

the artery

Serving Michigan's bleeding disorders community

Winter 2017/2018



hfm®

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



**Nearly 100 community
members attended HFM's
Butterfly Breakfast at the
Cider Mill! pg. 20**

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

We Are Community, We Are Family!

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*Susan Fenters Lerch, HFM
Executive Director, at HFM's
Butterfly Breakfast at the
Cider Mill in November.*



Dear HFM family and friends,

This is the time of year when many of us reflect on both the struggles and blessings we've faced as the year comes to a close.

My hope is that you have found comfort, friendship, and support - together with educational programming, access to up-to-date information, enhanced advocacy efforts and a variety of learning opportunities - as well as comradery and understanding with HFM. We exist to enhance the quality of life for individuals and loved ones impacted by bleeding disorders and as we look toward the new year, there are incredible advances in care now available with more on the horizon.

Yet, as always in life, challenges remain and opportunities exist to further our efforts and services. With the advent of new treatments and new pharmaceuticals there come questions of available funds from long-term partners as resources are adjusted.

To continue to provide excellent education and services we must find new ways to support HFM chapter programs.

I am delighted that we have grown community involvement and participation with education, conferences and retreats, legislative advocacy, summer camp programs, our walks and benefits. Many community members have evaluated these programs as priorities in their lives. We hope that you will as well by making a donation to HFM. **Your financial gift will help ensure that these programs are available to everyone in the community.** You may wish to make a year-end gift to honor a loved one or to acknowledge someone who has made a difference to you or your family this past year. As you reflect on both the challenges and blessings in life please consider how you would like to recognize what HFM means to you and your loved ones.

Wishing you and yours a beautiful holiday season,

Susan Fenters Lerch
Executive Director -
Great Lakes Region V-E Treatment
Center Network Director



We are grateful to everyone who supports HFM. On pages 3 and 4 of this issue, we have listed, with our gratitude, our 2016 members, along with donors who have given \$100 or more. We'll be sharing our 2017 member and donor list in our Spring issue and hope you'll be a part of it. Thank you!

PAID CONSUMER OUTREACH INCLUDED IN THIS NEWSLETTER.

With gratitude



HFM Members & Donors - 2016

HFM invites you to join us in our work as a dues-paying member. Members help direct the work of HFM by actively voting on important issues that affect the Michigan bleeding disorders community and by making an annual membership contribution. Lifetime members make a sustaining financial contribution to ensure HFM's ongoing work. We are very appreciative of our 2016 annual members and are especially grateful for our lifetime members. Thank you.

2016 Annual Members

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Linda & James Wilson
Jessica Wolfe

Lifetime Members

Judith Andersen Berk & William Berk
Deanna Mitchell & Gary Rich
Laura & Bill Sparrow

If you would like to become a member, please contact Gwyn Hulswit at ghulswit@hfmich.org or 734.544.0015. All of your gifts – your time, your involvement and your financial contributions – are greatly appreciated.

Thank you to our individual financial donors. **This list represents contributions recorded from January 1, 2016 through December 31, 2016** outside of program or registration fees. HFM is grateful to our many supporters that make our community programs and services available.

We would like to acknowledge the following individuals and families who supported our efforts throughout the 2016 calendar year. **Please consider making a year-end donation to HFM in 2017. We would love to see you on next year's list, which will be published in our Spring 2018 Artery chapter newsletter.**



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HFM Donors - 2016 *With gratitude*

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Christina Zulick Kozub

Donors (under \$100)

