

the artery

Serving Michigan's bleeding disorders community

Fall 2017



hfm[®]

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

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**HFM's Eagle Journeys:
fun, family, friendship,
and so much more!**

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



Dear friends,

Our hearts are broken for the victims and their families of the Las Vegas shooting. And, our hearts go out to all of those across the United States who are facing such extraordinary natural disasters in California, Florida, Texas, Louisiana and Puerto Rico. Together with our national organizations and sister chapters, HFM has been in touch with bleeding disorder community members who are impacted by these terrible circumstances to provide a bit of comfort and support.

Our community understands the value of coming together to be there for one another like family – and HFM's Eagle Journeys camping programs demonstrate this deep commitment. This summer we welcomed 214 campers directly affected by bleeding disorders to our four camp programs: Camp Bold Eagle, Eagle Outpost, Eagle Quest, and Eagle Expedition. Our team's commitment to leadership development, independence, and learning about each camper's individual challenges, hopes and desires are of paramount importance. We pride ourselves on opportunities for campers and staff to learn from one another together with our dedicated medical care providers. We are community and family.

We've enhanced many HFM activities with clear education and materials regarding the significance of sharing your story with state and federal legislators. Legislative advocacy to maintain access to medical care is extraordinarily important. It remains imperative that our community share personal experiences that demonstrate the necessity of access to appropriate medical care. HFM continues to grow our advocacy efforts which work best with community engagement and participation.

HFM's very first Executive Director, Marv Williams, passed away in September. Marv was devoted to Michigan's bleeding disorders community. I hope you will read the beautiful tribute from his family on page 20. Marv made a significant difference that remains with HFM today.

There are many individuals, families, care providers, supporters, and partners who care deeply about our bleeding disorders community. Though our community has had excruciating challenges, we also have amazing hope now, and for the future. For many of our community's kids and adults, camp is a place they consider home. We welcome you to consider HFM's many educational programs and services as places to feel at home as well. We have a talented, committed Board of Directors and staff. We'll be introducing our team in future newsletters. Take good care.

Fondly,

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

PS: I hope you'll consider joining us at one or all of these FREE HFM events:

- Butterfly Breakfast at the Cider Mill
Saturday, November 4, in Plymouth (page 21)
- Community Nights: Bowling for Bleeders
Friday, November 10, in Lansing (page 18)
- End of the Year Community Gathering,
Saturday, December 2, in Troy (back page)

PAID CONSUMER OUTREACH INCLUDED IN THIS NEWSLETTER.

Camp Bold Eagle 2017



Kids from HFM's Camp Bold Eagle share what camp means to them.



Colin, 11
Having fun.



Bryce, 11
Camp means fun,
awesome, amazing.



Gavin, 11
Camp means awesome.



Vincent, 12
Camp means home,
a second home.



Aoi, 11
Camp made me feel happy
and comfortable being
around people that know I
have hemophilia and didn't
treat me differently.



Caden, 12
Learning about your
medical condition and
seeing people with it so
you don't feel alone.



Marteice, 11
It means family and fun.



Jimmy, 12
It's kind of something so
important to me. It would be
like they were taking away
a part of me. I've met so
many friends here.

What does camp mean to you?

"It's my second day here and I already love it!"

~ 2017 1st year camper



“We swam all the way across the lake and all the way back. Being at the doctor’s all the time, I’ve never ever done anything like that before. I felt so normal, I felt so proud, like ‘I did it!’”

Eagle Steps on the Water Sarah Procario

At Camp Bold Eagle (CBE), campers are challenged to safely explore their boundaries and live a life focused on possibilities rather than limitations. When campers accept this challenge and take a step outside of their comfort zone, it is called an “Eagle Step.” While everyone experiences different Eagle Steps, many campers find this step on the waterfront at Pioneer Trails.

Camp Bold Eagle’s waterfront staff is teamed with certified lifeguards who work with the campers to feel safe and comfortable swimming in the lake. CBE’s 2017 Waterfront Director, Kelly, shares, “Many of our children arrive at camp without the ability to swim. Our waterfront staff focuses on these children who haven’t had experiences in the water, and after camp they walk away with a lifelong skill.”

Even with supportive staff, for children who haven’t had swim lessons or trips to the lake, getting in the water can be quite daunting. Twelve-year-old camper, Tim, has been working on his swimming since he started coming to camp five years ago. “No one else in my life swims,” Tim shared. “I had to use life preservers last year, but this year I swam without a mask, all the way across the swim area. I’m still working on treading water though.” It has taken Tim years to overcome his fear of the water, but this year he felt prepared to pass his swim test.

