the anterverse of the serving Michigan's bleeding disorders community Fall 2018



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

CBE's 50th Summer





- 2 Message from HFM's Executive Director Sue Lerch
- 3,5 50 Summers of Camp
- 6 Eagle Outpost CBE Campers Share Their Thoughts
- 10 Eagle Expedition Eagle Quest
- 11 Medicaid Senate Bill 87 and HB 5716
- 11 Community Nights
- 14 Swinging for Smiles Golf Outing
- 14 Delta Dental Insurance
- 15 SpringFest

MC 1176 JR

- 16 Scholarship Awardees
- 19 Butterfly Benefit HFM's Women's National Conference
- 22 Lansing Days
- 24 Calendar and End of the Year Gathering

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We Are Community, We Are Family!



Dear HFM family,

Welcome to our camp issue celebrating 50 summers of HFM's Camp Bold Eagle!

Throughout The Artery you'll find fun, sweet pictures and interesting stories highlighting HFM's 2018 camp programs as well as our history as we honor our past, present - and future. It is a tribute to those who founded HFM and camp that CBE and our other HFM Eagle Journeys' programs continue to have an extraordinary impact on those who participate as campers, staff, leaders and supporters.

Camp's original 'can-do' spirit remains paramount.

HFM works year-round to provide nearly seven weeks of outstanding, quality summer camp programming. We have enhanced our summer offerings and include fall and winter specialized youth weekend retreats and education, recently adding our swim program, **Detroit Swims**, in collaboration with Children's Hospital of Michigan and the Boll Family YMCA in Detroit.

This past summer while I spent time at Camp Bold Eagle on Pioneer Trails' Big Blue Lake, I thought about my first years at camp back in the 1980s and early 1990s. Our campers, counselors and HTC medical staff worked so closely as we faced the crushing reality of HIV/AIDS. **Camp provided an expanded source of love, camaraderie and family that was so deeply needed as our hearts were breaking.**

I know that the influence and authenticity of CBE's history continues today. As treatment modalities evolve with tremendous advancements together with the further expansion of science's understanding of bleeding disorders, **I believe camp will continue and perhaps expand in importance to our community.** We now have campers who have never "experienced" a bleed thanks to prophylactic treatments. For some kids there will be subcutaneous treatment rather than ports or self infusion. Girls and women affected by bleeding disorders are being recognized and listened to. This is an exciting and exhilarating time!

Yet, we believe campers will want to understand how their body is affected, understand break-through bleeds, realize that others also sometimes feel different, make friends who really get it when you talk about living with hemophilia - or von Willibrand disease - or carrying the gene - or another rare bleeding disorder. Camp Bold Eagle, Eagle Quest, Eagle Outpost, Eagle Expedition each offer opportunities to share challenges, dreams and desires under the stars with people who understand living with a rare disorder.

This summer watching our youngest campers become comfortable swimming in the lake, the delight of hearing first-hand from Jace that he accomplished his Butterfly Award, seeing my grandchildren play on the beach while their dad worked like crazy running the camp – this brought complete joy.

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

PAID CONSUMER OUTREACH INCLUDED IN THIS NEWSLETTER.



Sarah Procario

Camp Bold Eagle–originally called Camp Bold Eagle Highlands–celebrated 50 summers of camp in July 2018. Throughout the past 49 years, Camp Bold Eagle has grown in numbers, changed directors, moved locations, and survived deeply challenging times.

HFM created the first camp for children with bleeding disorders, starting in 1969 at Clear Lake. Dr. John A. Penner, a founding member of the Hemophilia Foundation of Michigan, and Dr. Jeanne Lusher were instrumental in establishing Camp Bold Eagle (CBE). As the first camp of its kind in the nation, CBE accepted children from across the country, including Wisconsin, Delaware, Missouri, Texas, Indiana, Ohio, Illinois, and New Jersey. There were even children from Belgium and France. (To this day, HFM welcomes teens from Germany on Eagle Outpost.)

In 1975, Camp Bold Eagle was recognized for pioneering the hemophilia camping program. Marv Williams, HFM's first executive director, shared that HFM received an enormous amount of help from the University of Michigan, Eastern Michigan University, and Michigan State University to make camp a reality. And, similar to our 2018 camping experience, camp in the early days employed counselors, CIT's, and college students.

