

the artery

Serving Michigan's bleeding disorders community

Fall 2019



We're still celebrating the
50th Anniversary of
Camp Bold Eagle



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



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



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Susan and granddaughter Margeaux Elise at the 2019 Detroit Unite for Bleeding Disorders walk.

Dear HFM friends and family -

As our weeks of summer camp come to a close and we celebrate our annual Unite Walk in Detroit we know that fall is imminent. For me, fall is my favorite season, yet it is always tinged with a little bittersweet feeling that summer has flown by!

This summer we celebrated the 50th anniversary of HFM's Camp Bold Eagle (CBE) camp program. In 2018 we acknowledged the 50th summer of CBE with 2019 the true anniversary year of our beloved program. The first camping program for children and teens living with hemophilia and other bleeding disorders began in the summer of 1969. Dr. John Penner and Dr. Jeanne Lusher established the program with HFM to create a place for young people and their medical care providers to spend time together in support of one another in a positive, "can do" environment surrounded by nature. We're so proud to be affiliated with the very first camp program ever in the United States, and we believe, first in the world! As we continue to welcome campers with bleeding disorders from Michigan and from across the country (and a few from other countries!) the success of CBE is abundantly clear - camp offers tremendous value for our community. The value of learning about your disorder, including treatment and independence, as well as the camaraderie that develops at camp spread across the community and summer camp programs have become a priority for a multitude of chapters and treatment centers throughout the United States.

As treatment continues to evolve and many people living with bleeding disorders are impacted differently now, camp remains a cornerstone program for HFM. The need to learn about your disorder, spend time with other affected individuals, and have opportunities for leadership development while making lifetime connections are as strong as ever, and we are proud that this summer included seven weeks of various summer camp programs via HFM's Eagle Journeys. The opportunity for our community to have these experiences is amazing.

This year at our Detroit Unite Walk we celebrated Camp Bold Eagle's golden anniversary. Fifty years of summer camp and the legacy it continues to provide is genuinely remarkable. Our deepest appreciation to all who have committed time and energy, resources and ideas to create, build and grow the best camp program ever for our community.

Susan Fenters Lerch
HFM Executive Director,
Federal Great Lakes –
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To view more Unite walk photos, go to
www.hfmich.org/unitedetroitphotos19

PAID CONSUMER OUTREACH INCLUDED IN THIS NEWSLETTER.

To view more photos, go to www.hfmich.org/butterflymemorialphotos

Photos: ©2019 Rena Lavery



Carrying our Memories Forward

HFM's Updated Butterfly Memorial and Garden By Shari Luckey

In 2005, with over two hundred community members present, the Hemophilia Foundation of Michigan (HFM) dedicated a glass sculpture in the shape of a butterfly engraved with the names of community members who had passed away. The intent of the memorial was to honor those with bleeding disorders, and those who had made a significant contribution to the quality of life for the Michigan bleeding disorders community, that had passed away.

Twelve years later, HFM contacted the original creators of the glass butterfly memorial to discuss adding names to the existing sculpture. After sharing our ideas of the project and submitting photos of the existing memorial, **Glass and Mirror Craft** offered to completely recreate the piece at no cost to HFM. Over the years, the weather had caused the glass to delaminate and many of the etched letters were wearing away. The design team worked closely with HFM over the past two years to ensure

a final piece that honors our community members who have passed away.

HFM quickly embarked on a campaign to gather the names of individuals in the community who were no longer with us. The intention was the same, to honor those that had a bleeding disorder or were closely involved in the community. We reached out to the community in a number of ways, including SpringFest, email, and Facebook posts. We also meticulously researched our database to compile a list of names to be added to the new memorial. The original butterfly had 103 individuals represented on it. **Today, the butterfly honors 303 individuals who forged the path before us and helped us grow into the community that we are today.**

It was important to the staff at HFM that we honored the original piece as closely as possible. With expert recommendations from our designer we kept the integrity of

the original design shape and updated the materials, colors, and opacity to ensure longevity in the weather and visibility of names. We also updated the inscription to be inclusive of all members of the Michigan bleeding disorders community who have passed on.

The second part of our project was to update the Memorial Garden courtyard. We added butterfly attracting plants and expanded the garden area to create a living space of reflection. As we move forward we will continue to add flora and maintain this symbolic area of our community headquarters.

