else and therefore, we encourage our consumers who need infusions to come to our center and bypass the infusion clinic and emergency department. We pride ourselves in providing state of the art medical treatment, home visits, school visits, case management, and counseling. We are involved in research and will also refer candidates to larger centers so they can participate in the latest trials.

### What inspires your staff?

It is absolutely our patients and families. Being able to participate in their bleeding disorder care is a privilege and a wonderful partnership.

### Are you Sparty fans or Wolverine fans?

Unfortunately we can't all be fans of the only school that matters—and I am sure you know which one that is!

**The Northern Regional Bleeding Disorder Center at Munson Medical Center**  
1105 Sixth Traverse City, MI 49684  
Phone: 231.935.7227  
Adult After Hours: 231.935.5000



# Let's get together to talk about IXINITY®

Partnering with patients living with a rare disease is an honor for me. Individuals in the bleeding disorders community inspire me with their resilience and commitment.

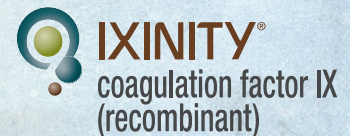
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► Contact Megan at 810-614-5292 or [langm@apvo.com](mailto:langm@apvo.com)



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## hfm End of the Year Community Gathering

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To view photos, go to  
[www.hfmich.org/holidayparty19](http://www.hfmich.org/holidayparty19)

Special thanks to Project LEAD from Troy High School for hosting our community again!

We are also grateful to community member Antonio Jenkins for filling in for Santa!

Additionally, we are grateful to the many individuals and companies who generously donated toys for the children in our diverse community.







SPECIAL THANKS TO OUR  
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*By Anthony Stevens*

HFM began the **LAUNCH Vocational Job Training Assistance Program** in 2019 to provide unemployed and underemployed individuals with hemophilia support as they pursue academic completion, certification training, and improved job placement. National research has shown that young men with hemophilia are less likely to have completed high school compared to the general population and that the unemployment rate for men ages 18-34 with hemophilia is 19%.

Our goal is to reduce the number of unemployed and underemployed men with hemophilia in our community and to help place participants in jobs that are more conducive to financial stability and provide a better quality of life.

Through the LAUNCH program, individuals work with the HFM Educational Services Manager to assess their current

academic and employment needs and through practical and supportive services, work to complete degrees or certification programs as well as procure employment.

At the moment, participants are completing certification programs in the following areas: information technology, pharmacy technician, and phlebotomy. Additional individuals have participated in the career workshop programs we have held, creating updated resumes and cover letters and learning insights about job application processes.

We are inspired by the dedication our current participants have exhibited and hope to serve more individuals in 2020!

**To learn more about LAUNCH, contact Anthony Stevens at [astevens@hfmich.org](mailto:astevens@hfmich.org).**



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S51573 10/19





# Highlights from Michigan's Unite for Bleeding Disorders Walks

By Carrie McCulloch

I am filled with gratitude for the hundreds of walkers that joined us at the Detroit Zoo and Fifth Third Ballpark. These events provide meaningful support for HFM programming, but are also a wonderful way to reconnect with the community, and to introduce family and friends to the HFM mission.

## Some of my favorite (and fun) highlights of 2019!

- Mikey's Minions and Jacey's Crazies both celebrated 10 years of being a walk team! Congratulations!
- Pre-event fundraising! Krystal Minton hosted a spaghetti dinner and Rebecca Godin committed to hosting one fundraiser each month throughout the year to help her hit her goal.
- Speaking of Rebecca Godin: She did a wonderful job as Detroit walk chair!
- New walk program booklets that shared information and inspiring stories.
- Can you say "treats?" Ice cream at the zoo, and Halloween candy in Grand Rapids means that everyone left the walks with their sugar fix. (Sorry, parents!)
- Mark Javorka, father of Daphne, really put his head on the line to support his daughter. Literally! Mark volunteered to shave his head if his friends and family donated \$500 to the Grand Rapids walk.

- Our Bleeder & a Buddy teens! They handed out candy during the trick or treating in Grand Rapids and volunteered in the Kid Zone helping children decorate pumpkins, play games, and walk away with trinkets and prizes.
- Awarding fundraising prizes on-site. Did you see those Unite hats!?
- Team Captains: As always, you bring the spirit, joy, and can-do attitude to the walk.

Each walk happens just one morning a year, but their impact is felt year-round. If you, or someone you care about, have ever attended an HFM program or received an HFM service, they were able to do so because of the community members that fundraise and walk each year.

## Please plan to join us for the fun again next year

- August 23rd at the Detroit Zoo
  - Stay tuned for Grand Rapids info
- It just won't be the same without you!**

To view walk photos go to:

[www.hfmich.org/unitegrphotos19](http://www.hfmich.org/unitegrphotos19)  
[www.hfmich.org/unitedetroitphotos19](http://www.hfmich.org/unitedetroitphotos19)

**Thank you to our National Sponsors and partners (for both walks)**

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*The hemophilia treatments  
of today were once  
the dreams of yesterday.  
Proof that when*

## SCIENCE AND THE COMMUNITY

*come together, great things happen.*

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[GenentechHemophilia.com](http://GenentechHemophilia.com)

*Let's put science to work*

HTCs recognize that bleeding disorders are chronic and lifelong, that is why we strive to help our patients in all aspects of their lives.



