

the artery

Serving Michigan's bleeding disorders community

Winter 2018/2019



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

hfm

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

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**HFM's first-ever
National Conference
for Women with
Hemophilia is an
amazing success!**

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We are all in this together



Susan Fenters Lerch,
HFM Executive
Director with
granddaughter
Margeaux Elise



Dear friends,

On behalf of HFM, please know how grateful we are to be a part of an extraordinary community of individuals with bleeding disorders, together with their families, physicians, friends, social workers, loved ones, nurses, caregivers, physical therapists, data managers, and all who care so deeply about those who are impacted by hemophilia, von Willebrand disease, and the many rare bleeding disorders that affect people in all aspects of their lives.

Recently, HFM hosted the first-ever weekend for women with hemophilia (often considered symptomatic carriers) with 100 women from across the United States. What an amazing experience to hear from these women and the many challenges they face! Our renowned volunteer speakers benefited from the opportunity to hear first-hand from affected women as well as sharing their medical perspectives and wisdom.

This is a very personal, yet shared, experience for women with hemophilia - the bonding and understanding that their challenging experiences were shared with others seemed to lighten spirits and provide a sense of camaraderie with one another. Though the experiences of women who are carriers vary greatly, there are many who experience significant personal health issues in addition to their experiences related to motherhood.

For me this is personal - I care deeply about all those affected by bleeding disorders and the devastation of Hepatitis C, HIV/AIDS, as well as the complications of arthritis and other issues.

Now I have my dear son-in-law and granddaughter who are directly impacted by hemophilia and as an obligate carrier, respectively. I am committed to each of you and most especially to our sweet Margeaux Elise as we move forward to enhance care and opportunities for all in our community.

We are all in this together, those directly affected and those who provide care and support. I wish you and yours a holiday season filled with light and love.

Blessings,

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



PAID CONSUMER OUTREACH INCLUDED IN THIS NEWSLETTER.

Hemophilia Adoption Program supported by HFM

With an open heart and a desire to help children across the world, HFM is working to help find forever homes for children with hemophilia.



Courtesy of Lindsey VanTiem Photography, with permission ©2018 Steven Miller

HFM Eagle Journeys Camping Programs Celebrates our 50th Anniversary in 2019!

As the oldest and largest camp program for children and young adults with bleeding disorders, the Spirit of the Bold Eagle continues to create transformative moments as friendship bonds are formed and campers learn how to live a life focused on possibilities rather than limitations.

Your support is imperative to continue HFM's educational programs and services.



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Medical Independence

HFM supports all the many ways individuals treat their bleeding disorder. Medical staff at camp and at infusion boot camps throughout the year provide guidance and encouragement for children and teens who self-infuse.



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HFM SpringFest

A weekend of celebration and education awaits the 650+ community members who come together with the HFM family to learn from national experts and from one another the joys and challenges of living with bleeding disorders.

HFM provides education, support, and services to individuals and families across Michigan with rare bleeding disorders. **We will be sharing our 2018 member and donor list in our upcoming Spring issue and hope you'll be part of it.** Thank you.

Your support creates smiles, milestones & connections!

This is the time of year where we reflect on the many gifts we have been given, and for the Hemophilia Foundation of Michigan, **we have much to be thankful for this year.** A record number of children and teens created friendships at camp and learned how to treat their bleeding disorders as we celebrated our 50th summer of camping programs. We continue to have one of the country's highest attended and most exciting annual consumer education weekends at SpringFest. We made great strides in educating our state decision makers on the needs of the bleeding disorders community. We even created and hosted the first national conference for women with hemophilia and symptomatic carriers. 2018 has been a year of smiles, milestones, and connections.

As we make plans for the coming year, HFM is excited to build upon these efforts. But we truly can't do this work without YOU! We value your participation at our events as walkers, volunteers, and advocates. And we rely on your financial generosity and gifts to bring our work and our community together.

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 of charge throughout the year. Donations can be made directly to

HFM at 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 brings to the Michigan community.

We are grateful to be alongside all of you at HFM's many events and programs. **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.**



hfmich.org/donate

"My greatest hopes for our conference have been surpassed! Attendees did indeed make meaningful connections with similarly affected women, and the resources and experts on hand did in fact help them understand the options available to improve their quality of life. This first-ever event has been a wonderful and much needed beginning to what we hope will be an ongoing conversation about recognizing the needs for women with hemophilia."