For the newer generation, Pioneer Trails has always been the home of Camp Bold Eagle, but in the early years, camp traveled from area to area. After the first year at Clear Lake, camp was held at Mill Lake, Cedar Lake, Camp Nahelu, Camp Wathana, Camp Hayo Went Ha (Torch Lake), U of M Fresh Air Camp (Pinckney), Camp Copneconic, and finally, in 1994, Camp Pendalouan which later became Pioneer Trails. (I highly recommend studying this list for future camp trivia nights!)

In the 1980s, camp, and the entire bleeding disorders community, began to feel the devastating impact of the HIV/AIDS epidemic. In 1982, the CDC reported the first HIV/AIDS cases among people with hemophilia due to the use of contaminated blood products. Through the next decade, about half of the hemophilia population became infected with HIV and thousands died. Around the same time, 44% of all people with hemophilia contracted the hepatitis C virus. As the community became sick, so did CBE camp counselors. The



Ken Martin

I first attended camp at age 7 in 1974. I went every year through 1992, I believe. I participated as a camper, an initial Eagle Outpost member, a CIT, and as a Counselor. I also ran Outpost with Rick McCoy 1989-1992.

Favorite memories of camp:

Tie-dyeing your camp shirt when you get to camp, catching bull frogs at Cedar/Mill Lake and having races with other kids, swimming a mile, watching Friday the 13th with the staff on their day off as a 12-year-old, learning responsibility and life skills, receiving trust and respect, and while not my favorite but equally important, providing comfort when needed. And most importantly, having memories that will last a lifetime and being proud to know that Bold Eagle has made me who I am today and what I pass on to my sons. PAID CONSUMER OUTREACH



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

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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. Canadian Hemophilia Society. Factor replacement therapy. http://www.hemophilia.ca/en/bleeding-disorders/hemophilia-a-and-b/ the-treatment-of-hemophilia/factor-replacement-therapy/. Accessed May 18, 2018. 3. Franchini M, Mannucci PM. The history of hemophilia. *Semin Thromb Hemost*. 2014;40:571-576. 4. Hvas AM, Sørensen HT, Norengaard L, Christiansen K, Ingerslev J, Sørensen B. Tranexamic acid combined with recombinant factor VIII increases clot resistance to accelerated fibrinolysis in severe hemophilia A. *J Thromb Haemost*. 2007;5:2408-2414. 5. Antovic A, Mikovic D, Elezovic I, Zabczyk M, Hutenby K, Antovic JP. Improvement of fibrin clot structure after factor VIII injection in haemophilia A patients treated on demand. *Thromb Haemost*. 2014;111(4):656-661. 6. Berg JM, Tymoczko JL, Stryer L. Many enzymes are activated by specific proteolytic cleavage. In: *Biochemistry*. 5th ed. New York, NY: WH Freeman; 2002. https://www.ncbi.nlm.nih.gov/books/NBK22589/. Accessed May 18, 2018. 7. Shire. Shire's 70+ year commitment to the hemophilia community. https://www.shire.com/en/ newsroom/2018/january/7sossj. Accessed June 6, 2018.

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50 Summers of Camp continued from page 3

counselors eventually became so sick, many were unable to work at camp, while others tragically passed away due to the virus. In 1994, the camp director, Shelley Gerson, Head Counselor, Chris Althouse, and Dr. Kathy Fessler discussed camp's biggest problem-how hard it was to find counselors. They needed staff to fill the gap while they waited for the younger campers to become old enough to become the next generation of counselors. Kathy remembers thinking, "Med students would do anything to get out of the hospital in July." Althouse, Gerson, Fessler, and then Health Center Director, Sue Adkins began to plan it out. Medical students would have a health center rotation in their schedule to satisfy medical school requirements. Kathy

Fessler then contacted the Pediatrics Department at the University of Michigan– who were very supportive–to sponsor the program.

The next year, Dr. Cindy Ruiz became one of the first medical students to attend camp. "She was instrumental in recruiting the next class of students," Gerson says. "The medical student program raised the bar for our staff. Everyone understood that we almost lost camp."

As the years went on, camp continued to grow and Eagle Outpost was added in 1982. Over twenty years later in 2004, HFM started a special adventure camp, Eagle Expedition, a long time dream of former camp director, Andy Voegtle. And finally, our newest camp, Eagle Quest was added in 2015 as a way to continue the camping experience for adults with bleeding disorders.