# We Are Here to Help

*By Annie Phillips, LMSW*

It's a Wednesday afternoon and a team made up of a doctor, nurses, physical therapist, social worker, dental hygienist and a psychologist are meeting in a conference room, and collaborating on how they can meet all of their patients needs. Soon, 5-6 patients will be arriving for their yearly comprehensive clinic exam. The Hemophilia Treatment Center (HTC) staff is ensuring that all of the patient's individual medical and psychosocial issues are addressed and taken care of to the best of their ability.

A nationally recognized HTC must follow the Comprehensive Care model, which provides access to a multidisciplinary team of healthcare professionals. This team strives to emphasize prevention services to help and reduce complications in all aspects of the patient's life.

HTCs are proven to improve the patient's health. **A CDC study has shown that people with hemophilia who were followed by a HTC were 40% less likely to die from hemophilia-related complications, compared to those who did not seek care at an HTC.** They were also 40% less likely to be hospitalized for bleeding complications.

In addition to providing hematological care, the team at your HTC typically works with your primary care physician/pediatrician, dentist, and any other specialists to assure that all of your other providers are educated to provide the best care possible.

HTCs recognize that bleeding disorders are chronic and lifelong, that is why we strive to help our patients in all aspects of their lives. Most HTCs also assist with practical life matters like meeting with the schools, home visits, insurance/financial issues, mental health needs, and job searching. HTCs also collaborate with multiple community organizations in the area to assist with access to resources. One of the most important community partners that Hemophilia Treatment Centers usually have is their local chapter. The Children's Hospital of Michigan Hemostasis and Thrombosis Center is lucky to have the Hemophilia Foundation of Michigan (HFM) located in our state. They do a wonderful job collaborating with the staff at HTCs to extend the patient's care outside of the hospital. HFM provides many programs including camp, community support events, and emergency financial

assistance, dental insurance, and much more.

HTCs are also very highly focused on research. The Center at Children's Hospital of Michigan always has ongoing research that our patients participate in. This is very important to the bleeding disorder community because the technology and innovation of treatment would not be possible without this research and our wonderful patients participating in it.

HTCs are compassionate, comprehensive, innovative and so much more. HTCs don't just treat people with bleeding disorders; they empower them and provide them with tools to navigate difficult life situations. Living with a chronic illness is challenging and we are here to help!

**For a listing of Michigan, Indiana and Ohio HTCs, go to [hfmich.org/treatment-centers/](http://hfmich.org/treatment-centers/)**



## HFM Events/ Activities 2020

**March 6-8**  
**Teen Retreat**  
Location TBD

**April 3-5**  
**SpringFest**  
Amway Grand Plaza Hotel  
Grand Rapids

**May 7**  
**Butterfly Benefit**  
The Grand Rapids Art Museum  
Grand Rapids

**May 19-20**  
**Lansing Days**  
The Kellogg Hotel and Conference  
Center, East Lansing

**June 6**  
**VWD Education Day  
and Symposium**  
SE Michigan

**August 23**  
**Unite for Bleeding Disorders  
Walk-Detroit**  
Detroit Zoo, Royal Oak

**Fall TBD**  
**Unite for Bleeding Disorders  
Walk-Grand Rapids**  
Location TBD

**Fall TBD**  
**Upper Peninsula  
Education Weekend**  
Marquette

**Fall TBD**  
**Bleeder & a Buddy**  
Location TBD

**Fall TBD**  
**Old Beagle**  
Pioneer Trails

**September 12-13**  
**Women's Retreat**  
Location TBD

**October 9-11**  
**National Conference for  
Women with Hemophilia**  
Westin, Detroit Metropolitan Airport

**November TBD**  
**Advocacy Summit**  
SE Michigan

**December TBD**  
**End of the Year Community  
Gathering (aka holiday party)**  
Troy High School, Troy



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[www.hfmich.org](http://www.hfmich.org)

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To learn more, go to [www.hfmich.org/camp](http://www.hfmich.org/camp)

## 2020 Camp Dates

Registration opens February 1, 2020

**June 6-12**  
**Eagle Quest**  
(Ages 18+)

**June 28-July 4**  
**CBE Teen Camp**  
(Ages 13-17)

**July 6-25**  
**CIT Program**

**July 12-16**  
**CBE Session One**  
(Ages 6-9)

**July 18-24**  
**CBE Session Two**  
(Ages 10-12)

**July 28-August 6**  
**Eagle Expedition**  
(Ages 16+)

**August 9-15**  
**Eagle Outpost**  
(Ages 14-15)



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