Serenity, a first year camper, also found the edge of her comfort zone in the water. As a Session Two camper, Serenity participated in Lake Swim, a favored camp activity where campers swim across the lake with supervision

and comprehensive support from waterfront staff. Serenity explained, “We swam all the way across the lake and all the way back. Being at the doctor’s all the time, I’ve never ever done anything like that before. I felt so normal, I felt so proud, like ‘I did it!’ I’m coming back [to camp].”

By empowering and motivating the campers to safely take that first step into the water, Camp Bold Eagle staff shows campers the lengths of their potential. Eagle Steps play a large role in creating a transformative camp experience that campers take with them throughout their lives. If you know someone who went to camp, ask them what Eagle Steps they took while they were there!

FEIBA
[anti-inhibitor
coagulant complex]

LIVE IN THE BLEED-FREE MOMENT

...with FEIBA prophylaxis patients can have more bleed-free days as compared to on-demand treatment.

Every joint bleed has the potential to do permanent damage^{1,2}

Median ABR with prophylaxis vs. on-demand^{*3}

72%

REDUCTION

in median ABR with prophylaxis treatment³

28.7 median ABR with on-demand treatment^{3,4}

629 bleeding episodes occurred during on-demand treatment^{3,4}

VS

7.9 median ABR with prophylaxis treatment^{3,4}

196 bleeding episodes occurred during prophylaxis treatment^{3,4}

NO BLEEDS

occurred in 18% (3 out of 17) of patients on FEIBA prophylaxis in a clinical study^{†3}

*Based on the results from the FEIBA PROOF clinical study of 36 hemophilia A and B patients with inhibitors receiving FEIBA for prophylaxis or on-demand treatment for 12 months.⁴

†Of those patients who achieved zero bleeding events, two-thirds completed 12 months of the study.⁴

FEIBA is the ONLY FDA-approved treatment indicated for use in hemophilia A and B patients with inhibitors for routine prophylaxis.³

Actual FEIBA patient.

Indications for FEIBA [Anti-Inhibitor Coagulant Complex]

FEIBA is an Anti-Inhibitor Coagulant Complex indicated for use in hemophilia A and B patients with inhibitors for:

- Control and prevention of bleeding episodes
- Use around the time of surgery
- Routine prophylaxis to prevent or reduce the frequency of bleeding episodes.

FEIBA is not indicated for the treatment of bleeding episodes resulting from coagulation factor deficiencies in the absence of inhibitors to coagulation factor VIII or coagulation factor IX.

Detailed Important Risk Information for FEIBA

WARNING: EVENTS INVOLVING CLOTS THAT BLOCK BLOOD VESSELS

- **Blood clots that block blood vessels and their effects have been reported during postmarketing surveillance following infusion of FEIBA, particularly following the administration of high doses and/or in patients with a risk of forming blood clots.**
- **If you experience any of these side effects, call your doctor right away.**

You should not use FEIBA if:

- You had a previous severe allergic reaction to the product (reactions causing discomforts that are damaging and life threatening)
- You have signs of development of small blood vessel clots throughout the body
- You have sudden blood vessel clots or blocked blood vessels, (e.g., heart attack or stroke)

Events involving blood clots blocking blood vessels can occur with FEIBA, particularly after receiving high doses and/or in patients with risk factors for clotting.

Infusion of FEIBA should not exceed a dose of 100 units per kg body weight every 6 hours and daily doses of 200 units per kg of body weight. Maximum injection or infusion rate must not exceed 2 units per kg of body weight per minute.

References: 1. Pergantou H, Matsinos G, Papadopoulos A, Platokouki H, Aronis S. Comparative study of validity of clinical, X-ray and magnetic resonance imaging scores in evaluation and management of haemophilic arthropathy in children. *Haemophilia*. May 2006;12(3):241-247. 2. Gringeri A, Ewenstein B, Reininger A. The burden of bleeding in haemophilia: is one bleed too many? *Haemophilia*. Jul 2014;20(4):459-463. 3. FEIBA Prescribing Information. 4. Antunes SV, Tangada S, Stasyshyn O, et al. Randomized comparison of prophylaxis and on-demand regimens with FEIBA NF in the treatment of haemophilia A and B with inhibitors. *Haemophilia*. 2014;20(1):65-72.