As we reflect on the past summer, we also reflect on the past 49 years of camp. The bleeding disorders community has created a camp environment of community, understanding, and support over the past 50 summers. CBE would not be the place it is today without the dedication and commitment of all those who came before us. We bring their memory and spirit with us as we continue the Camp Bold Eagle tradition.

Tim Wicks

- · Attended Outpost once as a camper in 1999
- Has worked at CBE and Outpost since 2000 (Missed 2002 Outpost)
- Attended or worked Expedition from 2005-2015
- Currently, HFM Youth Services Manager and Camp Director

"In 1999, my first camp interaction with HFM, I remember singing the banana song and going bananas at the end. Chris Althouse turned to Mistie Sharkey and said, 'We gotta get him as a CIT next year.' It was the first time I remember the staff at a camp invested in keeping me around for the long-term."



"Camp is the place I feel the most at home."

~Tim Wicks

Fall '18 hfmich.org 5



Outpost: From Camper to Counselor

Emily Albright

2018 was my first summer as a counselor at Eagle Outpost. As a former camper at Outpost, I was really interested in seeing the program from a new perspective. The weeklong camping trip around northern Michigan included many fun and unique experiences such as climbing a high ropes course, visiting Oswald's Bear Ranch, seeing the Great Lakes, and traveling around Mackinac Island.

Outpost taught me great leadership qualities as a camper and it was one of the first moments that I remember being entrusted with true responsibility and independence at camp. It was really awesome to come back as staff and help provide the same experience to the next generation of leaders. The week included many inspiring moments from the campers. Seeing them overcome fears and take big steps towards adulthood was particularly special. Whether it was buying and cooking meals, learning how to pitch a tent, or being on the cleaning crew, the campers challenged themselves to grow as individuals and become better leaders.

Camp has been such an integral part of my personal development; I hope to continue to share my passion for camp as a counselor.

More photos at www.hfmich.org/eagle-outpost18

Camp Bold Eagle Campers Share Their Thoughts

What do you love about camp? Aidan: You get to swim & do archery, it's fun!



What is your favorite part of camp? Skylar: This is my first year. The lake is my favorite. I'll come back, I really like it. Have you met anyone at camp? Brady: a bunch of weird people!

What is your favorite part of camp? Jacob: I've been making a book in arts & crafts. What do you love about camp? Jazelle: I liked yoga this morning, I always wanted to try that. Camp is special because I actually get to take time away from home and do things I don't normally do and see old friends.

What is your favorite part of camp? Scout: How understanding people are about my food allergies. I like how everyone cares. How everyone needs to care about something, like hemophilia. They're really understanding.

6 hfmich.org Fall '18



With gratitude

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- Colburn-Keenan Foundation
- CSL Behring
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- Sterling Heights Kiwanis High Noon Club
- Warren Rotary Club
- West Michigan Bike and Fitness
- Youth Foundation of America

And all our many individual supporters who have attended and participated in HFM's events and fundraisers throughout the year!

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2018 is our most attended year yet! More than 200 campers and staff participated in Eagle Journeys' Camp Bold Eagle!

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Eagle Expedition

Anthony Stevens

Eagle Expedition 2018 was a year of growth in leadership for the participants and for me. Directing Eagle Expedition this year reminded me what it is like to step outside of my comfort zone and face new challenges while also maintaining the role as the leader. I, for example, do not normally participate in water sports. You might even say that I prefer dry land. Balancing my fear of the water and responsibilities to lead the group was new to me. I learned at Expedition that I could do both by accepting help from the other staff and participants instead of shouldering all of it on my own.

Our participants were also given the opportunity to lead in and out of their comfort zone within the same day, going from leading a cook crew to guiding a raft of six down a Class II Rapids. Their ability to adapt to each role was amazing to watch. Everyone has a comfort level when it comes to leading and our participants proved that they are willing to experience those different levels and broaden theirs. It's safe to say that the bonds created on this trip and the shared experiences will last much longer than the week we spent together on our California adventure.

More photos at www.hfmich.org/eagle-quest18

The Possibilities of Quest

"I learned a lot about camping and improved my overall backpacking expertise. I learned more about our bleeding disorders from others and how they dealt with it during the trip, and I learned a great deal about myself and expanded my comfort zone, both physically and socially.