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

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

We hope to see you **April 20-22**

SpringFest 2018

Ann Arbor Ypsilanti Marriott at EAGLE CREST, Ypsilanti



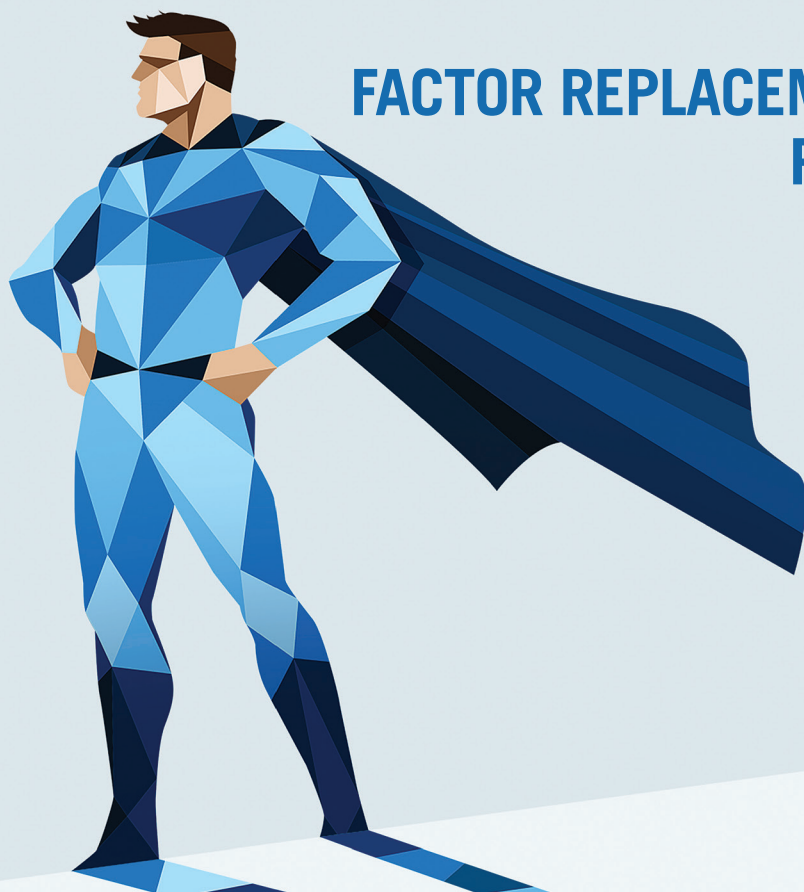
- Registration opens **March 1, 2018**
- Fun activities for children and teens!
- Special community talks on women's health issues & von Willebrand testing and treatment
- Update on medical treatment advances
- Roundtable and individual sessions
- Affinity/support groups & industry medical talks
- Celebratory evening activities
- Our HFM resource room will be expanded to a lounge this year!
- **More information will be coming your way in the new year!**

Holiday Greetings!

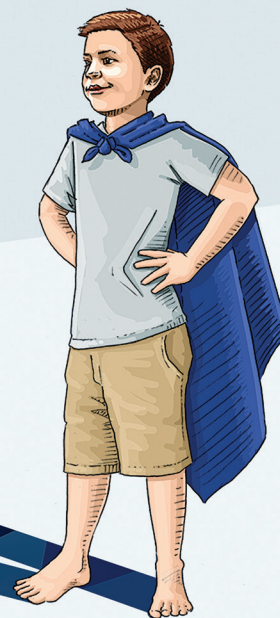
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WITH LOVE, FROM YOUR HFM FAMILY!





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References: **1.** Peyvandi F, Garagiola I, Young G. The past and future of haemophilia: diagnosis, treatments, and its complications. *Lancet*. 2016;388:187-197. **2.** Wolberg AS. Plasma and cellular contributions to fibrin network formation, structure and stability. *Haemophilia*. 2010;16(suppl 3):7-12. **3.** King MW. Introduction to blood coagulation. <http://themedicalbiochemistrypage.org/blood-coagulation.php>. Last modified January 2, 2017. Accessed January 2, 2017.

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HFM's Bleeder and a Buddy Weekend

October 20-22, 2017 *David Lattas*

A supportive cry of “You can do it” and “Keep up the good work” could be heard in the outdoor air as 26 teens gathered at Bair Lake Bible Camp in lower southwest Michigan for HFM’s annual Bleeder and a Buddy retreat. The teens kicked off their weekend by taking “Eagle Steps,” a camp term for stepping out of your comfort zone, with support from your peers. The teens tested their limits on a 200-foot zip line and by climbing and jumping off a 26-foot telephone pole (with a full body harness and belay rope).

Bleeder and a Buddy is a weekend retreat for teens with bleeding disorders ages 13-19, and one of their non-affected friends. Affected and unaffected teens participate in team building activities, practice leadership skills, eat plenty of good food, and enjoy quality time unplugged

from the usual day-to-day distractions. Most importantly, Bleeder and a Buddy focuses on education and personal advocacy.

Affected teens shared personal stories about living with a bleeding disorder. Many of the “buddies” knew their friends had a bleeding disorder, but learned much more about the unseen impact. With the help of Camp Director Tim Wicks and Treatment Center Nurse Jennifer Luitje, the teens discussed details of the individual disorders of the group and graphed the possible genetic possibilities of having a bleeding disorder.

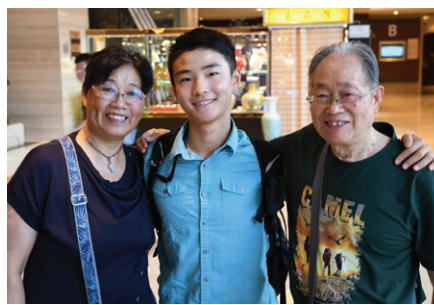
Saturday night the teens traveled to the 4-mile long Shipshewana Corn Maze. After enjoying an adventurous time finding special maze posts with a riddle game, the group warmed themselves around a campfire. All in all, it was a

great night and no one was lost in the maze! The teens then traveled back to the camp for the last night to share stories, play games, watch a movie, and eat more snacks.

Special thanks to Angela Bebee, Emily Albright and Jennifer Luitje for volunteering their time to support this weekend retreat.