~ Susan Fenters Lerch, HFM's Executive Director



2018 National Conference Being Visible: Women with Hemophilia

For women who have hemophilia and/or are symptomatic carriers

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

Women with hemophilia from across the country came together to connect, share their experiences, learn from experts and most importantly, support one another. We are so excited that women from the following states joined us and will BE VISIBLE as they return to their home communities with a desire to advocate and be seen.

Alabama, Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Florida, Georgia, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Missouri, Nebraska, New York, New Hampshire, New Mexico, Nevada, Ohio, Oklahoma, Oregon, Texas, Virginia, Washington and Wisconsin.

Thank you to all of our participants for joining us. You truly made this weekend's conference a success.



Gwyn Hulswit

When you know you are on the verge of a historic moment, how do you mark such an occasion? At the opening of the Hemophilia Foundation of Michigan's 2018 National Conference "Being Visible: Women with Hemophilia" Dr. Roshni Kulkarni noted the moment by lighting a candle and sharing that an initiative begun during Diwali, the Indian Festival of Lights, was bound to be auspicious. In Dr. Kulkarni's words, this moment was an occasion to mark the victory of light over darkness, knowledge over ignorance, and good over evil. For women with hemophilia, this ceremony opened the weekend's conversation and invited a light onto personal

stories of medical need and treatment; frustration with proper diagnosis; and the shared histories of hope, hurt, and healing that brought participants together.

Girls and women with bleeding disorders have long struggled to receive the level of care and treatment that they need medically. And for women with hemophilia, this struggle has included outright denial of their symptoms and their factor levels. At the Amway Grand Hotel in Grand Rapids, Michigan, over 100 women from around the country gathered to listen to health experts discuss diagnosis, treatment and genetics of women with hemophilia. For

continued on page 6



Photos ©2018 HFM

HFM's national ground-breaking conference the weekend of November 9-11, "Being Visible: Women with Hemophilia," could not have happened without the support of our sponsors.

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

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



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.

Conduct scientific research on the most challenging unmet needs in hemophilia, including long-term joint health and the formation and treatment of inhibitors.

Help to close the treatment gap in the developing world. Our unprecedented donation of factor therapy, with Sobi, has already treated nearly 16,000 people in 40 countries through the WFH Humanitarian Aid Program.

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



Anonymous quotes from our evaluations:

- I'm not alone.
- So much ♥
- I want to make this connection again!
- (As a result of this conference) I'm not afraid to learn to infuse.
- (I learned that) my periods are not normal.
- (I learned that) I need to schedule my hematologist appointment.
- (I learned that) it is so important for women to be identified as hemophiliacs for many health reasons.
- Much more needs to be done to teach doctors about women with hemophilia.
- We all struggle with our disorder.
- We are stronger united.
- Having a conference just for us and us alone is very important because we deal with issues that VWD patients will never understand or comprehend.
- The hemophilia community is unique and amazing.
- I really enjoyed learning more about MYSELF and knowing what to do health-wise moving forward.
- I am not alone in this fight.
- Knowledge is power.
- There are great organizations and medical professionals fighting beside us.
- Strength is in numbers.



More photos at www.hfmich.org/womens-conference18-photos

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many women, frustration was palpable as they discussed their previous appeals to doctors for care and treatment, and how they had been dismissed. Speakers were patient and empathetic, informing the women that they shared their frustrations and were advocating for changes in the field, educating HTC staff, and making changes on the national level for inclusion of women with hemophilia. Small group breakout sessions further enhanced conversations as participants discussed issues ranging from addressing mental health challenges, parenting with a chronic condition, enjoying sexual activity, managing heavy periods, and cultivating self-assurance.

"Being Visible" brought together an incredible group of women with hemophilia; we are so thankful for their participation, their openness, and their demand to create rightful recognition of their space in the bleeding disorders community. We are grateful to the world-class faculty who donated their time and expertise and who are sharing their passion, care, and influence to these efforts. Together, we are setting a new national conversation. And while recognizing that this is still a first step, it is a truly historic moment. HFM is honored to have been a part of these efforts.