On June 22, 2019 we welcomed 74 guests to the Butterfly Memorial and Garden Dedication. The weather was beautiful for the outdoor program and memorial and garden viewing. It was a wonderful day of remembrance for the community.

With gratitude... HFM's Butterfly Memorial and Garden Dedication was made possible, in part, through a grant from

CK Colburn  **Keenan Foundation, Inc.**

Matt Manzo

Information specialist

About Matt

Matt is a Hemophilia Community Liaison with almost 16 years of experience working within the hemophilia community. The commitment of patients and families to learning about this condition motivates him to be an information source for those living with hemophilia in the Midwestern area.

Hobbies

- Cross-country skiing
- Cycling

"It really is a privilege to get to know people living with hemophilia and everyone in the community."

Connect with Matt

ZZMQ@novonordisk.com
(248) 303-5848

Hemophilia Community Liaison





Left: Michelle Cecil's mark of the Bold Eagle helps her during difficult times of transition.



Right: A camper included the mark in their drawing depicting everything that makes them who they are.



DISCLAIMER:
If you are considering getting a tattoo, please consult with your medical provider first. HFM does not endorse or suggest permanent "Mark of the Bold Eagle" tattoos.

The Mark of The Bold Eagle

A Summer Tradition with a Year-Round Impact By Anne Henningfeld, MA, CTRS

According to Camp Bold Eagle lore, on the last night of camp, while everyone is asleep, the Bold Eagle leaves its mark on all campers—a small footprint in marker on their hand or leg, representing the strength and bravery that is available to all campers who call on the Bold Eagle. In that small mark, just three simple lines, is a message to all campers: **camp is always with you.** The safety, belonging, and strength you found here at camp will help you move through new experiences away from camp.

This is because the mark of the Bold Eagle is a type of "transitional object." Transitional objects are most often discussed in relation to young children and items like stuffed animals or blankets that help them transition from being fully dependent on adults into a new, more independent world. The mark of the Bold Eagle can serve a similar purpose for campers of all ages. In the same way a stuffed animal can make the transition from home to preschool easier, the mark of the Bold Eagle can be a bridge between a child's camp experience and their home life. As a transitional object, the mark of the

Bold Eagle can help campers maintain their best camp self in the wider world.

Former Bold Eagle camper and staff member Michelle Cecil says that during difficult times of transition in her life, the mark of the Bold Eagle, "...is a symbol of strength and courage, and a permanent reminder that even if I can't be there, camp is always there for me." Some campers have used the mark of the Bold Eagle in their artwork, and some former campers have even chosen it as a tattoo. To staff member Jaden Letts he felt because of the mark, "When I went home, I still had a part of camp with me." It is a powerful symbol to many in the Bold Eagle family.

If you know a Bold Eagle camper, or happen to have one in your family, ask them to show you their mark of the Bold Eagle when they get home. Ask them what it means to them. And then help them remember the mark all year long. Draw it on their factor boxes. Use a dry erase marker on their bathroom mirror on the first day of school, or before a difficult event. Take a picture of their marks each year and make a collage. Encourage them to find the Bold Eagle

within themselves, and use to the mark of the Bold Eagle whenever they need a bridge between their best camp self and the challenges of life.

The mark of the Bold Eagle reminds us all about the importance of community, the community we find at camp, and in the greater bleeding disorders world. As the Legend of the Bold Eagle says, "Behold the Bold Eagle who lives deep within us, giving us strength now to reach far and wide. The courage is gained from those we encounter, leaving their mark and their wisdom to guide."

Anne Henningfeld, MA, CTRS was the director of Camp Bold Eagle from 2005-2009. She is currently the managing partner of Beyond Recreation; a consulting firm dedicated to helping people make deep connections through recreation. Through Beyond Recreation, she presents camp staff training and programming at camps across the country.



ADYNNOVATE

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ADYNNOVATE® is FDA approved for children and adults with hemophilia A

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*ADYNNOVATE allows you to infuse on the same 2 days every week. Work with your doctor to determine an infusion schedule that is appropriate for you.