"Quest is amazingly fun, cathartic and peaceful, and an honestly great exercise. It brings together old friends, forms new friendships, and helps make one more comfortable with the natural world around them, and that's why I really want to keep going back." ~ Tyler "Things I learned:

Deer like to eat urine because of the salt content. Lake Michigan is WAY colder and way more oceanlike than I was expecting. Green water tastes as gross as it looks. It is possible to pick a hammocking spot that allows two people to talk without getting out of bed. I'm probably not sensitive to poison ivy. *crosses fingers*

"And on a more serious note, which you were probably looking for... I learned that, contrary to previous belief, I am physically capable of going on a backpacking trip and carrying everything I need, INCLUDING factor and meds.

"With a little effort put in, I'm able to get along with a totally mixed bag of people and make friends.

"I have it in me to be strong and self-sufficient both mentally and physically!"

advocacy update sarah Procario

Medicaid Senate Bill 87 and HB 5716

On Friday, June 20, 2018, Governor Snyder signed the Medicaid work requirements bill.

The final bill applies to the Healthy Michigan expansion population-Michiganders who are between 100-138% of the federal poverty limit, about 670,000 people in the state.

The bill requires those who do not qualify for an exemption to work, train, and attend school for 80 hours a month to receive benefits. It is important to remember that not all Medicaid recipients will be subject to the work requirements. If you receive traditional Medicaid due to disability or income below 100% of the federal poverty limit, you will see no change.

The bill also includes exemptions for disability caretakers, parents of children under six, pregnant women, people

receiving disability benefits, and those who are medically frail, which may include patients diagnosed with hemophilia, VWD, and other factor deficiencies.

A few caveats...

The passage of this legislation does not immediately change Medicaid. The work requirements legislation requires the Michigan Department of Health and Human Services to apply for an 1115 waiver that will allow the state to make the intended changes. (Medicaid is a joint state and federal program, so Michigan must get approval from the federal government-the Centers for Medicaid and Medicare-for changes to the program.) If the federal government approves the waiver, Michigan will begin to implement changes to the Medicaid program.

There is language in the bill that would end the expansion altogether if the federal government does not approve the waiver within one year.

After patients are on Healthy Michigan for four years, their premiums will increase from 2 to 5% of their income.

On July 9, Michigan released a Section 1115 Demonstration Extension Application for the Healthy Michigan Plan. However, the state failed to adhere to federal rules for the comment period by not including an estimate of expenditures. HFM and the Hemophilia Federation of America signed on to a letter requesting that the comment period be reopened for 30 days.

The waiver is currently under review by the Centers for Medicare and Medicaid. HFM is monitoring its process and will keep the community informed.



In 2016, HFM created "Community Nights" to increase community connection and education for individuals across the state. We have currently held two of our four annual Community Nights for 2018. On April 6, 50 attendees joined HFM at Merri-Bowl in Livonia for dinner, bowling, and discussion of bleeding disorders across the life span. And on June 8, 66 attendees joined HFM at Craig's Cruisers in Grand Rapids, with 25 more on the waitlist. HFM shared resources on dental hygiene before community members enjoyed the fun. With such a large state, opportunities to connect with fellow bleeders in a casual setting are invaluable.

We hope to see more community members from Traverse City on October 26 and from Lansing on November 2. Register through Carrie McCulloch at cmcculloch@hfmich.org, 734.961.3503

Special thanks to our sponsors for both our Livonia and Grand Rapids events.

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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 ADYNOVATE 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 \geq 12 years (N=137) evaluated the efficacy, PK, and safety of ADYNOVATE 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 bleeds¹

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

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

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 (HCP) 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.

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADYNOVATE?

Do 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 HCP if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

What should I tell my HCP before using ADYNOVATE?

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 ADYNOVATE passes into your milk and if it can harm your baby.
- Are or 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).

What important information do I need to know about ADYNOVATE?

- 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.
- Do not attempt to infuse yourself with ADYNOVATE unless you have been taught by your HCP or hemophilia center.

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. 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 ADYNOVATE?

• The common side effects of ADYNOVATE are headache and nausea. These are not all the possible side effects with ADYNOVATE. 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 ADYNOVATE on the following page and discuss with your HCP.

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

References: 1. ADYNOVATE 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.

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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.
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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.shirecontent.com/PI/PDFs/ ADYNOVATE_USA_ENG.pdf or 855-4-ADYNOVATE.

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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Grace Lawrence

When Tim Wicks asked me to speak at HFM's Golf Outing I was nervous, not because I wouldn't know what to talk about, but because I had too many good things to say about camp and barely knew where to begin.