Click below to hear from a few of our attendees:



www.hfmich.org/WC1



www.hfmich.org/WC2



www.hfmich.org/WC3



www.hfmich.org/WC4



www.hfmich.org/WC5



From Sports Bar to High Tea: 2018 Fall Women's Retreat

Shari Luckey

It was a pleasure to be a part of the team at HFM that hosted the 2018 Fall Women's Retreat. In September, more than 20 women from the Michigan bleeding disorders community gathered for a two-day retreat in Plymouth, focused on self-care and rejuvenation.

Our Saturday started with some fun get-to-know-you activities with old friends and new. Kelly Savino, Director of the Hands-On Studio at Toledo Botanical Gardens, then taught us how to bullet journal as a way to organize our lives and express our creativity through personalizing the journals. We closed the night with dinner at CJ's, a favorite Plymouth sports bar. The food was amazing and the companionship was even better, I hadn't laughed so hard in quite some time.



Sunday morning, after breakfast, we learned important lessons about how to manage the many hats women wear today and the importance of self-care, especially for the caregivers in the group. We concluded our fall weekend with a wonderfully relaxing High Tea at the Sweet Afton Tea House. We enjoyed hot tea, followed by many courses, while surrounded by quaint decorations and much laughter.

It's always wonderful to be with other women who support each other and lift one another up. The sense of community is strong and the connections are lasting. It was a weekend that left me with a feeling of rejuvenation and agreeing that laughter is the best medicine.



Special thanks to our sponsor



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HFM's Bleeder & a Buddy

The weekend before Halloween, teen "bleeders" and their buddies joined HFM at Camp Roger on the west side of the state for Bleeder & a Buddy. This annual teen retreat focuses on bleeding disorders education and personal advocacy as teens practice sharing information with their friends about their disorders.

This year, the teens also learned about what it means to be a part of the bleeding disorders community and the importance of volunteerism. On Saturday, the teens supported HFM's Unite for Bleeding Disorders Walk in Grand Rapids, helping to hand out candy and staff the kids' zone.

After supporting HFM's Unite Walk, the group enjoyed some chilly time outside on a ropes course and later at a zombie paintball adventure. As always, it was a joy to spend time with teens in our community and watch them grow year after year.

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**Community Night
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Community Nights



Carrie McCulloch

HFM's Community Nights were a huge success this year! Almost 200 community members bowled, shared meals, played, and laughed together. Community members also learned together, as each event included an educational component. Our focus this year was the importance of dental care while living with a bleeding disorder. Our thanks to Hemophilia Treatment Center hygienists: Heather Messenger, B.A., M.S., Jennifer Kearns, B.S. R.D.H., and Christy Clark, R.D.H., for presenting!

Our 2018 season concluded with back-to-back events in Traverse City and Lansing. On October 26th Incredible Mo's hosted our Traverse City

group. Community members bowled, played in the arcade, and enjoyed the excellent pizza that Incredible Mo's is known for!

Spare Time Entertainment was the hot spot for the Lansing HFM community on November 2nd. HFM was treated to our own private lanes, pizza, salad, and cookies. Our Lansing group was energetic and the adorable little bowlers in attendance were a blast to watch.

Thank you to everyone that joined us in Livonia, Grand Rapids, Traverse City, and Lansing. We look forward to planning more fun events in 2019 and hope to see you there!



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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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Let's put science to work



State Senator O'Brien Visits West Michigan Cancer Center & Institute for Blood Disorders



For those of us who want to share our stories with our elected representatives, there are year round opportunities to do so. We can all work toward creating moments of advocacy in action—it really is as simple as telling your story and inviting people to learn more. They often say “yes!” Staff from the West Michigan Cancer Center and Institute for Blood Disorders (WMCC) share how they did just that.

In May, the Hemophilia Foundation of Michigan hosted their annual legislative event, Lansing Days, where HFM staff met with the office of Margaret O'Brien, State Senator-20th District, which includes Kalamazoo County. Senator O'Brien and her staff were excited to learn that a Hemophilia Treatment Center (HTC) is based in her district at WMCC. In June, Senator O'Brien, several of her staff members, and HFM's Advocacy Manager, visited WMCC and spent time with our hemophilia team. We shared the Hemophilia Treatment Center care model and explained how a multidisciplinary team can improve outcomes and decrease costs. The team was able to review specific case studies and explain the impact of medical, psycho-social, vocational, and financial issues on those patients.