**Special thanks to our
Team Building Sponsor**





Left: The Luckey Family in the ancient water town of Zhouzhuang. • Top right: The Luckey Family at the Great Wall of China • Bottom Left: Nai Nai, Luke, and Ye Ye. Foster grandparents. • Bottom right: Mama Li, Luke, and Ba Ba Ni; foster parents Luke lived with at 5 years of age.

Culture, Connections, and Consciousness

Shari Luckey

Our family had the life-changing opportunity to travel to China this summer and visit the homeland of our youngest son, Luke. We toured the popular attractions in Shanghai and Beijing, learning about the rich **culture** and history of the vast country that is home to over 1.35 billion people.

The primary focus of our trip was visiting Nanjing, where Luke spent the first nine years of his life. While there, we were privileged to **connect** with Luke's foster grandparents that have known him since he was 1½ years old and with whom he still keeps in touch. We also met his foster family that he had lived with when he was 5 years old. The care that he received from them, while he waited for us to find him, was such a gift. Sadly, most waiting children in China are not fortunate enough to have a foster family give them this personal love and attention.

We were permitted to visit the new Social Welfare Institute, a home for children awaiting adoptions, just completed a few weeks prior to our visit. It was amazing to meet the caregivers and tour the facility. While there, I was able to check on two waiting children,

whose parents are working diligently to bring them home. They were thrilled to receive updated pictures of their youngsters. During our visit it became apparent that the nannies truly care for the children they are responsible for and give the greatest attention possible. Despite this, these children still need the consistent love of a family and one-on-one attention from a parent to reach their fullest potential.

Amazingly, after almost 8 years, many of the caregivers still remembered Luke. They looked at him in wonder, seeing how tall he had grown, touching his arms and feeling his strength. Each one reached out to touch his right knee (a former target joint), which he would bend to show how it has healed. They were so happy to see how regular prophylactic treatment has changed his life in such a positive way.

They could see proof that children with hemophilia need to be made available for adoption as early as possible, to receive early medical treatment, not to mention the love of a permanent family.

Luke was also able to reconnect with an older friend, who regrettably aged out of the Social Welfare System at age 14, and could not be adopted. This young man, now 20, lives in the Adult Social Welfare Institute and has a full-time job washing dishes at a local hotel. While he is lucky to be able to work, he was unable to grow up with a family of his own.

Our trip to China was transformative for our entire family. We were able to reunite Luke with those that had loved him before we knew he was ours. We now have extended family in China that we will continue to keep in touch with. Furthermore, we are acutely **conscious** of how fortunate we are to live in a nation where our children with hemophilia can get the medical care they need to live happy, healthy, and productive lives. So many children do not have that basic benefit. There are too many children that wait in institutions for their forever families to find them and bring them home.

If you are considering adopting a child with hemophilia, please contact me at **sluckey@hfmich.org**.

Adoption Opportunities



ADRIAN

Adrian is 2 years old and diagnosed with severe Hemophilia A and post-op right parietal occipital craniotomy. A recent update confirms that Adrian is growing and making good progress. This sweet boy is already 31 ½ inches tall, weighs 24 pounds, and has 20 teeth! New videos show he has gained some gross motor function in his left arm. Although not potty trained yet, he can stand and is walking. His caregivers report that he is attending preschool in the orphanage and participates in parallel play with his peers. This wonderful boy deserves to have parents who will love him and give him every possible chance at making a full recovery as he learns and grows.



DEVIN

Devin is a 7 year old boy who likes to play and be creative. He loves to help and is one of the first kids to volunteer; he takes pride in assisting others. One of his favorite past times is being outdoors and jumping on the trampoline, riding his bike, and playing baseball. Devin is in need of a family of his very own.

We're
looking for
forever families!
IS THAT YOU?

For more information on hemophilia adoption opportunities, please contact HFM's Advocacy and Outreach Coordinator, Shari Luckey, at sluckey@hfmich.org.

Help us enhance HFM's programs & services!
Take HFM's community needs assessment survey
www.hfmich.org/communitysurvey

HFM Women's Retreat 2017

"I just want to thank everyone that worked on putting on the women's retreat this past weekend. I went as a woman with a bleeding disorder and it had been years since I was able to attend a retreat. It was truly a blessing to my mom and I to attend. I had so much fun and met new people and learned a thing or two, as well! Thank you and can't wait for next year's retreat!" ~ Shari Luckey

Special thanks to our wonderful presenters, Sue Geraghty, BSN, MBA; Sue Kovats-Bell, RN, BSN; Nayan Spangler, BSN, RN, CHC; Dr. Ruth Mulvaney, PT, DPT, MS; along with HFM's Lisa Clothier, LMSW, Outreach and Community Education Manager, and Patrice Thomas, MS, MSW, Program Services Director.