The pediatric study of children <12 years of age (N=66) evaluated the immunogenicity, efficacy, PK (as compared to ADVATE® [Antihemophilic Factor (Recombinant)]), and safety of ADYNNOVATE twice-weekly prophylaxis (40-60 IU/kg) and determined hemostatic efficacy in the treatment of bleeding episodes for 6 months.^{1,2}

The pivotal trial of children and adults ≥12 years (N=137) evaluated the efficacy, PK, and safety of ADYNNOVATE twice-weekly prophylaxis (40-50 IU/kg) vs on-demand (10-60 IU/kg) treatment, and determined hemostatic efficacy in the treatment of bleeding episodes for 6 months.¹

†Children (<12 years) experienced a median overall ABR of 2.0 (IQR: 3.9) and a median ABR of zero for both joint (IQR: 1.9) and spontaneous (IQR: 1.9) bleeds.^{1,3}

†38% (n=25) of children (<12 years) experienced zero total bleeds; 73% (n=48) experienced zero joint bleeds; and 67% (n=44) experienced zero spontaneous bleeds.¹

Talk to your doctor to see if ADYNNOVATE treatment may be right for you and visit ADYNNOVATE.com

ADYNNOVATE [Antihemophilic Factor (Recombinant), PEGylated] Important Information

What is ADYNNOVATE?

- ADYNNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency).
- Your healthcare provider (HCP) may give you ADYNNOVATE when you have surgery.
- ADYNNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNNOVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADYNNOVATE?

Do not use ADYNNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNNOVATE or ADVATE [Antihemophilic Factor (Recombinant)]

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

What should I tell my HCP before using ADYNNOVATE?

Tell your HCP if you:

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

What important information do I need to know about ADYNNOVATE?

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

What else should I know about ADYNNOVATE and Hemophilia A?

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

What are possible side effects of ADYNNOVATE?

- The common side effects of ADYNNOVATE are headache and nausea. These are not all the possible side effects with ADYNNOVATE. Tell your HCP about any side effects that bother you or do not go away.

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

For additional safety information, please see Important Facts about ADYNNOVATE on the following page and discuss with your HCP.

For full Prescribing Information, visit www.ADYNNOVATE.com.

References: 1. ADYNNOVATE Prescribing Information. 2. Mullins ES, Stasyshyn O, Alvarez-Román MT, et al. Extended half-life pegylated, full-length recombinant factor VIII for prophylaxis in children with severe haemophilia A. *Haemophilia*. 2017;23(2):238-246. 3. Data on file.



ADYNOVATE

[Antihemophilic Factor (Recombinant), PEGylated]

Patient Important facts about

ADYNOVATE® [Antihemophilic Factor (Recombinant), PEGylated]

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

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

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

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

What is ADYNOVATE?

ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNOVATE when you have surgery. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

Who should not use ADYNOVATE?

You should not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE® [Antihemophilic Factor (Recombinant)]

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

How should I use ADYNOVATE?

ADYNOVATE is given directly into the bloodstream.

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

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

Reconstituted product (after mixing dry product with wet diluent) must be used within 3 hours and cannot be stored or refrigerated. Discard any ADYNOVATE left in the vial at the end of your infusion as directed by your healthcare professional.

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

How should I use ADYNOVATE? (cont'd)

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

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

You should tell your healthcare provider if you:

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

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You can have an allergic reaction to ADYNOVATE.

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

The common side effects of ADYNOVATE are headache and nausea. Tell your healthcare provider about any side effects that bother you or do not go away.

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

What else should I know about ADYNOVATE and Hemophilia A?

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

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

The risk information provided here is not comprehensive.

To learn more, talk with your health care provider or pharmacist about ADYNOVATE. The FDA-approved product labeling can be found at www.ADYNOVATE.com or 1-877-825-3327.

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

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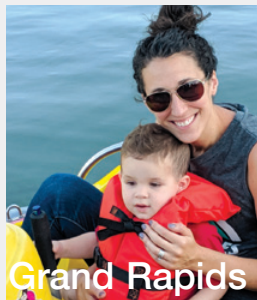
Camp Bold Eagle

HFM Community Nights (Livonia & Grand Rapids)

Thank you to everyone that made our Grand Rapids and Livonia Community Nights so much fun! Next up: Let's have a great time in Traverse City on September 27th, and Lansing on November 8th!



Livonia



Grand Rapids

Photos: ©2019 HFM

HFM is grateful to the following companies who partially sponsored
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Photos with permission from Days for Girls



Visit saveonelife.net to learn more about the Women and Girls Initiative.

Growing HFM's Days for Girls Program

By Shari Luckey

It has been an exciting year for our Ypsilanti, Days for Girls (DfG) Team! In April we sent 50 DfG menstrual hygiene kits to the Philippines, which were distributed at a meeting for women with bleeding disorders. Andrea Trinidad, from the Philippines, reported that the women loved them and she ran out of kits very quickly. In July we sent an additional 80 DfG kits to Save One Life, for delivery to Kenya and Uganda.