Patients with bleeding disorders require a lifetime of care and guidance. The good news is that healthcare continues to

improve with the comprehensive care model—involving physicians, nurses, social workers, physical therapists, dietitians and dental clinicians—at the forefront. We were thrilled to share stories of resilient bleeding disorder patients and families thriving in the community, and living beyond their medical diagnoses. **WMCC was honored for the opportunity to engage with our state representative to provide updates on patients living in her district; and how policy changes can impact people in our community. The opportunity to advocate and highlight the importance of comprehensive care with Senator O'Brien and her team was priceless. Thank you to our HFM colleagues for coordinating advocacy in action!**

Do you depend on copay assistance?

If so, you should know that some insurance plans have changed how you can use copay assistance programs.

Sarah Procario

Pharmaceutical companies have long provided manufacturer copay assistance to patients with rare diseases, including those with bleeding disorders. In the past, these dollars have applied to patients' deductible and copays, and likely met your out-of-pocket maximum for the year, making the costs of living with a bleeding disorder more manageable.

Now, some plans will still allow you to use the copay assistance card but when the card is exhausted your accumulator (how the insurance company keeps track of what you've paid) is reset to zero and you will still be responsible for paying your full insurance deductible and all copays until you reach your out-of-pocket maximum. If your insurance plan has introduced this “co-pay accumulator” program, you may

be required to pay thousands more for your factor.

Don't be taken by surprise. Check with your insurance plan during open enrollment.

**Open enrollment
ends December 15.**



Yoga for Women with Bleeding Disorders

Sarah Procario

Yoga. I am sure you've heard the word. Images of tiny women in expensive leggings may come to mind, or maybe you envision people attempting contortion-like postures. For those in the bleeding disorders community, this picture of yoga may not seem like it was made for them.

Yoga (a Sanskrit word meaning 'to unite') is actually an ancient spiritual, physical, and mental practice that originated in India and only recently traveled to the West. Yoga is made up of eight parts—moral teachings, self-restraints, postures, breathing techniques, withdrawal of the senses, concentration, meditation, and enlightenment. Only ONE aspect of yoga is physical and all of yoga can be modified to fit your specific needs.

In September, HFM and the University of Michigan Hemophilia and Coagulation Disorders Program collaborated to provide a six-week yoga program specialized for women with bleeding disorders, led by a certified yoga teacher and a licensed physical therapist. The Yoga for Women with Bleeding



Disorders program introduced women to yoga postures and modifications, breathing techniques, and meditation practices in a safe and controlled environment. The combination of these practices has been shown to increase flexibility, build muscle tone and strength, improve balance, and lower blood pressure. But beyond these physical improvements, yoga has been shown to decrease anxiety, build a better body image, increase body awareness, alleviate pain, reduce the physical effects of stress on the body, and provide a sense of peace.

Women left with a better understanding of yoga, a deeper awareness of their bodies, the ability to utilize their breath to calm physical responses, and the practice of nonjudgmental reflection of one's thought patterns.

We are hoping to continue the program for all members of the bleeding disorders community. If you are interested in participating, please contact Sarah Procario at sprocario@hfmich.org

End of the Year Community Gathering

Check out our 2018 photos at
www.hfmich.org/holidayphotos18

We are once again grateful to the students of Troy High School for hosting our diverse community for a festive end of the year community gathering. Children and adults alike enjoyed a fun afternoon of activities, music, yummy treats, and good company. Our youth (under the age of 16) received a gift and visit with Santa Antonio!

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Special thanks to our sponsors



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The Stitches Doll Project Travels to Scotland

Kathy Gerus-Darbison & Bill Darbison

The ClotNot Club doll collection is part of The Stitches Doll Project which started in 1999. These red fabric dolls are decorated and given a voice by girls and women living with bleeding disorders. Each doll expresses her own message about the thoughts, feelings, and emotions of what it's like to live with the daily challenges that come with such a diagnosis.

Every two years, the World Federation of Hemophilia (WFH) holds an international summit to share new information on research, therapies, and care in the bleeding disorders community. In 2016 the meeting was held in Orlando, Florida and for the first time there was a booth dedicated specifically to women's issues. The booth was planned and funded personally by one woman from the U.S., Cheryl Nineff-D'Ambrosio, a

mother of two daughters who have a rare factor deficiency. She had the foresight to organize women from all over the world and invited them to share their local projects during the conference. This is how our humble project became part of the first-ever WFH Women's Booth.