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Science matters. Because patients matter.TM

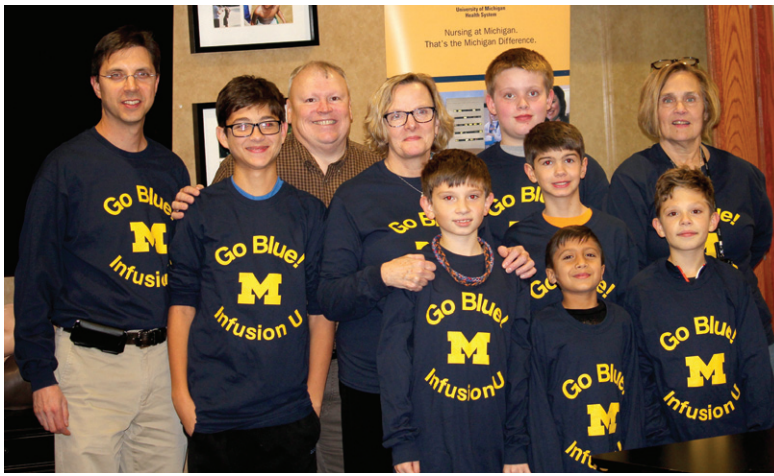
It's because of this belief that we:

Brought the leading extended half-life therapies to people with hemophilia—innovation that has changed the way hemophilia can be managed.

Sponsor free genetic testing for people with hemophilia and carriers through *My Life, Our Future*. Together with program co-founders the American Thrombosis and Hemostasis Network, Bloodworks Northwest, and the National Hemophilia Foundation, we are advancing disease understanding and research for the entire community.

Transformed humanitarian aid in hemophilia, with Sobi, by committing to donate up to one billion IUs of factor therapy over 10 years to help close the treatment gap in the developing world. More than 12,300 people have been treated through the WFH Humanitarian Aid Program, which is receiving 500 million IUs over five years.

We not only believe great science can conquer the toughest medical challenges, we live it every single day.



Photos © 2017 HFM

Kids Take a Poke at Self-Infusion



Self Infusion Program *Diana Mathis, RN*

Learning self-infusion requires a lot of supervised practice. Many children learn to self-infuse at Camp Bold Eagle with the support of dedicated HTC nurses. However, one week at camp does not offer enough opportunity to master the skill at home, returning to one's HTC to practice self-infusion often requires missing school or work.

Through a partnership with the Hemophilia Foundation of Michigan and funding from the Hemophilia Federation of America, The Go Blue Infusion U Program was created to provide further education about bleeding disorders and an opportunity to learn and practice self-infusion under the direction of HTC nurses.

The program involves a series of 6 weekly sessions held at the Hemophilia Foundation of Michigan. University of Michigan treatment center staff work one on one with children to foster independence. Sessions begin with

educational presentations, interactive discussion, repetition, and reinforcement of concepts throughout the program. Children are then given time to practice infusion techniques with the help of rubber dummy arms used to demonstrate and practice infusions. Children are encouraged to work at their own pace with encouragement to complete the learning objectives for each session. Skills learned in class are practiced at home during the week and built upon during the next session with the goal of gradual transfer of skills to a home environment.

Parents are invited to join the children during the very last session to discuss progress at home, problem solve, and address issues or concerns in addition to a final practice session.

Our experience has been overwhelmingly positive. Eight children, ages 7 to 14, enrolled in the program with skill sets ranging from no self-infusion experience at

home to having successfully done a few infusions by themselves. After four weeks in the program, all eight participants have been able to successfully infuse themselves at home! Carolyn, mother to one of our participants, shares how life changing the program has been to her family. "Alex has been adamant that he wasn't going to be able to do a self-infusion, and now wonders why we are making such a big deal about it. We are so proud!!

"Honestly, I thought it would be months to prepare him to transition him away from his port. But with the coaching and encouragement from HFM/UofM teams, and peers in the training – it has been remarkable, and really shocking! Self-infusion at home has made things so much easier. Self-infusing is more time efficient and comfortable and there is less anxiety about his port. Most of all, Alex is in control. It really is the best thing we have ever done! Cannot thank the program enough."

Hepatitis C: The virus you can cure

Dilip Moonka, MD

There has never been a better time to be treated for hepatitis C. With additional developments in the past few months, the extraordinary recent advances are worth reviewing. Medications can cure hepatitis C in almost all patient categories, they can do so with minimal side effects, and they are becoming increasingly affordable and available.

Until about 2013, the mainstay for hepatitis C treatment was interferon. This injected medication had significant side effects and limited efficacy. But in the past three years, we have seen the release of Harvoni and Viekira, and more recently, Zepatier and Epclusa. These medications consist of one, or a few, pills that can cure the hepatitis C virus in over 95% of individuals and in almost 100% of some patient populations.

The medications are also very well tolerated and allow treatment of almost all patient populations, including patients who were not able to tolerate interferon. In some cases, the medications have side effect profiles similar to a placebo, meaning very few patients have to discontinue the drugs that are typically taken for 12 weeks. While there are potential significant interactions with other medications, these interactions can be readily avoided or managed.