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At first sign or symptom of a sudden blood vessel clot or blocked blood vessel (e.g., chest pain or pressure, shortness of breath, altered consciousness, vision, or speech, limb or abdomen swelling and/or pain), stop FEIBA administration promptly and seek emergency medical treatment.

Allergic-type hypersensitivity reactions, including severe, sometimes fatal allergic reactions that can involve the whole body, can occur following the infusion of FEIBA. Call your doctor or get emergency treatment right away if you get a rash, hives or welts, experience itching, tightness of the throat, vomiting, abdominal pain, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Because FEIBA is made from human plasma it may carry a risk of transmitting infectious agents, e.g., viruses, the variant Creutzfeldt-Jakob disease (vCJD) agent and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent.

The most frequent side effects observed during the prophylaxis trial were anemia, diarrhea, bleeding into a joint, signs of hepatitis B surface antibodies, nausea, and vomiting.

The serious side effects seen with FEIBA are allergic reactions and clotting events involving blockage of blood vessels, which include stroke, blockage of the main blood vessel to the lung, and deep vein blood clots.

Call your doctor right away about any side effects that bother you during or after you stop taking FEIBA.

Please see next page for Important Facts about FEIBA.

To see the Full Prescribing Information, including BOXED WARNING on blood clots, go to www.FEIBA.com.

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

Shire

Important Facts about FEIBA (Anti-Inhibitor Coagulant Complex)

What is FEIBA used for?

FEIBA (Anti-Inhibitor Coagulant Complex) is used for people with Hemophilia A or B with Inhibitors to control and prevent bleeding episodes, before surgery, or routinely to prevent or reduce the number of bleeding episodes. It is NOT used to treat bleeding conditions without inhibitors to Factor VIII or Factor IX.

When should I not take FEIBA?

You should not take FEIBA if you have had hypersensitivity or an allergic reaction to FEIBA or any of its components, including factors of the kinin generating system, if you have a condition called Disseminated Intravascular Coagulation, which is small blood clots in various organs throughout the body, or currently have blood clots or are having a heart attack. Make sure to talk to your healthcare provider about your medical history.

What Warnings should I know about FEIBA?

FEIBA can cause blood clots, including clots in the lungs, heart attack, or stroke, particularly after high doses of FEIBA or in people with a high risk of blood clots. Patients that have a risk of developing blood clots should discuss the risks and benefits of FEIBA with their healthcare provider since FEIBA may cause blood clots. FEIBA can cause hypersensitivity or allergic reactions and infusions site reactions, and these reactions can be serious. Because FEIBA is made from human plasma, it may carry the risk of transmitting infectious agents, for example, viruses, including Creutzfeldt-Jakob disease (CJD) agent, and the variant CJD agent. Although steps have been taken to minimize the risk of virus transmission, there is still a potential risk of virus transmission.

What should I tell my healthcare provider?

Make sure to discuss all health conditions and medications with your healthcare provider. If you are pregnant or are planning to become pregnant, or are a nursing mother, make sure to talk with your healthcare provider for advice on using FEIBA.

What are the side effects of FEIBA?

The most frequent side effects of FEIBA are: low red blood cell count, diarrhea, joint pain, hepatitis B surface antibody positivity, nausea, and vomiting. The most serious side effects of FEIBA include: hypersensitivity reactions, including anaphylaxis, stroke, blood clots in the lungs, and blood clots in the veins. Always immediately talk with your healthcare provider if you think you are experiencing a side effect.

What other medications might interact with FEIBA?

The use of other clotting agents with FEIBA is not recommended, for example, tranexamic acid and aminocaproic acid. Be sure to talk with your healthcare provider and pharmacist about all medications and supplements you are taking.

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

The risk information provided here is not comprehensive. To learn more, talk about FEIBA with your healthcare provider or pharmacist. The FDA-approved product labeling can be found at http://www.feiba.com/us/forms/feiba_pi.pdf or by calling 1-800-423-2090 and selecting option 5.



Eagle Quest

Eagle Quest is a unique camp experience for those 18 and older. While being responsible for their own medical needs, including prophylactic and on-demand treatment, as well as all gear, food, and water, campers experience daily moments of self-reliance and exploration on the uninhabited North Manitou island. David Lattas shares a snapshot of their weeklong adventure on the island.