Our volunteer-staffed booth was a huge hit that year and many people from all over the world visited to chat, gather information, and make dolls. Due to the exceptional interest from so many attendees, our doll project was invited to come to the 2018 WFH Global Summit that was held this May in Glasgow, Scotland.

This year's Women's Booth was organized by the Hemophilia Society of

Scotland, and what a wonderful job they did! It was staffed by several Scottish hemophilia nurses, Society staff, and female and male volunteers from around the world. During the week of the conference many women and some men created dolls to bring awareness to the issues of bleeding disorders in women. We captured all the them digitally so we can share them on our website, **www.stitchesdollproject.org**, but we allowed everyone to take their doll back to their home country. We encouraged everyone to use the dolls to further educate the greater community about the importance of knowledge around carrier testing, the need for further research on women, and the creation and availability of care and treatment for all people suffering with bleeding disorders worldwide.



Your dreams. Our dedication.

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

Michelle
vWD
Nevada



bleedingdisorders.com



Days for Girls Sewing & Potluck

Shari Luckey

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

On a warm Saturday in September, 10 dedicated women came together at HFM in Ypsilanti for our 3rd Days for Girls Sewing event of 2018. With rotary cutters spinning, sewing machines whirring, irons steaming, women chatting, and crockpots

warming, we completed 47 reusable menstrual and hygiene kits for girls/women around the world. We are sending 70 kits to Nigeria this month and hope to send another 30 kits out by the end of the year. These kits will allow girls and women to experience greater independence and lead fuller lives.

Please consider joining us for our next Work Day and Potluck **Saturday, January 19, 2019** from 10am-4pm, as we embark on our next 100 kits. If you are unable to donate your time, consider a monetary or materials donation.

Wish list

Fabric (new or like new):

- 100% cotton material solids or prints (minimum ½ yard)
- Flannel solids or prints (minimum ½ yard)
- Light canvas material (minimum ½ yard)

NOTE: no holiday, animals/bugs, words, or flags

Kit supplies:

- Cotton wash cloths (no white)
- Girls sizes 10, 12, and 14 panties
- Gallon size Ziploc bags (no sliders)

If ordering online through

Amazon, please go to [Smile.Amazon.com](https://smile.amazon.com) and designate the Hemophilia Foundation of Michigan as your charity and HFM will receive 0.5% of the purchase price of eligible items, at no additional cost to you.

Donations can be sent to:

Shari Luckey c/o HFM
1921 W Michigan Ave.
Ypsilanti, MI 48197

Or, contact Shari Luckey at sluckey@hfmich.org to make other arrangements.

Delta Dental Insurance

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.



Save the date!

SpringFest 2019

Friday, April 26 - Sunday, April 28, 2019
Ann Arbor Ypsilanti Marriott At Eagle Crest

Please join us for this wonderful weekend filled with amazing speakers, the latest medical information and opportunities to connect and learn from people who bring their own unique wisdom and experiences of living with a bleeding disorder.

HFM's SpringFest is our largest annual consumer education conference and is open to all Michigan individuals and families in the bleeding disorders community.

Registration will Open March 11, 2019 & Close April 2, 2019

Stay tuned to hfmich.org/facebook and hfmich.org for more information.

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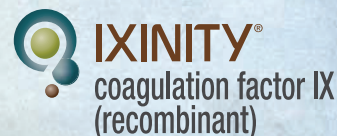
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► Contact Arica at 614-519-3052 or desilvestria@apvo.com



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OR WITHOUT FACTOR VIII INHIBITORS**

GO SEEK. GO EXPLORE. GO AHEAD.



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What is HEMLIBRA?

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

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

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

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


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

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

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

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

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

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:

– confusion	– stomach (abdomen) or back pain
– weakness	– nausea or vomiting
– swelling of arms and legs	– feeling sick
– yellowing of skin and eyes	– decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:

– swelling in arms or legs	– cough up blood
– pain or redness in your arms or legs	– feel faint
– shortness of breath	– headache
– chest pain or tightness	– numbness in your face
– fast heart rate	– eye pain or swelling
	– trouble seeing

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

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

What is HEMLIBRA?

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

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

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

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

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

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

How should I use HEMLIBRA?