We are able to treat patients with depression and anxiety, those with liver cirrhosis, those with heart and lung problems and those with autoimmune diseases or who have had organ transplants. Zepatier, in particular, is safe and effective in those with advanced kidney disease, including those on dialysis. These medications are well tolerated in patients who are co-infected

with the HIV virus and hepatitis C and give cure rates equivalent to patients solely infected with hepatitis C.

As effective as these drugs are, we recently saw the release of two even more advanced drugs, Mavyret and Vosevi. Mavyret will allow a majority of patients to be treated with just eight weeks of therapy with very high cure rates while Vosevi is highly effective in the few patients who were not cured with the first generation of oral agents.

Importantly, with time and the release of more and more agents, the prices of these drugs have come down significantly and the drugs have become more readily available. Over a million people have been treated and over 95% have been cured.



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**A ONCE-WEEKLY SUBCUTANEOUS (GIVEN UNDER THE SKIN) INJECTION FOR
PEOPLE WITH HEMOPHILIA A WITH FACTOR VIII INHIBITORS**

We extend our appreciation to the individuals, families, and healthcare providers who participated in the clinical trials that led to the approval of HEMLIBRA®. We thank you and celebrate with the community who made it a reality.

Discover **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 with hemophilia A with factor VIII inhibitors.

WHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use. HEMLIBRA may cause the following serious side effects when used with 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 signs and symptoms of TMA during or after treatment with HEMLIBRA.
- **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 the signs or symptoms of blood clots during or after treatment with HEMLIBRA.

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.



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.

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 OTHER POSSIBLE SIDE EFFECTS OF HEMLIBRA?

The most common side effects of HEMLIBRA include: redness, tenderness, warmth, or itching at the site of injection; headache; and joint pain. These are not all of the possible side effects of HEMLIBRA.

You may report side effects to the FDA at (800) FDA-1088 or www.fda.gov/medwatch. You may also report side effects to Genentech at (888) 835-2555.

Please see Brief Summary of Medication Guide on the following page for more important safety information, including **Serious Side Effects**.

PAID CONSUMER OUTREACH

Medication Guide Brief Summary 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.

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HEMLIBRA may cause the following serious side effects when used with 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 with hemophilia A with 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.
- 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.
- 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 before the next scheduled dosing day and then continue with your normal weekly dosing schedule. Do not double your dose 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 7 days at 86°F (30°C) or below.
- 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

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

This Medication Guide has been approved by the U.S. Food and Drug Administration
Issued: 11/2017



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Mentoring Mondays Have Returned!

Torey Allen

Mentoring Mondays have returned, but with a new twist! With the generous support of a grant through the Hemophilia Alliance Foundation and a strong partnership with the Children's Hospital of Michigan, HFM has initiated a tutoring/mentoring program for a small group of school-aged children with bleeding disorders living in Detroit. The mentoring program began last school year, but has expanded and improved for the 2017-2018 school year.

Every week, a group of adult mentors who are living with bleeding disorders transport kids to the Detroit Medical Center campus. There, the participants prepare and eat dinner, exercise together, and then work with a mentor to complete homework or academic studies.

Additionally, the students look forward to upcoming special outings, which are designed to promote social connection and foster positive communication between the participants and the mentors. These outings may include playing laser tag, visiting the Detroit Institute of Arts, or checking out the Henry Ford Museum.

Last school year we saw positive outcomes for both students and mentors. The goals of the mentoring program are to support the children through improving their academic grades, expanding their social and emotional support systems, enhancing their participation, creating an increase in self-esteem, and providing additional information and knowledge of their bleeding disorder and appropriate self-care. Meeting once a week has led to improvements in the students' schoolwork. Beyond academics, the kids have developed deep relationships with one another and with their mentors.

We are encouraged by the excellent start to the mentoring program and hope for a positive school year working with the students!

Facts about **Bleeding Disorders** in Michigan

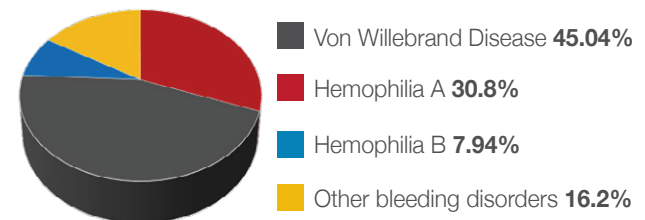
- 1 A bleeding disorder is a rare and complicated disorder in which the blood does not clot properly due to a missing protein called factor.
- 2 Symptoms include spontaneous bleeding into muscles, joints, and organs.
- 3 The most common types of bleeding disorders are hemophilia and von Willebrand Disease (VWD).

2,006 Total Number of Bleeding Disorder Patients seen at a Hemophilia Treatment Center (HTC) in Michigan*

**CDC estimates that 70% of patients are seen at HTCs.*

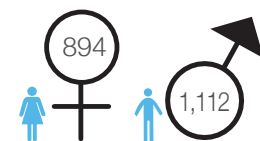
Michigan HTC Patients by Bleeding Disorder

Patients receive comprehensive care from medical experts at federally-funded treatment centers. Michigan is home to treatment centers located in Ann Arbor, Detroit, East Lansing, Flint, Grand Rapids, Kalamazoo, and Traverse City.