"North Manitou Island features almost 23 miles of maintained trails. These trails wind through beautiful woods of beech and maple, across old farm fields, and along bluffs that border Lake Michigan. The terrain is gentle on the island and we found it level and relaxing.

Our trip started at the Ranger Station on the east side and continued into the "Wilderness." We camped at Old Stormer Camp, at the site of the Crescent Dock, and spots overlooking Lake Michigan. Our water came from Lake Manitou, near the Pole Bridge and Lake Michigan (filtered of course). Breakfast and dinner were cooked in camp with our new stoves using freeze-dried food, all of which was delicious.

The nights were filled with the sounds of whispering winds, lake waves, deer roaming nearby, a few snores, and even a wayward coyote. Best of all was the sense of adventure and camaraderie shared by those who hiked together. It was a trip to remember and cherish."

We hope you consider taking a break from our plugged-in lives next year to join us on the personal journey that is Eagle Quest.

Eagle Outpost

Tim Wicks

HFM's Eagle Outpost is a weeklong adventure throughout Michigan where teens learn leadership skills, team building, and outdoor survival skills while tent camping and participating in high and low adventure activities.

This year, our Outpost group consisted of all boys (though Outpost is not exclusive to boys). The teens started the week at Grace Adventures in Mears, MI, to test their limits on a high ropes course, zip-line, and giant's ladder under the supervision of the Eagle Outpost staff, along with the guidance of Grace Adventures staff. From there, the group traveled north to set up camp at Traverse City State Park. Throughout the week, our teens participated in a climbing tower, laser tag, and tubing down the Platte River, and even a relaxing time at Grand Traverse Bay.

As the week progressed, the group experienced moments of struggle and success as they worked together through challenge courses and cook crews, each experience fostering a greater sense of friendship and community.

"It was a joy to spend time with the young men in our community and even more exciting to watch their self growth throughout the week."





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Eagle Expedition

Eagle Expedition is a weeklong adventure to Northern California in which participants learn leadership skills in a high adventure environment. Adventures include white water rafting, sea kayaking, and tent camping. For many participants, these activities are a step outside their comfort zone and push them to grow individually. Troy, 21, shared how his first time attending Expedition impacted his life.

“My first experience with the HFM community was at Eagle Expedition in 2014. I didn’t know what to expect; I didn’t know anyone from HFM and

wasn’t completely comfortable with the experience that was about to happen. Within the first day, the group was embarking on life changing experiences and I already felt welcomed in the HFM family.

Throughout the week, I got to know the HFM community and felt more comfortable in my surroundings. I bonded with many of the Camp Bold Eagle lifeguards attending Expedition and by the end of the week I was lucky to call them close friends. Our daily adventures of white water rafting brought out my love for swimming and the CBE

lifeguards continually tried to convince me to work on the waterfront at camp. Their stories about camp and the community of people I had come to know convinced me to go the next year; I even got my lifeguard certification.

Now, I can’t wait to come back each year to camp to develop the bonds I’ve created within the HFM community. I was lucky enough to join HFM for Eagle Expedition again this year and once again experienced a week filled with life changing moments and new friends.”

PAID CONSUMER OUTREACH



Science matters. Because patients matter.TM

It's because of this belief that we:

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

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

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

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



10 Lessons to Take Home from Camp Bold Eagle

Luna Zhang

- 1** The best way to start the day is with a complete body submersion in cold water—recommended method of submersion: jumping into a lake staffed by awesome lifeguards
- 2** Make some time each day to dedicate towards an individual choice or PAC (personal adventure for campers)—something that YOU enjoy doing and want to get better at or have fun with
- 3** Incorporate some movement into each day—stretching (with Anna or Gracie if they're around), running (preferably while playing Eagle Rush), or walking
- 4** A good playlist can get you hyped for anything—shout out to Cory's DJ skills. Clean up after yourself and if you're done with that, help those around you clean up—Haley's not a maid (neither were your counselors)!
- 5** You're never too cool to dance or sing a song—Keep showing us how to get D, O, W, N and stay on the sunny side
- 6** Being afraid to try something new is completely normal, but don't let fear stop you—shout out to all of you who followed up on Joe's challenge and slept outside your tent as well as those of you who completed your butterfly award!
- 7** Drink water—you CAN have too much bug juice
- 8** It's okay to miss home and at the same time not want to leave where you are—it just means you love home, but also have found a new home
- 9** You will always have a family at Camp Bold Eagle that understands your bleeding disorder; we support you and always hope for the best wherever your journey takes you
- 10** Last but not least, don't forget that the lessons you've learned (whether mentioned above or not) at Camp Bold Eagle will stay with you wherever you are or go!