I have been lucky enough to go to camp since I was 7 years old. I grew up looking forward to that one week every summer when I could sleep in bunk beds, swim in the lake, do arts and crafts, and see all of my close camp friends.

At 16 years old, I was able to return to camp as a counselor-in-training, a 'CIT,' where I witnessed first hand how Camp Bold Eagle changes the lives of children with bleeding disorders. Campers get to stay away from home, some for the first time ever. With this freedom, their confidence and independence begin to shine through. They learn to deal with homesickness, meet new people, and

More photos at www.hfmich.org/golfphotos

generally challenge themselves everyday. Some campers even learn how to infuse their own factor, which is a skill that makes them feel empowered and a little more in control of their own lives. The lessons learned at camp, the skills adopted, support these children even as they leave the camp environment.

But most importantly, they are surrounded by kids who are just like them. For the first time they don't have to explain what hemophilia or VWD is to their peers. It is these relationships that have the most profound impact on children–these bonds will last a lifetime, for myself, the other staff, and most importantly, the campers.

It was a true pleasure to share my personal experience at camp with the golfers. Thank you to all those who participated in the Golf Outing. Your support of camp truly changes lives.

Delta Dental Insurance

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











SpringFest 2018, which took place the third weekend in April, showcased a number of national speakers from the bleeding disorders community. We were thrilled to have Patrick James Lynch (www.patrickjameslynch.com) share his challenging life story with us on Friday evening. He has a wonderful way of mixing humor and compassion into his storytelling that brings a smile to our faces while we are also confronted with our sadness for the loss of so many in our community, including Patrick's brother at a young age. Patrick is involved in many creative projects including his video web series "Stop the Bleeding" (www.hfmich.org/stopthebleeding), which showcases the foibles and antics of a group of people helping out the bleeding disorder community in a manner that educates while having fun.

We were excited that **Chris Bombardier** (www.bombardierblood.com) also

joined us for the weekend, leading programming for our teens on Saturday and speaking to our community on Sunday morning. Chris has an amazing life story that is currently being made into a film by Patrick James Lynch's production company, Believe Limited. The movie chronicles Chris' efforts and ultimate success to summit Mt. Everest as the first person with hemophilia to attempt this feat.

Katherine High, M.D., presented the latest findings in gene therapy studies. Dr. High explained the different approaches to gene therapy and the AAV trials that are moving forward. Her expertise, clarity, and passion brought an excitement to the presentation.

We were very fortunate to have Jeanne White-Ginder join us in our remembrance room on Saturday and speak to our group on Sunday. She shared her experiences as a spokesperson for people living with a bleeding disorder and HIV/AIDS, and the joys and struggles of her son Ryan White.

In addition to these wonderful speakers, SpringFest welcomed 54 additional speakers throughout the weekend event, presenting on topics such as genetic testing, insurance, pain management, and participating in a research study. The 650 attendees from the Michigan community truly had a remarkable weekend learning and talking with these experts as well as with one another.

We utilized Facebook Live to capture several talks from our speakers. To view this feed, visit HFM's Facebook page.

Thank you to everyone who joined us for a weekend of education and connection. We look forward to seeing you all back at the **Marriott at Eagle Crest, April 26-28, 2019**.



Scholarship Awardees

HFM awards two \$2,500 academic scholarships every year at SpringFest. The 2018 recipients are Troy Longman & Rachel Basela.

Troy and Rachel both spent their summer before school working at Camp Bold Eagle, Troy as the Waterfront Director and Rachel as a lifeguard and cabin counselor. Troy and Rachel are such positive young adults who have made significant contributions to our community through their work at camp. We wish them the best of luck on their next adventures.

These awards were presented by Committee Chair and first-ever HFM scholarship recipient Lynn Ray Allen.



Troy Longman

I completed my bachelor's degree in criminal justice from Ferris State University in 2017 and will be attending law school beginning August of 2018. I sincerely appreciate the support of HFM and the value they place on higher education. Pursing a law degree is challenging and comes at a high cost. It is encouraging to know that those at HFM believe in my abilities and support my goals.



Rachel Basela

The Hemophilia Foundation of Michigan has been a constant source of support in my life ever since my younger brother was born in 2005. Receiving this scholarship means that I can continue my efforts to give back to the community that has always provided me with so much. Last year, I was lucky enough to attend Camp Bold Eagle for the first time as a Counselor In Training. CBE showed me the lives of these children in a way that is very hard to put into words (anyone who's ever been to camp will understand this). I love camp, I love this community, and I love the pure inner-strength that these children encompass. I'm looking forward to seeing where this community will take me next.