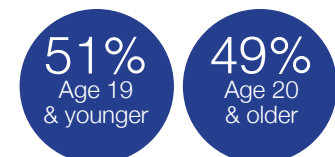


Ethnicity Affects all racial and ethnic groups equally.

Gender



Age



Treatment

Treatment varies by diagnosis. Most patients need to take an intravenous injection of clotting factor.

Average annual cost to treat hemophilia per patient. **\$250,000****

Data has been provided by the US Hemophilia Treatment Center Network, Hemophilia Data Set, 2016

***Data provided by Hemophilia Federation of America*

Cut here to create a bookmark

Michigan Bleeding Disorders

Advocacy

Get to Know Your Legislators

Help us to raise awareness of bleeding disorders and build relationships with local legislators by sharing your personal story. Go to www.hfmich.org/advocacy to see who represents you.

**Tell
your
story!**

- 1 Share the facts about bleeding disorders in Michigan.
- 2 Make it personal—share YOUR experience.
- 3 Be clear & concise—help them understand.
- 4 Follow up—write a thank-you email, send a letter, connect via social media, or participate in another meeting!



Nearly 100 community members attended HFM's 2017 Lansing Day event to share their story with legislators.



www.hfmich.org
734.544.0015

The Hemophilia Foundation of Michigan (HFM) is the only agency in the state that provides education, advocacy, and supportive services for those affected by bleeding disorders, including family members and caregivers, well over 4,000 individuals combined.

“Advocacy needs to be a basic part of life, especially when you are in the bleeding disorders community.”

~Michael Bradley

Taking Advocacy on Tour

Sarah Procario

As health reforms continue to be proposed at the state and national levels, legislative advocacy is more important than ever for the bleeding disorders community. Changes to health policy, insurance, costs, quality of coverage, prescription availability—and more—affect patients. If decisions are being made that will impact you, it is important to be a part of those discussions.

Over the past year, HFM has been travelling across the state to increase grassroots advocacy through “Community Night” gatherings. Community Nights are structured to educate and expand our outreach efforts so that patients and family members have the knowledge and tools to contact and educate their elected representatives.

The failure of attempts to repeal and replace the Affordable Care Act throughout 2017 is a prime example of the impact grassroots advocacy can have on the decisions being made about our health care. In March, May, July, and September, Congress attempted to make changes to the ACA with provisions that would have negatively affected our bleeding disorders community. Led by our national organizations, our community activated each time reforms were introduced. We made calls, attended town halls, and shared our stories across social media. Our voice was loud.

Interest in health reform remains high at the state and national levels. As members of the bleeding disorders community, as patients and caregivers, we need to be informed and engaged healthcare consumers. We need to share our stories with lawmakers to help them make informed decisions on health policies that may impact our community's access to quality and affordable health care at the state and national levels.

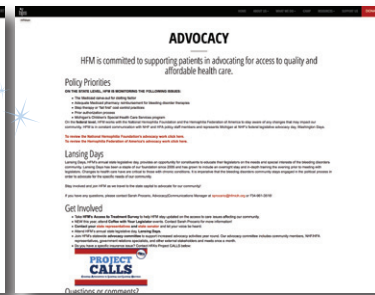
In 2017, more than 160 community members attended our Community Nights and received education and training on policy and advocacy issues. But we want YOU to get involved too.

- Find out who is representing you in Michigan and in DC.
- Call, write, tweet, and email your representatives.
- Attend a meeting or town hall and talk about the needs of the bleeding disorders community.
- Join HFM at our annual legislative advocacy event, Lansing Days, on May 22 and 23, 2018.
- Visit NHF, HFA, and HFM's websites for health policy updates.

We want you to continue reaching out. Like any relationship, our relationships with our legislators need attention. If an issue arises, HFM must be able to count on our Michigan community to activate.

Questions? Contact Sarah Procario at sprocario@hfmich.org or 734.961.3516.

Cut here to create a bookmark



Check out our new website – hfmich.org

Donated by the nonprofit group, GiveCamp.org

Sarah Procario

In September, HFM received a true gift! We were accepted to participate in GiveCamp—a weekend-long event where technology professionals, including designers, developers, and database administrators, donate their time to support non-profit organizations.

During the weekend of September 15, we went to work building a new website with our team of volunteer tech gurus in a small room at Washtenaw Community College. At times stressed, at times jovial, and at times a bit slap happy,

our team built out a new website for hfmich.org one page at a time. In addition to the technology expertise and design, GiveCamp provided meals, snacks, and pop to keep us energized from sun-up to the early hours of the morning. Our team generously worked around the clock to take the concept we had envisioned and ensure we would have a functional website. By midday Sunday, www.hfmich.org went live!