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IDELVION®
Coagulation Factor IX (Recombinant), Albumin Fusion Protein





hfm
Walk'n'
on the **wild** side





Left: Becky Eckstein & her family; middle: Jackson Eckstein earned his place in NHF's Factor Club as one of our top fundraisers; right: brother James Eckstein, also earned a place in NHF's Factor Club as one of our top fundraisers. Thanks guys!

Walkin' Wild Team Love!

Becky Eckstein

It's Sunday, August 27, 2017, 7:30 am, tables are prepared, volunteers are in place, our team has our tent up and it's GO-time – Check-In for "Walkin' on the Wild Side" Detroit Zoo Hemophilia Walk.

What an amazing feeling to see the sea of red shirts stream forward as Jackson's Jungle team members gather. This year there are 85 physically-present supporters, as well as many others from across Michigan and the US who sent their well wishes and on-line contributions to support Jackson and the Hemophilia family at large. Love is the common theme as we join together emotionally, financially, and spiritually in a common cause that benefits so many children and families across Michigan and the entire country.

It's easy to raise money when family, friends, and neighbors and their family, friends, and neighbors come together to make it happen. Walk day culminates the efforts of so many who extend their love and support. Many months before, bottle drives kick-off our fundraising. What a joy to witness strangers respond in such a kind way to our porch-delivered flyer request. It asks them to place their "returnables" on their porch for pick-up on a predetermined day to be donated in support of children with bleeding disorders, raising community awareness at the same time.

It is apparent watching everyone who is here at "Walkin' on the Wild Side" that hope really does spring eternal, that love absolutely conquers all, and – most importantly – that miracles and cures are possible when everyone comes together for a common cause and unites together in love. This is why our family walks.

HFM thanks all of our walkers and team captains who joined us for this year's Walkin' on the Wild Side. Almost 1,000 walkers participated and we are grateful for all of your efforts. Whether you joined us as an individual, a small team, or a large team, your efforts all contributed to this year's success. Thank you!

Save the 2018 date!

Walk on the Wild Side with us next year, at the Detroit Zoo, on **Sunday, August 26, 2018**



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WALK FRIENDS



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

UNLOCKING YOUR SELF-POTENTIAL



ONLY ADVATE® HAS 13 YEARS OF EXPERIENCE IN THE REAL WORLD AS A RECOMBINANT FACTOR VIII¹

- Proven in a pivotal clinical trial to reduce the number of bleeding episodes in adults and children when used prophylactically*²
- Third-generation full-length molecule, similar to the factor VIII that occurs naturally in the body^{1,2}

*Multicenter, open-label, prospective, randomized, 2-arm controlled trial of 53 previously treated patients with severe hemophilia A. Two different ADVATE prophylaxis regimens (standard, 20-40 IU/kg every 48 hours, or pharmacokinetic-driven, 20-80 IU/kg every 72 hours) were compared with on-demand treatment. Patients underwent 6 months of on-demand treatment before 12 months of prophylaxis.²

The market leader in Hemophilia A treatment (as of October 2016)³

Learn more at ADVATE.com

ADVATE [Antihemophilic Factor (Recombinant)] Important Information

Indications

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 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

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.

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.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

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.

You can have an allergic reaction to ADVATE.

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.

Side effects that have been reported with ADVATE include: cough, headache, joint swelling/aching, sore throat, fever, itching, dizziness, hematoma, abdominal pain, hot flashes, swelling of legs, diarrhea, chills, runny nose/congestion, nausea/vomiting, sweating, and rash.

Tell your healthcare provider 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.

Please see the following page for the ADVATE Important Facts.

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. Elsayed M. Hemophilia Treatment. London, United Kingdom: Datamonitor Healthcare; 2016.

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532116 07/17



[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.
- Are pregnant or planning to 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 are the possible side effects of ADVATE?

You can have an allergic reaction to ADVATE.

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.

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 1-888-4-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.

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HTC News



Congratulations to **Laura McGinity, LMSW** on her appointment as Chair of the NHF Social Work Working Group. Laura is with the University of Michigan HTC.