The Hemophilia Foundation of Michigan with Laura-Jean Siggins and Jennifer Wakefield started the YpsilantiMI DfG Team in 2015. Since then our mission has evolved **to equip women and girls in bleeding disorder communities around the world to manage their menstrual health, leading to freedom and independence.**

As HFM began looking for international bleeding disorders community partners to support the distribution of DfG menstrual hygiene kits, we found a natural partnership with Save One Life. They consistently strive to identify unmet needs in the bleeding disorders community in developing countries. Save One Life focuses on using social and economic programs

to address the compounded challenges of living with a bleeding disorder while living in poverty. Throughout their travels and discussions with program partners and community members around the world, Save One Life recognized that women and girls with bleeding disorders are often untreated, undiagnosed, and neglected in health care systems.

As HFM and Save One Life build this partnership and program to provide menstrual kits, we also aim to expand our educational efforts to highlight the specific challenges and needs associated with women and girls with bleeding disorders. Our hope is to increase the number of women and girls that are educated, diagnosed, and receiving proper care for their bleeding disorder. Through education and empowerment these women and girls can become advocates for increased awareness about bleeding disorders within their families and communities.

Learn how you can help women around the world manage periods with dignity, contact Shari Luckey at sluckey@hfmich.org.

Thank you to Sue Drew for donating a serger – this will make a huge impact in our productivity!

Twelve individuals from the bleeding disorders community enjoyed another wonderful HFM Eagle Expedition adventure to Northern California whitewater rafting, rock climbing, sea kayaking and sleeping under the stars.

Eagle Expedition



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IN THIS TOGETHER

Saturday, 7:18 pm

Checking out a music festival
with his girlfriend

Marc, hemophilia A

Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world, is stronger than ever. **Let's make today brilliant.**

bleedingdisorders.com



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Not an actual patient

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



Chris Liddell

Southern OH, MI, KY, IN

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



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

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

The First Eagle Outpost

1983 Eagle Outpost

You can do anything you want, at Bold Eagle Highlands Camp By Ken Martin

In 1983, nine years after I first attended what was then Bold Eagle Highlands, Camp Director Steve Foley and the Hemophilia Foundation of Michigan (HFM) decided that there should be a camp program for adolescent campers transitioning into Counselors-in-Training (CIT) and eventually into adult camp counselors. We were fifteen to eighteen-year-olds at the time and this experience was separated purposely both in time and space from the regular sessions of Bold Eagle... it was to be named, "Eagle Outpost."

Eagle Outpost was based off of the Boy Scouts of America camping and merit badge programs. When we arrived at Torch Lake we were buddied up with fellow campers to spend the week in tents that we, the campers, had to set up, keep clean, and then take down at the end of the week. We were then told that we, the campers, needed to come up with a menu for the week and that we, again the campers, would be going to the grocery store to purchase the food for that menu and then take turns cooking for the entire camp staff and fellow camp-

ers. We even had the pleasure of doing the dishes too. The week didn't have a set schedule like Camp Bold Eagle. We were going to take a canoe trip along the beautiful Jordan River and do some canoeing "exercises" but for the most part it was up to us to decide what we wanted to do together as a group.

In Traverse City we were given some money and told to not go anywhere alone but to be back by 4:00pm and to have fun. No staff, no parents, just us. We cooked hot dogs that were so black that if left in the sun they would automatically re-heat themselves. I never saw a life-guard that week, but we took canoes out to 50-foot-deep water and then "tipped them over" so that we knew what it was like to go in the water and right the canoe and continue on without panicking. We climbed a fire tower so high you could see Lake Michigan from miles inland. We all came home no worse for the wear.

For the not yet named Generation X-ers of us diagnosed with hemophilia and VWD, we were the first to have, 1. true

clotting factor, 2. home care, and 3. most importantly... the opportunity to find out and figure out for ourselves what the limits were for each of us individually. Our parents and health professionals hadn't a clue because they were also learning as we did. Our modest camp director looked past our diagnosis and simply saw young adults with potential. He knew we could reach that potential if we were just given a chance.