We could not have accomplished such a grand goal without the support and

generosity from GiveCamp and each member of our team. Our weekend with our team of volunteers was a true gift to the community! As the season of giving approaches, GiveCamp is a reminder of the many ways one can give by sharing their talents, time, and passion with community members in need.

We'll be adding information to the site over the next several months. Feel free to contact us with any suggestions.

Advocacy Summit

On November 20, HFM organized our annual Advocacy Summit to discuss bleeding disorders advocacy priorities in Michigan. HFM's advocacy committee, including NHF and HFA policy experts, government relations specialists, HTC staff members, and HFM community members, discussed policy issues impacting Michiganders affected by bleeding disorders.

Are you interested in participating on HFM's Advocacy Committee? **Contact Sarah Procario at sprocario@hfmich.org**



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To learn more about Delta Dental insurance, go to www.hfmich.org/dentalinsurance. If you have questions about the program or eligibility, contact Lisa Clothier, LMSW, Outreach and Community Education Manager at lclothier@hfmich.org or 734.961.3512.





Butterfly Breakfast at the Cider Mill

Gwyn Hulswit

The HFM community came together on November 4 at the Plymouth Orchards and Cider Mill to learn more about health care policy updates and advocacy efforts across the state. While enjoying donuts and cider, nearly 100 community members had the opportunity to meet with Representative Jeff Noble, State Representative of Michigan's 20th District, and to share their stories. As Rep. Noble explained, "Hemophilia is new to me and I need, we [other state legislators] all need, to understand your experiences."

Anya Luckey spoke to the group and not only discussed her own personal experiences educating lawmakers and but also explained how as a teen with a bleeding disorder, advocacy was a necessity. "A bleeding disorder is a part of my identity, and advocacy comes along with that." Rep. Noble emphasized Anya's call to action and encouraged those in attendance to become active participants in the legislative process. "It is imperative that you let your voices be heard. Often people don't understand that we need to hear from you. Share what is going on."

"A bleeding disorder is a part of my identity, and advocacy comes along with that."

~ Anya Luckey

Special thanks to our event sponsors

Bioverativ

Aptevo Therapeutics | CSL Behring | Octapharma

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



Photos ©2017 HFM

hfm End of the Year Community Gathering

Check out our holiday party photos at
hfmich.org/holiday17photos

SPECIAL THANKS TO OUR SPONSORS

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Community Nights: Bowling for Bleeders

Gwyn Hulswit

Special thanks to our
Lansing event sponsors

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Grifols
Novo Nordisk
Pfizer Hemophilia

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We loved seeing our bleeding disorders family this year in Canton, Traverse City, Grand Rapids, and most recently, Lansing. Throughout the year, more than 160 community members joined us for our Community Nights: Bowling for Bleeders.

Families and individuals came together to enjoy some friendly competition on the bowling lanes, share a meal, and learn more about how we all can best tell our stories, get to know our legislators, and advocate for the needs and interests of the bleeding disorders community.

We hope many of you will join us for Lansing Days in 2018 to continue raising awareness, sharing your stories, and building relationships with our local state representatives.

As we plan our 2018 Community Nights, we very much want to hear your thoughts. Love bowling? Interested in another activity? We want to hear from you. **Please email Carrie McCulloch at cmcculloch@hfmich.org and let us know.** We hope to see you next year!

Photos ©2017 HFM, Sarah Procaro



What are your ideas for HFM's 2018 Community Nights?
Please share your thoughts with Carrie McCulloch at cmcculloch@hfmich.org

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 **BAYER**
access solutions



**Don't let insurance or financial challenges
get between you and your treatment**

- **Free Trial Program***: Talk to your healthcare provider about requesting a free trial of KOVALTRY[®], Antihemophilic Factor (Recombinant), or KOGENATE[®] FS, Antihemophilic Factor (Recombinant), with Vial Adapter
- **Loyalty Program†**: Redeem points to receive KOVALTRY[®] or KOGENATE[®] FS at no cost if you experience gaps or challenges with insurance coverage
- **\$0 Co-pay Program‡**: You may be able to receive up to \$12,000 in assistance per year
- **Live Helpline Support**: Our experts are waiting to help you with any insurance coverage questions you may have

*The KOVALTRY[®] or KOGENATE[®] FS Free Trial Program is available to newly diagnosed patients and patients who are currently using other therapy. Patients currently using KOVALTRY[®] and KOGENATE[®] FS are not eligible for the Free Trial Program. Participation in the KOVALTRY[®] or KOGENATE[®] FS Free Trial Program is limited to 1 time only. The medication provided through this program is at no cost to patients and is not an obligation to purchase or use KOVALTRY[®] or KOGENATE[®] FS in the future. Reselling or billing any third party for the free product is prohibited by law.

†Patients who have government insurance (Medicaid, Medicare, Tricare, VA/DOD) are not eligible for the Loyalty Program. The program does not guarantee that patients will be successful in obtaining coverage for products. Support medication provided through Bayer's assistance programs is at no cost to patients and is not contingent on future KOVALTRY[®] or KOGENATE[®] FS prescriptions. Reselling or billing any third party for free product provided by Bayer's patient assistance programs is prohibited by law. Bayer reserves the right to determine eligibility, monitor participation, determine equitable distribution of product, and modify or discontinue the program at any time.