The Social Work Working Group (SWWG) is a professional working group under the organizational auspices of the Medical and Scientific Advisory Council (MASAC) of the National Hemophilia Foundation (NHF). The SWWG is a group of social work leaders from the national bleeding disorders community and represents eight federally funded HRSA regions. The primary goal of the SWWG is to actively initiate, plan, and assume responsibility for special Working Group projects including the psychosocial

programming track of the NHF Annual meeting.

It is also a wonderful opportunity to represent, advocate and promote the social work profession at a national level.

Robert F. Loudon MSW, LCSW, Social Worker Indiana Hemophilia and Thrombosis Center, Inc. is the new Regional V East representative for the SWWG. Congratulations!

Community Nights: Bowling for Bleeders



HFM continued outreach efforts across Michigan with two Community Nights in September. In addition to family fun at bowling alleys in Traverse City and in Grand Rapids, nearly 80 participants learned more about current legislative issues and HFM's advocacy efforts on the state and federal levels.

Special thanks to our Traverse City event sponsors

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Special thanks to our Grand Rapids event sponsors

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Join us in Lansing on Fri., Nov. 10th!

Spare Time Entertainment Center
3101 E Grand River Ave, Lansing, MI 48912
RSVP to Carrie McCulloch, 734.961.3503 or
cmcculloch@hfmich.org

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

Adoption Opportunities



ADRIAN

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



DEVIN

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

Looking
for **FOREVER**
FAMILIES
for these
children!

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

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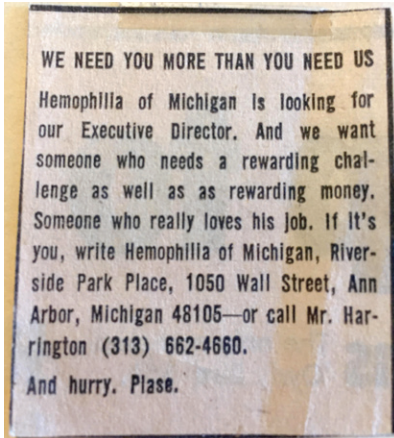
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Thank you Marv Williams!

We honor Marv Williams as a wonderful advocate and dear friend to Michigan's bleeding disorders community



Left: A recent photo of Marv Williams with his wife, Sandra; right: Marv circa 1970s, from HFM archives.



Marv Williams responded to this ad for HFM's first Executive Director.

Late summer in 2016 I met Marv Williams when my husband and I attended Dr. John Penner's private memorial service in Grand Haven. Dr. Penner had been instrumental in hiring Marv as HFM's first Executive Director. Along with Dr. Penner and Bob Molhoek, Marv played an important role in creating HFM's Camp Bold Eagle. I had heard wonderful things about Marv throughout the years - and had recently attempted to locate him online. So, following a beautiful service which culminated in the release of butterflies to celebrate Dr. Penner's life, Marv and I, together with our (very patient!) spouses, Sandra and Dan, spent the afternoon reminiscing about Dr. Penner, Camp Bold Eagle and Marv shared his early experiences working with the community to help build HFM. Last year, Marv assisted our HFM team in pulling together information for HFM's 60th anniversary article. I am so grateful I had the opportunity to spend such a special afternoon with Marv Williams. ***HFM's deepest appreciation to Marv and his family for their dedication to Michigan's hemophilia community.***



Marvin Wayne Williams, 81 of Spring Lake, passed away peacefully on September 25, 2017, at home. He is preceded in death by his parents, Berwick and Inez Mossman Williams, of Burton, Michigan. He is survived by his wife, Sandra, with whom he celebrated their 56th wedding anniversary on September 1, his sister, Lee Ann and husband, Grant, of Swartz Creek and his children, Matthew of Mt. Dora, Florida, Paul and wife, Wendy, of Grayling, Michigan, daughter Ellen and husband, Craig Byron, of Macon, Georgia, and daughter Betsy and husband, Tom Dansbury, of Enterprise, Alabama. His greatest joy came from engaging and watching his grandchildren, Taylor Rae and partner Tyler, Grace, Julia, Will, and great grandson, Jayce, learn and grow. He enjoyed the love and affection of the extended Phillips family and friendships that spanned his lifetime.