After a week that went by in a blink of an eye, we formed friendships that still remain today and I have the gratification of my children knowing those that were at that first Outpost. Regrettably there are too many friends that were there that are no longer with us. While I'm sure we often told our parents and doctors that we could do anything and everything, at least for me, this was a week where I proved to others and most importantly to myself that I could take care of myself and help others. I use my experience from that first Eagle Outpost in everything I have done in my life.

2019 Eagle Outpost





Photos: ©2019 Rena Lavery



Lansing Days

Community Members Standing Up for Health Care

By Sarah Procario

People across the country are deeply invested in improving and protecting access to quality and affordable care. For those in the bleeding disorders community, this is not new. To ensure their health and safety, community members have historically been engaged in advocacy efforts at the local, state, and federal levels to make sure policies support patients with high-cost, chronic conditions.

The advocacy need remains. In May 2019, HFM hosted 60 community advocates in Lansing for HFM's Lansing Days, one of the biggest advocacy programs for bleeding disorders in the country. Community members in Michigan showed up stronger than ever this year. Meeting with 40 offices, the same number as 2018 even with a smaller group of advocates. It was especially important to us to maintain a high number of meetings with 74 new legislators in the State Capitol; most began their tenure unfamiliar with the bleeding disorders community.

As a two-day event, we were able to once again create an evening training for teens, children and adults, to ensure community advocates felt prepared and comfortable as they entered their meetings. The next day, advocates set out to meet with their state legislators to educate them on the needs and interests of people affected by bleeding disorders, especially as related to access to affordable, comprehensive, and quality health care.

HFM is incredibly proud of the passion, commitment, and on-going growth in our community advocates. It is so important that we continue to stand up, make noise, and demand the coverage and care our community deserves. Because if not you, who?

Join us next year, May 19-20, 2020.

HFM is grateful to the following companies who partially sponsored
HFM's Lansing Days

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Center of Care

Children's Hospital of Michigan Hemostasis and Thrombosis Center

Photo - top left to bottom right: Madvhi Rajpurkar, MD; Michael Callaghan, MD; Emigh Litch, RN, BSN; Bulent Ozgonenel, MD; Charity Stadler, RN, BSN; Quinn Jones MLS(CSMLS); Meera Chitlur, MD; Annie Phillips, LMSW; Wendy Hollon MT(ASCP) SBBBCM; Bhuvana Umamaheswaran MT(ASCP); (Missing is Linda Percy RN, MSN)

What area do you serve?

Children's Hospital in Detroit, Michigan

What is your catchment area?

Detroit and Metro Detroit

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

We primarily serve pediatric patients but we continue seeing patients until they are ready to transition to Henry Ford or the Detroit Medical Center HTC. Our goal is to transition patients once they complete college, so we have quite a few adults.

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

The HTC was formally opened in October of 1982, but Children's Hospital was seeing bleeding disorders patients for many years before that. The late Dr. Jeanne Lusher founded our Hemophilia Treatment Center. We would not be here today if it was not for her hard work and dedication to the bleeding disorders community.

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

Our clinic has:

- Weekly comprehensive clinics for hemophilia patients

- Biweekly comprehensive clinics for VWD patients
- Monthly girl's clinic for females affected by a bleeding disorder

Our clinic strives to provide outreach and social support to our diverse patient population. Some of our programs include:

- Quarterly Hispanic and Arabic support group programs. All programs are done in the patients' native language
- A weekly swim program for children and adolescents with bleeding disorders at the Bolls Family YMCA in Detroit, in partnership with HFM
- Monthly support group dinners
- Infusion education days (when necessary)
- Custom made educational binders (coming soon)

Do you have any new staff members?

Our newest staff member is the wonderful Charity Stadler. She is the new nurse coordinator and our clinic is so lucky to have her. She was previously an inpatient pediatric nurse at Hurley Medical Center in Flint for the last eighteen years. She has quickly become a valuable asset to our team and is so enthusiastic about serving the bleeding disorders community.

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

1. Our center is extensively involved in hemophilia research.
2. We have four hematologists on staff that are trained in hemophilia care.
3. We have an "open door" policy and patients can be seen five days a week in our clinic for acute bleeds. This is possible because we have a wonderful nurse practitioner who is trained in hemophilia care.
4. A dedicated and knowledgeable comprehensive team.

What inspires your staff?

It sounds cliché but it is definitely our patients and their families. The strength and resilience that we witness at our center motivates us to be our best.