‡People with private, commercial health insurance may receive KOVALTRY[®] or KOGENATE[®] FS co-pay or co-insurance assistance based on eligibility requirements. The program is on a first-come, first-served basis. Financial support is available for up to 12 months. Eligible patients can re-enroll for additional 12-month courses. The program is not for patients receiving prescription coverage for product under any federal-, state-, or government-funded insurance programs, or where prohibited by law. All people who meet these criteria are encouraged to apply. Bayer reserves the right to discontinue the program at any time.



Call 1-800-288-8374

8:00 AM–8:00 PM (ET) Monday–Friday.
Spanish-speaking Case Specialists are also available.

Nine Year Old Takes Top Fundraising Award!

Carrie McCulloch

Walkin' West took place on Saturday, October 7th at the Fifth Third Ballpark. More than 145 walkers joined together to walk along the White Pine trail, but one in particular took home a special award that is now proudly displayed in her bedroom.

Introducing Kaytlyn Chisholm!

C: Kaytlyn, how old are you?

K: I'm 9 years old and I'm in 4th grade.

C: You won a special award at Walkin' on the West Side. Can you tell me what that was?

K: I was the Top Fundraiser.

C: Yes, you raised over \$1,000, which is so impressive! Can you tell me a little bit about how you and your family did it?

K: Once every year there is a fundraiser that my Aunt Krissa puts together, and we got all of the money from that. Family members donated too!

C: You walked at both Walkin' Wild at The Detroit Zoo, and Walkin' West at the Fifth Third Ballpark. What was your favorite part of each walk?

K: At the zoo I liked seeing my camp counselors at the walk. I also liked the hula hoops. I did at least 10 hula hoops at the same time! At the ballpark, I liked being able to see my cousins Maryssa, Taegan, and Carlee. We also ran one lap around the field and when we were done with that we got to go to the playground.

C: Kaytlyn, why do you think others should participate in a walk?

K: Because you help raise money for HFM and Camp Bold Eagle and because it's just fun.

C Anything else we should know?

K: I've been to Camp Bold Eagle for three years now! My favorite things to do are swimming and Gaga (a camp game).



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FRIENDS OF HFM



WALK FRIENDS



DJ Kelly Kel
Hypeman Enterprises LLC

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Save the dates for our 2018 Unite for Bleeding Disorders Walks

August 26, 2018
Detroit Zoo, Royal Oak

Fall 2018
Fifth Third Ballpark, Grand Rapids



2018 Events

April 20-22

SpringFest

Ann Arbor Ypsilanti Marriott
at EAGLE CREST, Ypsilanti
pthomas@hfmich.org

Spring TBA

Butterfly Benefit

Grand Rapids Art Museum (GRAM)
cmcculloch@hfmich.org

May 23-24

Lansing Days

Kellogg Center, East Lansing
sprocario@hfmich.org

June 4

Swinging for Smiles

Golf Outing

The Polo Fields-Washtenaw
Ypsilanti
cmcculloch@hfmich.org

June & July Camp Dates

See panel to the right.

August 26

Unite for Bleeding Disorders Walk

(Walkin' on the Wild Side)
Detroit Zoo, Royal Oak
cmcculloch@hfmich.org

September 14-16

Camp Old Beagle

Pioneer Trails
twicks@hfmich.org

Date TBA

HFM Women's Retreat

Location TBA
pthomas@hfmich.org

Date TBA

Unite for Bleeding Disorders Walk

(Walkin' on the West Side)
Fifth Third Ballpark, Grand Rapids
cmcculloch@hfmich.org

October 27-29

Bleeder and a Buddy

Location TBA
twicks@hfmich.org

**Stay tuned for
upcoming dates
for HFM's 2018**

Community Nights



734.544.0015

www.hfmich.org

1921 West Michigan Ave.
Ypsilanti, Michigan 48197

Camp Registration Opens February 1, 2018!

Questions about camp? Please contact
Tim Wicks or Torey Allen @ 734.544.0015

*Stay tuned to hfmich.org and HFM's facebook page
(www.hfmich.org/facebook) as dates may change.



June 2-8

2018 Eagle Quest
(Ages 18+)

June 17-23

2018 Eagle Outpost
(Ages 14-15)

July 1-7

2018 CBE Teen Camp
(Ages 13-17)

July 9-28

2018 CIT Program

July 11-14

2018 Camp Staff Training

July 15-19

2018 CBE Session One
(Ages 6-9)

July 21-27

2018 CBE Session Two
(Ages 10-12)

August 1-9

2018 Eagle Expedition
(Ages 16+)

September 14-16

2018 Camp Old Beagle
Pioneer Trails
18+ former campers and
staff and their families

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