Born in Dexter, Missouri, in 1936, Marv grew up in Flint, Michigan, where he attended Mandeville Schools. Upon graduation from high school, he joined the US Air Force and spent two years of his service stationed in Spain, which engendered a lifelong love of the Spanish language. He furthered that love by attending and graduating

from the University of the Americas in Mexico City, Mexico after his discharge. Heeding the call by John F. Kennedy to serve his country, he later joined the CIA, where he worked as a field agent in Latin America. Upon leaving the agency, he returned to Michigan with his young family where he was appointed the first Executive Director of the Hemophilia Foundation of Michigan when it was in its infancy. Marv considered his work for that body to be the most important of his life.

Under his leadership, the foundation initiated a statewide census of the population, expanded the summer camp, laid the foundation for the development of home treatment, and created a scholarship program. Ever the humble man, Marv would never take full credit for those accomplishments, always citing the support, wise counsel, and friendship he received from Bob Molhoek and Dr. John Penner. Marv would later move his growing family to the Upper Peninsula, where he would serve as a social worker for Community Mental Health for Alger-Marquette counties until retiring. Following retirement, he moved to Florida to help care for his father and mother-in-law, Albert and Bernice Phillips, and became a well-

known and respected handyman in Mt. Dora, Florida. Working with his hands had always brought him pleasure, which was magnified when that work brought people happiness.

Marv would be the first to say that a measure of person isn't the work one does, but the relationships one keeps. At every step of his life, his family, wife, Sandra, children Matt, Paul, Ellen, and Betsy, father and mother-in-law, sister Lee Ann, brothers and sisters-in-law, daughter-in-law, Wendy, and sons-in-law, Craig and Tom, nieces, nephews, and eventually grandchildren were his greatest source of joy. Marv had a way with people. He was a magnificent storyteller, captivating people with his voice and his choice of words. He could create intimacy and allow others to unfold their lives to him in conversation, and this meant that his life was filled with too many dear friends to count, all of whom Marv loved deeply. His was a life well lived and well loved.

In lieu of flowers, donations in Marv's honor may be made to the Hemophilia Foundation of Michigan and designated for the scholarship fund, which Marv established in 1971.



Join us
for this
FREE
event!



Butterfly Breakfast at the Cider Mill

Saturday, November 4, 2017
10am – 12pm

Join us for a morning of fall, family fun at the Plymouth Orchards and Cider Mill. Enjoy a tractor wagon ride, visit with farm animals, participate in fun kids' activities and watch apple cider being made. While enjoying cider and donuts, we'll learn more about HFM's advocacy efforts across the state. It's a great event to connect with others in the bleeding disorder community. **RSVP REQUIRED:** go to www.hfmich.org/cidermillreg, or contact Meghan Mair Crosslin at mmcrosslin@hfmich.org. We hope you can join us for this complimentary event! **Please dress to be outside.**

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

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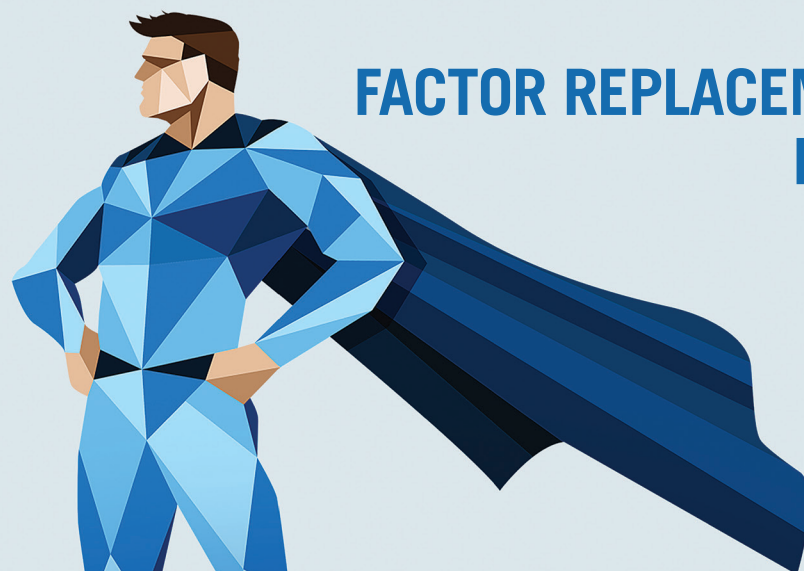
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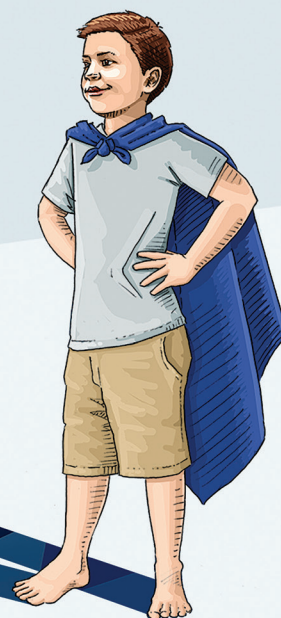
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References: **1.** Peyvandi F, Garagiola I, Young G. The past and future of haemophilia: diagnosis, treatments, and its complications. *Lancet*. 2016;388:187-197. **2.** Wolberg AS. Plasma and cellular contributions to fibrin network formation, structure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