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

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.
- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.

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

What are the possible side effects of HEMLIBRA?

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

The most common side effects of HEMLIBRA include:

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

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

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

How should I store HEMLIBRA?

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

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

General information about the safe and effective use of HEMLIBRA.

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

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

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

Manufactured by: Genentech, Inc., A Member of the Roche Group,
 1 DNA Way, South San Francisco, CA 94080-4990
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For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.

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



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Believe Limited's 2018 Teen Impact Award

Michigan community member, Ismael Jaber, shown here with HFM's Anthony Stevens, received the Teen Impact Award from Believe Limited at NHF's annual conference. The Teen Impact Awards recognize teens in the community who are making a positive impact in homes, schools, and the community.

www.hfmich.org/ismaelteenimpact



GREAT LAKES REGION V-EAST

HFM hosted the Great Lakes Region V-E Annual Meeting in Sandusky, Ohio. Every HTC in Michigan, Ohio, and Indiana was represented at this educational gathering. We are fortunate to have many exemplary care providers in our region with a commitment to patients and our federal requirements.



Photos © 2018 HFM



in Collaboration with

MICHIGAN STATE UNIVERSITY

Center for Bleeding and Clotting Disorders

UP Retreat: Beyond the Bridge



Lisa Clothier

For bleeding disorders community members living in the Upper Peninsula, it can be hard to travel downstate for community events and education sessions. So, in collaboration with the Michigan State University Center for Bleeding and Clotting Disorders, HFM hosted our Patient and Family Upper Peninsula Retreat in beautiful northern Michigan. Patients, caregivers, providers, and HFM staff gathered for a weekend of community and education. Friday evening's bowling event kicked off the retreat with an evening of fun and opportunity to connect with others. Saturday featured educational sessions presented by MSU's Marcia Bird, LMSW, HFM's Sue Adkins, BSN, RN, Lisa Clothier, LMSW, ACSW, and Gwyn Hulswit, MA, HFM Associate Director, and included Emergency

Preparedness, Life Transitions, Self-Care, The Art of Speaking Up, and Industry Patient Assistance Programs.

While the parents and caregivers were in session, the kids were breaking out-of a Camp Bold Eagle themed escape room created by HFM's very own Tim Wicks, Anthony Stevens, and David Lattas.

Participants shared that in addition to receiving valuable information, they really enjoyed the opportunity to connect with the community and the Hemophilia Foundation of Michigan and Hemophilia Treatment Center staff. We appreciated the opportunity to share resources and education and get to know the Upper Peninsula bleeding disorders community!

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Happy Campers



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Unite for ALL Bleeding Disorders

Carrie McCulloch

Our walk program included so many new and exciting elements this year! In April, we rolled out our new name: Unite for Bleeding Disorders Walk. For the first time, our walk name acknowledges that we walk with the purpose of serving people with all types of bleeding disorders. We are United in purpose, we are United with each other, and we are United with the more than 40 walks happening across the country in support of bleeding disorders.

Our walk in Detroit had a new layout, and a new attitude. Walk chairs, **Elliot and Shannon Jones**, did a fantastic job encouraging team captains leading up to the walk, and led everyone in the brand new pinwheel ceremony. Unite walkers could be found throughout the zoo watching penguins zip around, feeding giraffes, and enjoying the company of a community united. Upon returning to the pavilion, they enjoyed our very first ice cream social.

Samantha Javorka chaired our Grand Rapids walk. A few days before walk day, Samantha and her adorable daughter Daphne were invited to visit Wood TV in Grand Rapids to talk about Daphne's journey (see "unitewalk-woodtv" link below right) and the upcoming walk with Wood TV anchor, Emily Linnert. Wood TV also generously promoted the Unite for Bleeding Disorders walk on the morning of the event.

Because the Grand Rapids walk was toward the end of October this year, we decided to add a Halloween theme. The Kid Zone included Halloween games and pumpkin decorating. Walkers came in costume, and were able to trick or treat during the walk. What made this so special, however, is that it was our very own Bleeder and a Buddy teen retreat attendees that were handing the candy out! Among the teens was **Ismael Jaber**, who had recently received the Teen Impact Award from NHF via Believe Limited (see page 18 to read more about his award). Ismael shared with the attendees why it's so important for him to give back and how meaningful the support of programs, like Camp Bold Eagle and Bleeder & a Buddy, have been to him.