Are you Sparty fans or Wolverine fans? HOUSE DIVIDED

Children's Hospital of Michigan Hemostasis and Thrombosis Center

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Detroit, MI 48201

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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
injection for subcutaneous use | mg/mL

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

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

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

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

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

– confusion	– 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.

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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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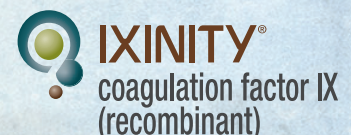
—Megan Lang, your resource for all things IXINITY



► Contact Megan at 810-614-5292 or langm@apvo.com



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FUN-draising for Camp

By Carrie McCulloch

Support for HFM programs and services is a community wide effort. Programs such as Camp Bold Eagle don't just happen on their own; it is because of a collective fund-raising effort from neighbors, friends, industry support, and staff. Thank you to those who supported camp and other programs through **HFM's Butterfly Benefit** and **Swingin' for Smiles Golf Outing**.

The Butterfly Benefit

The Butterfly Benefit, held at the Grand Rapids Art Museum on May 23, 2019, has become a favorite event on the West Side of the state. Over shared stories, memories, and smiles, attendees supported camp in the form of generous donations and an auction that had people leaving with treasured, and hard-won items.

Thanks to Dr. James Fahner, MD, Division Chief, Pediatric Hematology/ Oncology at Helen DeVos Children's Hospital, Rachael Miller, camper and community member, and Camp Director Tim Wicks, we looked

at the impact of camp: past, present, and future, and celebrated our 50th anniversary.

We are already planning and looking forward to the Butterfly Benefit next year and we will be including some new exciting elements. Want to join in the fun? Mark your calendar for **May 7, 2020**. Tickets will be available early in the new year.

Swingin' for Smiles Golf Outing

Golfers at the HFM outing have one thing in common: they are all Swingin' for Smiles. The name of this event is apt, because on June 3 our golfers were, indeed there to provide the camp experience to our youth that fills them with smiles and giggles.

This year, volunteer Carey Spangler added a fun element by giving the golfers a chance to play a hand of blackjack in support of camp. It was a creative way to add some entertainment to the day, and to raise funds for camp. In addition to blackjack, golfers supported camp through general

donations, purchases of foursomes, and by participating in a silent-as well as a surprise live-auction. The day was a joy, and made only better by the fact that the fun happened to support Camp Bold Eagle!

Often, when talking with our event participants, I will refer to FUN-draising. While this may seem a bit tongue-in-cheek, it really isn't. Just consider: Would you enjoy an evening having dinner with friends? Would you enjoy a sunny day on the golf course? How about a day at the zoo with family and friends? You can enjoy yourself while supporting a cause that you care about!

Our next FUN-draising event is the **Unite Walk in Grand Rapids on Saturday, October 12**, which will feature trick-or-treating (for both kids and adults) at the Fifth Third Ballpark. I hope to see you there! To register, go to: hfmich.org/unitewalkgr



Event photos: www.hfmich.org/butterflybenefitphotos

HFM is grateful to the following companies who partially sponsored **HFM's Butterfly Benefit**

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Event photos: www.hfmich.org/golf19photos

HFM is grateful to the following companies who partially sponsored **HFM's Swingin' for Smiles Golf Outing**

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Learn more at ADVATE.com

ADVATE Important Information

What is ADVATE?

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

ADVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADVATE?

Do not use ADVATE if you:

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

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

What should I tell my HCP before using ADVATE?

Tell your HCP if you:

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

What important information do I need to know about ADVATE?

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

What else should I know about ADVATE and Hemophilia A?

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

What are possible side effects of ADVATE?

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

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

Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

For additional safety information, please see Important Facts about ADVATE on the following page and discuss with your HCP.

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

References: 1. Grillberger L, Kreil TR, Nasr S, Reiter M. Emerging trends in plasma-free manufacturing of recombinant protein therapeutics expressed in mammalian cells. *Biotechnol J*. 2009;4(2):186-201. 2. ADVATE Prescribing Information. 3. The Marketing Research Bureau, Inc. The plasma proteins market in the United States. 2016.

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[Antihemophilic Factor (Recombinant)]



[Antihemophilic Factor (Recombinant)]

Important facts about

ADVATE [Antihemophilic Factor (Recombinant)]

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

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

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

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

What is ADVATE?

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

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

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

ADVATE is not used to treat von Willebrand disease.

Who should not use ADVATE?

You should not use ADVATE if you:

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

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

How should I use ADVATE?