PAID CONSUMER OUTREACH

In hemophilia B TAKE CONTROL TO A HIGH LEVEL WITH REBINYN®

In two phase 3 studies, factor levels were evaluated for 1 week after the first dose of Rebinyn® 40 IU/kg. The average levels after 7 days were 16.8% in 6 adults, 14.6% in 3 adolescents, 10.9% in 13 children ages 7 to 12 years, and 8.4% in 12 children up to age 6 years. Image of hemophilia B patient shown is for illustrative purposes only.

INDICATIONS AND USAGE

What is Rebinyn[®] Coagulation Factor IX (Recombinant), GlycoPEGylated?

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

IMPORTANT SAFETY INFORMATION What is the most important information

 I need to know about Rebinyn[®]?
 Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center. Carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing Rebinyn[®].

Who should not use Rebinyn®?

- Do not use Rebinyn[®] if you:
- are allergic to Factor IX or any of the other ingredients of Rebinyn[®].
 are allergic to hamster proteins.

What should I tell my health care provider before using Rebinyn[®]?

- Tell your health care provider if you: • have or have had any medical conditions.
- take on have that any medical conc.
 take any medicines, including non-prescription medicines and dietary supplements.
- are nursing, pregnant, or plan to become pregnant.
- have been told you have inhibitors to Factor IX.

How should I use Rebinyn®?

 Rebinyn[®] is given as an infusion into the vein. Call your healthcare provider right away if your bleeding does not stop after taking Rebinyn[®].

Factor IX

(FIX) levels

sustained after 7 days with a single 40 IU/kg dose in adults with ≤2% factor levelsª

• Do not stop using Rebinyn[®] without consulting your healthcare provider.

What are the possible side effects of Rebinyn®?

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

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

Clayton lives with hemophilia B.

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Coagulation Factor IX

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

Rebinyn® is a prescription medication. 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.



(Recombinant), GlycoPEGylated



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rebinyn®

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

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

Rx Only

This information is not comprehensive.

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

Read the Patient Product Information and the Instructions For Use that come with REBINYN® before you start taking this medicine and each time you get a refill. There may be new information.

This Patient Product Information does not take the place of talking with your healthcare provider about your medical condition or treatment. If you have questions about REBINYN® after reading this information, ask your healthcare provider.

<u>What is the most important information I need</u> to know about REBINYN[®]?

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

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

What is REBINYN®?

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

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

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

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

Who should not use REBINYN®?

You should not use REBINYN® if you

- are allergic to Factor IX or any of the other ingredients of REBINYN[®]
- if you are allergic to hamster proteins

If you are not sure, talk to your healthcare provider before using this medicine.

Tell your healthcare provider if you are pregnant or nursing because REBINYN® might not be right for you.

<u>What should I tell my healthcare provider</u> <u>before I use REBINYN®?</u>

You should tell your healthcare provider if you

- Have or have had any medical conditions.
- Take any medicines, including non-prescription medicines and dietary supplements.
- Are nursing.
- Are pregnant or planning to become pregnant.
- Have been told that you have inhibitors to Factor IX.

How should I use REBINYN®?

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

REBINYN® is given as an infusion into the vein. You may infuse REBINYN® at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your hemophilia treatment center or healthcare provider. Many people with hemophilia B learn to infuse the medicine by themselves or with the help of a family member.

Your healthcare provider will tell you how much REBINYN® to use based on your weight, the severity of your hemophilia B, and where you are bleeding. Your dose will be calculated in international units, IU.

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

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

<u>Use in children</u>

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

If you forget to use REBINYN®

If you forget a dose, infuse the missed dose when you discover the mistake. Do not infuse a double dose to make up for a forgotten dose. Proceed with the next infusions as scheduled and continue as advised by your healthcare provider.

If you stop using REBINYN®

Do not stop using REBINYN[®] without consulting your healthcare provider.

If you have any further questions on the use of this product, ask your healthcare provider.

What if I take too much REBINYN®?

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

What are the possible side effects of <u>REBINYN®?</u>

Common Side Effects Include:

• swelling, pain, rash or redness at the location of infusion

itching

Other Possible Side Effects:

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

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

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

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

These are not all of the possible side effects from REBINYN[®]. Ask your healthcare provider for more information. You are encouraged to report side effects to FDA at 1-800-FDA-1088.