While the walks were great events, one of the most exciting things to see was the creativity and drive from our walkers. Leading up to the walks, our community sold t-shirts, hosted paint and pours, raised money to take a pie to the face, hosted lemonade and cider stands, collected cans for change... the list goes on and on. Through gestures large and small, you, our community, made the walks great because of your determination to support HFM programs and services. Thank you to each and every one of you. I can't wait for next year!!!



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The Hemophilia Adoption Program

supported by HFM



Three boys with hemophilia, ages 3, 7, & 8, are waiting for their forever families to find them and bring them home. These boys need consistent medical care for their hemophilia but most importantly, they need the permanence of unconditional love which they have not yet experienced. If you are interested in more information about any of these three sweet boys, please contact **Shari Luckey – Advocacy and Outreach Coordinator: sluckey@hfmich.org**



Meet 3-year-old Adrian. He loves to smile and laugh and feel the warm sunshine on his sweet face. Due to a head bleed as an infant, he needs PT and OT to assist him in making a full recovery.



Meet Payne, a sweet and shy 7-year-old boy. He is smart and learns new things quickly! He loves to play with friends, but many times cannot because of his knee. He has difficulty walking due to frequent bleeds in his right knee.



Finally meet 8-year-old Devin. He loves animals, superheroes and being active. He enjoys playing outside and participated in track and T-ball this past year. He is creative, likes to be the leader and help others, and responds well to rewards. A complete home study or foster license is required to release his full profile.



Grant Opportunity

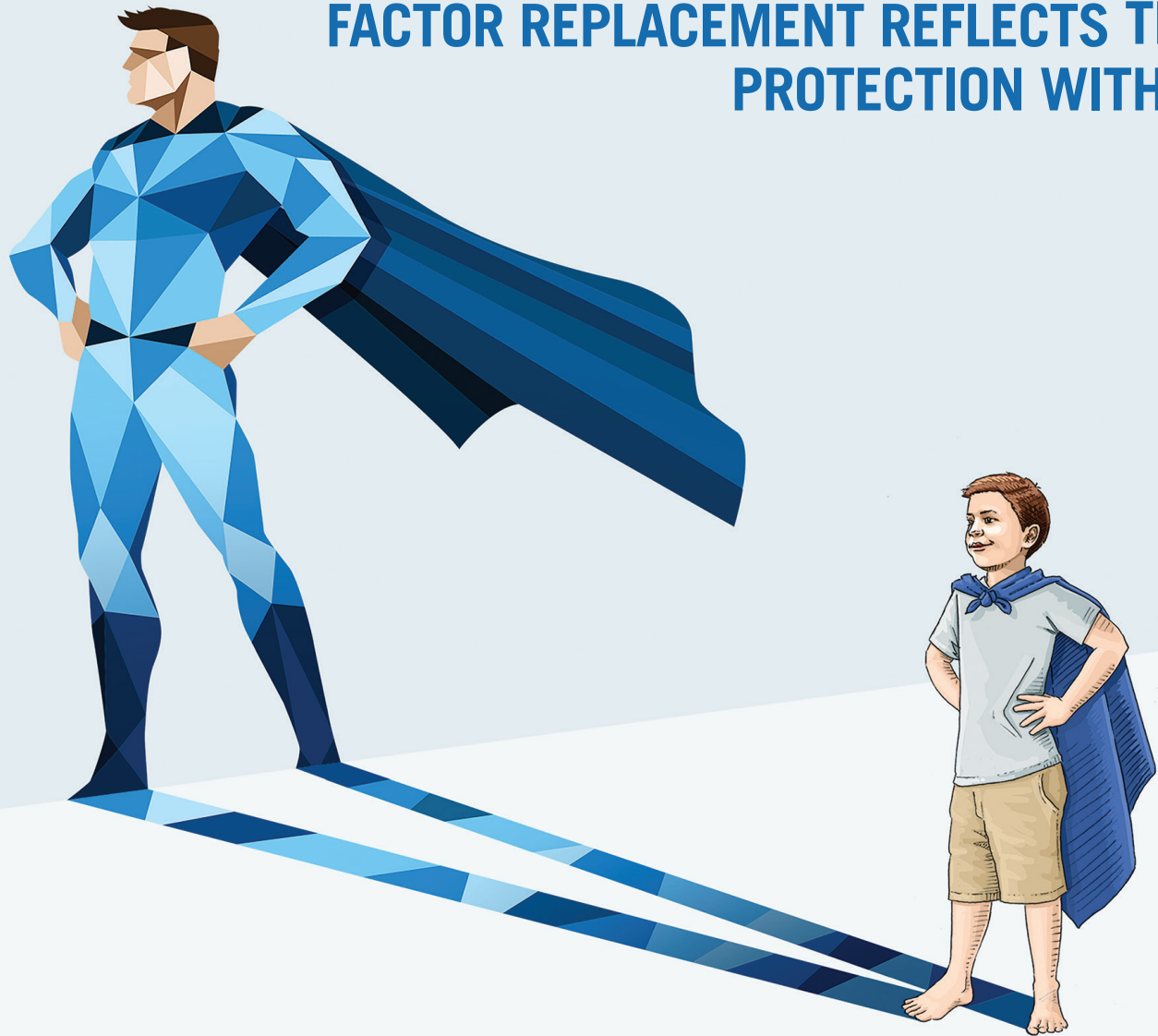
An adoptive family, in partnership with HFM, has established a new grant opportunity for prospective adoptive parents. Go to **www.hfmich.org/adoption**