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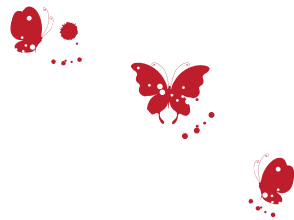
Delta Dental Program

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Dawn Bowles, Delta Dental Program Participant

“Your dental program saved my life! I have a lot to smile about!”



Many women find that receiving a bleeding disorder diagnosis can be a long and curvy road. Dawn Bowles is no stranger to that journey. She vividly remembers bleeding profusely into a towel after recovering from a tonsillectomy at eight years old. Her doctors could not identify the source, and her family, burdened with other bills, could not afford to follow up with additional testing. Although she had two uneventful births, Dawn suffered for many decades with heavy periods before she was finally diagnosed with Factor XIII deficiency. A second bleeding disorder diagnosis came in a most unusual way.

In early 2006, Dawn went for a routine physical with her primary care physician. At that time, they found a heart murmur. Further testing revealed major blockages and Dawn faced a triple bypass and mitral valve replacement. Although they treated her Factor XIII deficiency she experienced significant post-operative bleeding complications and was subsequently diagnosed with vWD.

In 2015, by chance, Dawn learned about the Hemophilia Foundation of Michigan and the Delta Dental Program funded through

Cascade. She, more than anyone, understands that our teeth are interconnected with our well-being and our health. Periodontal disease and tooth infections had caused Dawn to develop endocarditis, a bacterial heart infection which commonly occurs in people with certain heart conditions.

“I had been so sick with endocarditis. Finding the Delta Dental program was perfect timing because I could get the cleanings and dental work I needed.”

Regular dental cleanings help keep periodontal tissue healthy which is essential to prevent bleeding and tooth loss. But, as Dawn can agree, it also promotes good heart health.

“Your dental program saved my life! I have a lot to smile about!”

Dawn was able to have six teeth replaced through the program and plans to have regular periodontal cleanings with her dentist. “I wouldn’t want anyone else to go through what I went through. This program is wonderful,” Dawn states, as she smiles her beautiful new smile.

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.



2017 Events

November 4, 10am-12pm

**Butterfly Breakfast
at the Cider Mill**

Plymouth Orchard & Cider Mill
10685 Warren Road
Plymouth, MI 48170

RSVP online at:

www.hfmich.org/cidermillreg

Or contact Meghan Mair Crosslin
at mmcrosslin@hfmich.org

November 10, 6:30-9:30pm

**Community Nights:
Bowling for Bleeders**

Spare Time Entertainment Center
3101 E Grand River Avenue
Lansing, Michigan 48912

RSVP by contacting

Carrie McCulloch at
cmcculloch@hfmich.org
734.961.3503

December 2, 1-3pm

**End of the Year
Community Gathering**

Troy High School
4777 Northfield Parkway
Troy, Michigan 48098

RSVP by Tuesday, Nov. 28

Online:

www.hfmich.org/holidayparty

Or contact Carrie McCulloch at
cmcculloch@hfmich.org
734.961.3503

December 16, 3-7pm

Camp Holiday Party

HFM Office
1921 West Michigan Avenue
Ypsilanti, Michigan 48197

RSVP by contacting

Tim Wicks at
twicks@hfmich.org
734.961.3507

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learn more about
our 2018 offerings!**

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1921 West Michigan Ave.
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Join us at HFM's End of the Year Community Gathering!

Saturday, December 2, 2017, 1-3pm

RSVP by Tuesday, Nov. 28, Go to: www.hfmich.org/holidayparty

Or contact Carrie McCulloch at cmcculloch@hfmich.org, 734.961.3503