Tell your healthcare provider about any side effect that bothers you or that does not go away.

What are the REBINYN[®] dosage strengths?

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

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

Always check the actual dosage strength printed on the label to make sure you are using the strength prescribed by your healthcare provider.

How should I store REBINYN®?

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

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

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

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

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

After Reconstitution:

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

The reconstituted REBINYN[®] should be used immediately.

If you cannot use the reconstituted REBINYN[®] immediately, it should be used within 4 hours when stored at or below 86°F (30°C). Store the reconstituted product in the vial.

Keep this medicine out of the sight and out of reach of children.

<u>What else should I know about REBINYN® and hemophilia B?</u>

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

More detailed information is available upon request.

Available by prescription only. For more information about REBINYN[®], please call Novo Nordisk at 1-844-REB-INYN. Revised: 11/2017

REBINYN[®] is a trademark of Novo Nordisk A/S. For Patent Information, refer to: http://novonordisk-us. com/patients/products/product-patents.html

Manufactured by:

Novo Nordisk A/S

Novo Allé, DK-2880 Bagsværd, Denmark For information about REBINYN[®] contact:

Novo Nordisk Inc. 800 Scudders Mill Road

Plainsboro, NJ 08536, USA

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Meet Shelley, your CoRe Manager



Hello! I'm Shelley Gerson and I'm a CoRe Manager for Bioverativ. It is my job to connect you with others in the community, introduce our educational programs, and to support you on your journey. I am here so we can take action together! I also have severe hemophilia A.

Contact me!

shelley.gerson@bioverativ.com | 781.663.1807

Bioverativ 🚖

f Connect with Us @BioverativCoRes

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Sarah Procario

HFM's Butterfly Benefit was held on Thursday, May 10, 2018 at the Grand Rapids Art Museum. Through donations and a silent auction over the course of the evening, HFM raised \$27,500 to support HFM's camps, which serve over 200 children and young adults each year.

During the dinner programming, HFM's Camp Director, Tim Wicks, interviewed HFM teen camper, Ben Boelens, about his experience at camp and how it has shaped who he is today. Tim recollected his feelings about the Benefit, "Each year, I get to share my love for camp with over 110 people at the Butterfly Benefit. Camp played such a large role in my life growing up. As the camp director, it's my privilege and duty to pass on that experience to campers like Ben. I can only hope our mission resonates with others because without the support from the community, camp wouldn't be a reality for many of our kids."

During their discussion, Ben shared how camp changed his outlook on life by gaining an understanding of the challenges facing the bleeding disorders community. With this knowledge, Ben hopes to become an advocate for the community.

HFM was also honored to present the Dr. Penner Memorial Award to Dr. Deanna Mitchell for her outstanding support and dedication to the bleeding disorders community. Dr. Mitchell shared her own perception of camp as a provider to many of the campers. It was a beautiful and powerful evening. Thank you to all those who volunteered, donated, sponsored, and attended the event. We hope to see you all next vear!

Special thanks to our sponsors

Butterfly Kiss



Soaring Eagle

Bioverativ 🚍 A SANOFI COMPANY

Happy Camper



Friends of HFM



CSL Behring

Event Sponsors Accredo Pfizer Hemophilia

Check out the photos at www.hfmich.org/benefitphotos

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

We are grateful each time a story is shared

Thanks WOOD TV8!

Ben Boehlens and Dr. Mitchell were interviewed by the local NBC affiliate about the Butterfly Benefit and bleeding disorders prior to the event. View the segment here: www.hfmich.org/ **Ben-Boelens-Deanna-Mitchell**

More thanks WOOD TV8!

HFM's Carrie McCulloch and Sarah Procario were interviewed live on WOOD TV8 just prior to the Butterfly Benefit. View the segment here: www.hfmich.org/woodtvinterview-benefit

Thanks Spectrum Health!

In honor of Dr. Deanna Mitchell receiving the Dr. Penner Memorial Award, Spectrum Heath did a special piece on the Ramirez family. View it here: www.hfmich.org/hdvch-ramirez-story

2018 National Conference **Being Visible: Women with Hemophilia**

For women who have hemophilia and/or are symptomatic carriers

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

Women joining us will experience an amazing weekend learning from national expert health care providers, and have opportunities to connect with other attendees who each bring their own unique wisdom and experience of living with hemophilia.