ADVATE is given directly into the bloodstream.

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

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

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

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

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

You should tell your healthcare provider if you:

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

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

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

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

What else should I know about ADVATE and Hemophilia A?

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

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

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

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

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SpringFest: You've Got to Go

By Jim Mohnach, HFM Board President

"Are you going to SpringFest? You've got to go to SpringFest." That's what Lauren, my wife, and I heard at one of the first clinic visits after our son was diagnosed with severe hemophilia A. We didn't make it that first year. Aiden was a couple of months old and we were still adjusting to being parents for the first time. Let alone being parents to someone with a bleeding disorder.

The second year we knew we had to find our community. And we found it! We loaded up the family truckster and drove to Frankenmuth to check out our first HFM SpringFest. Lauren hosted a program, Aiden ran around the hotel,

and we met a ton of people who had already experienced, or were currently experiencing the same things we were. Whether we had questions about having a port put in, what camp was like, or sharing our stories of being diagnosed; it was evident we were not alone and we were surrounded and supported by our community.

SpringFest immediately became an event we looked forward to each year. It's wonderful to see old friends, meet new ones, and annually be impressed by the diversity of speakers and programming. There's always something that transcends the community (did you check

out the Bombardier Blood movie this year?!?!?).

As the Board President, one of the greatest privileges is to host the HFM Membership meeting each year at SpringFest. I love recapping the past year's programming and events. The consistent flow of new ideas coupled with the sheer quantity of programming is a true testament to the tireless work done by the staff at HFM. I'm looking forward to seeing what the latest iteration of **SpringFest** looks like as it moves to **Grand Rapids in 2020**. Can't wait to see everyone there: the weekend of **April 3-5, 2020!**



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Campers Brush Up on Dental Health

By Lisa Clothier, LMSW, ACSW

HFM would like to thank **Jennifer Kerns, BS, RDH, Northern Regional Bleeding Disorder Hemophilia Treatment Center Dental Hygienist**, for providing dental education at Camp Bold Eagle this summer. Jennifer donated her time to share important oral hygiene information to campers in both Session 1 and Session 2.

Through a **Building Brighter Futures Community Grant** we received from the Delta Dental Foundation we were able to provide a toothbrush, toothpaste, and floss for each camper. Jennifer's presentation helped the campers understand cavity prevention and the importance of oral health to overall health. Thank you again to Jennifer!



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Dental Facts: Did You Know?

By Jennifer Kerns, BS, RDH

That besides getting cavities from exposure to sugar, cavities can be caused by a simple bacterial infection, and just like any other common bacterial infection (ex: the common cold), it can be transmitted from person to person. Children under the age of four are particularly at risk of getting this type of infection. Sharing saliva with a child through toys, drinking cups, and silverware can all transmit cavity causing bacteria that can take root and last a lifetime. Help protect your child by limiting their exposure and taking care of your own dental health.

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

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Bleeder and a Buddy

Camp Roger
twicks@hfmich.org

October 12

UNITE for Bleeding Disorders Walk

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

November 1-3

HFM's 2019 National Conference for Women with Hemophilia

Westin Hotel, Detroit Airport
pthomas@hfmich.org

November 8

Community Night

Spare Time Entertainment Center
Lansing
cmcculloch@hfmich.org

November 25

Advocacy Summit

Zingerman's Roadhouse, Ann Arbor
sporcario@hfmich.org

December TBA

End of the Year

Community Gathering

(Holiday Party), Troy
cmcculloch@hfmich.org

2020

April 3-5, 2020

SpringFest

Grand Rapids
pthomas@hfmich.org

May 7, 2020

Butterfly Benefit

Grand Rapids Art Museum
cmcculloch@hfmich.org

May 19-20

Lansing Days

Location TBA
sporcario@hfmich.org



734. 544.0015

www.hfmich.org

1921 West Michigan Ave.
Ypsilanti, Michigan 48197

Tentative 2020 Camp Dates

To learn more, go to www.hfmich.org/camp

Dates TBA

Eagle Outpost
(Ages 14-15)

June 28-July 4

CBE Teen Camp
(Ages 13-17)

July 12-16

CBE Session One
(Ages 6-9)

July 28-August 5

Eagle Expedition
(Ages 16+)

June 6-12

Eagle Quest
(Ages 18+)

July 6-25

CIT Program

July 18-24

CBE Session Two
(Ages 10-12)

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