Happy holidays!

From your HFM team! Shari Luckey, Sharon Ceci, David Kaumeyer, Travis Tussing, Tim Wicks, Patrice Thomas, Anthony Stevens, Susan Fenters Lerch, David Lattas, Gwyn Hulswit, Lisa Clothier, Sarah Procario, Robin Whitfield, Carrie McCulloch, Sue Atkins, Laura Olson, Ashley Fritsch



FACTOR REPLACEMENT REFLECTS THE PROTECTION WITHIN



For people with hemophilia, Factor treatment temporarily replaces what's missing.^{1,2} With a long track record of proven results, Factor treatment works with your body's natural blood clotting process to form a proper clot.²⁻⁶

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Stay empowered by the possibilities.

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2019 HFM Programming & Events (partial list)

**NOTE: Camp & Teen Retreats
listed separately below, right.**

**Fri., April 26 - Sun., April 28
SpringFest**

Ann Arbor Ypsilanti Marriott
At Eagle Crest
pthomas@hfmich.org

Date TBA

Butterfly Benefit

West Michigan Location TBA
cmcculloch@hfmich.org

Tues., May 21 & Wed., May 22

Lansing Days Advocacy

Lansing Capitol
sprocario@hfmich.org

Monday, June 3

Swinging for Smiles

Charity Golf Outing

The Polo Fields Washtenaw
Ypsilanti
cmcculloch@hfmich.org

Friday, June 7

Community Night

Craig's Cruisers
Grand Rapids
cmcculloch@hfmich.org

Sunday, August 25

UNITE for Bleeding

Disorders Walk

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

Date TBA

UNITE for Bleeding

Disorders Walk

(Formerly Walkin'
on the West Side)
West Michigan Location TBA
cmcculloch@hfmich.org

Fall Date TBA

Women's Retreat

West Michigan Location TBA
pthomas@hfmich.org

December Date TBA

End of the Year

Community Gathering

Troy High School, Troy
cmcculloch@hfmich.org



734. 544.0015

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1921 West Michigan Ave.
Ypsilanti, Michigan 48197



Eagle Journeys Camping PROGRAMS

March 8- March 10

(Tentative)
Teen Retreat
Location TBA

June 8-14

Eagle Quest
(Ages 18+)

August 4-10

Eagle Outpost
(Ages 14-15)

June 30-July 6

CBE Teen Camp
(Ages 13-17)

July 8-27

CIT Program

July 10-13

Camp Staff
Development

July 14-18

CBE Session One
(Ages 6-9)

July 20-26

CBE Session Two
(Ages 10-12)

August 1-9

Eagle Expedition
(Ages 16+)

September 13-15

Camp Old Beagle
(Ages 18+)

October 18-Oct. 20

Teen Retreat
Location TBA

December 14

Camp Holiday Party

Camp Registration

Opens February 1, 2019
and closes May 31, 2019

**Questions about camp? Please contact
Tim Wicks or Anthony Stevens @ 734.544.0015**



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