- There is **NO CHARGE** for this weekend.
- Conference faculty & session information: www.hfmich.org/womens-conference
- To apply, go to www.hfmich.org/conf-apply
- Questions? Contact Patrice Thomas at pthomas@hfmich.org, 734.544.0015.

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Community Sponsor





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

PAID CONSUMER OUTREACH

UNLOCKING YOUR SELF-POTENTIAL

ONLY ADVATE[®] HAS 15 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 children and adults 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 to moderately 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 (Based on 2016 data published July 2017)³

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.

and

What else should I know about A Hemophilia A?

• Your body may form inhibitors to factor V..... ibitor 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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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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S32554 06/17





More photos at www.hfmich.org/lansingphotos

Pictured is Lynn Ray Allen, Community Advocate

Lansing Days 2018

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

Sarah Procario

What is advocacy? This buzzword is used so often, we don't think about what it actually means. The varying definitions typically center on the idea of an individual standing up for and defending the rights of oneself and/or others–we can also think of it as the act of publicly supporting a cause. In the bleeding disorders community, we advocate for the health and wellbeing of bleeding disorders patients and their families.

But why do we need to? Individuals with bleeding disorders did not always have access to treatment and/or adequate health insurance. Without the work of strong advocates through the years, our community would not have seen blood safety measures improve, support for families affected by HIV, or Children's Special Health Care Services expand coverage for adults. Change will not happen unless people stand up and make noise.

So to continue in our community's footsteps, every May, HFM hosts a group of bleeding disorders advocates in Lansing for our annual legislative event, Lansing Days. During Lansing Days, HFM aims to help state lawmakers understand the unique challenges and needs of the bleeding disorders community.

Through the generous support of our sponsors, we were able to offer an overnight dinner and training for our advocates at the Kellogg Hotel and Conference Center. The following day, groups of community members attended pre-scheduled meetings with their state representatives and senators– eighty participants attended forty legislative meetings! Participants wore red HFM "Bleeding Disorders Advocate" t-shirts, washing the capitol in a sea of red. A few participants were even able to sit in the Senate Gallery as Senator Rebekah Warren introduced our group on the Senate floor.

In the meetings, bleeding disorders advocates shared their personal story of living with a bleeding disorder. Since many legislators have heard of "hemophilia," but do not have a clear understanding of its affect on one's body or livelihood, advocates also shared general information about bleeding disorders and treatment options.

Thank you to each and every bleeding disorder advocate. Your voice matters.

"Advocacy is so important to me because there is a such small population that knows about hemophilia, and I want to educate the world! I advocate for my boys, so they will hit hemophilia head-on, not be afraid or embarrassed by it." ~ Amy Moon, Lansing Days participant



24

PAID CONSUMER OUTREACH

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2018 EVENTS

October 19-21 Bleeder and a Buddy Camp Roger, Rockford twicks@hfmich.org

October 20 UNITE for Bleeding Disorders Walk (Walkin' on the West Side) Fifth Third Ballpark, Grand Rapids cmcculloch@hfmich.org

October 26 Community Night Incredible Mo's, Traverse City cmcculloch@hfmich.org

November 2 Community Night Spare Time, Lansing cmcculloch@hfmich.org

FIRST EVER!

November 9-11 HFM's 2018 National Conference Being Visible: Women and Hemophilia Amway Grand Hotel Grand Rapids pthomas@hfmich.org

December 8 End of the Year Community Gathering (Holiday Party) Troy High School, Troy cmcculloch@hfmich.org

December 15 Camp Holiday Party HFM Office, Ypsilanti twicks@hfmich.org

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Merry Christmas! Happy Kwanzaa! Happy Chanukah! Season's Greetings! This celebration is inclusive and open to all of HFM's diverse community members.



SAVE THE DATE!

Saturday, December 8, 1-3pm

Santa will be giving a gift to each child, 16 & under, in attendance! We'll also have yummy food, along with crafts and NEW fun activities for the family to enjoy.

Join us at Troy High School

4777 Northfield Parkway, Troy, Michigan 48098 We are grateful to Troy High School for so generously hosting us again!

RSVP by Tuesday, December 4th

online at www.hfmich.org/holidayparty Or contact Carrie McCulloch at cmcculloch@hfmich.org, 734.961.3503

Industry may be present, yet will not display.