



THE ARTERY

FALL 2022

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TRAILS

DEAR HFM FRIENDS & FAMILY,

I hope you and yours have had a lovely Michigan summer! We are grateful HFM's summer camping programs were hosted in person this summer at Pioneer Trails on Big Blue Lake. Our exceptional Camp and Associate Camp Directors, Tim Wicks and Anthony Stevens, led five consecutive weeks of in-person camp: beginning with Camp Bold Eagle's Teen Camp, then staff training, including the Counselors-in-Training (CITs) program, two more sessions of CBE for campers from six to 12 years of age, Eagle Outpost for teens 14 and 15 years old, and our newest camp, Eagles Nest for families of children aged 5-9.

Dr. Amy Hepper, Sarah Spencer, and Matt Sterling led our medical team of University of Michigan physician residents, hemophilia treatment center nurses, social workers, and a medical student who provided onsite care for campers. Preventing the upheaval of COVID was a top priority for HFM. With our full team's collaborative and diligent efforts there were no COVID cases during our five consecutive weeks of camp! What an incredible feat. Congratulations and deepest appreciation to all.

FUN activities, being together, learning, swimming, safety drills, singing songs following two years of virtual Camp Bold Eagle at Home felt wonderful. Extraordinarily awesome and zany evening programs took place thanks to Anne Henningfeld, accompanied by daily swimming, arts & crafts, archery,



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nature, and all the usual CBE activities offered by our program area leaders. Thank you to Rachael Miller for leading our fantastic waterfront team that provided campers great attentiveness and care. Karl's kid-friendly and nutritious camp meals were devoured outside under a big tent by the lake.

New this year, campers and counselors created, earned, and traded buttons for their camp lanyards. The buttons were earned for participating in various traditional camp activities like waking up for a dip in Big Blue Lake (Polar Bear) or for eating a corn dog (possum on a stick)! Campers (and counselors) had a blast competing for the coveted buttons.

Deepest appreciation to Tim and Anthony, all our camp staff, volunteers, University of Michigan residents and medical student, HTC nurses and social workers, nursing students, financial supporters, HFM Board of Directors and our full HFM staff team. New program manager, Alyssa Siletti, was a wonderful addition to the Teen Camp staff. Carrie McCulloch, development director, and Sarah Procario, advocacy director, served as photographer's 'assistants.' I'm proud I did the Polar Bear Plunge

(once!) this summer and offer HFM's associate director, Gwyn Hulswit, huge congratulations for her plunge and swimming across the lake with Outpost!!

Camp is a huge undertaking that requires year-round effort. We are grateful to our campers who remind us that each of us can bring joy, give and receive unconditional acceptance. Thank you to parents and guardians for trusting HFM to create a place of challenge, camaraderie, acceptance, and love.

With gratitude and love,

Susan Fenters Lerch
HFM Executive Director
Regional Director, Great Lakes Federal
HTC Network

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*Denotes part-time



COMMUNITY SPRINGFEST2022 ABLOOM

TRIVIA TIME!!! DID YOU KNOW THAT VON WILLEBRAND DISEASE OCCURS EQUALLY IN MEN AND WOMEN? HOW ABOUT THAT IN 2021, HFM PROVIDED 856 COMPLIMENTARY MEDICAL ID TAGS TO THE MICHIGAN COMMUNITY? PERHAPS YOU HAVE HEARD THAT CAMP BOLD EAGLE INCLUDES 2 DOGS AMONG ITS CAMPERS NAMED WINNIE AND JACK?

SpringFest attendees walked away with HFM facts like these (and many more), as well as an abundance of new knowledge. Indeed, this year's virtual SpringFest was truly a celebration of our legacy, history, and an introduction on how to best care for ourselves and loved ones in the future. It was a joyful recognition of our community bond through every stage of life.

On Saturday, we were so grateful to be joined by Magdalena Lewandowska, MD, CACP, Indiana Hemophilia & Thrombosis Center, adult hematologist. Attendees were eager to learn about the topic of treatment advances in hemophilia and von Willebrand disease. Dr. Lewandowska was very informative and gave a stimulating presentation.

SpringFest programming is largely shaped by the guidance we receive from you, our community. One constant in the feedback we receive is that people wish they had a better understanding of the ever-changing landscape that is insurance. It is a big part of our lives, and is often very confusing. We get it! Enter: The SpringFest 2022 "Ask the Experts" session.

You brought your questions, HFM brought a group of professionals with extensive knowledge of health insurance, and together, a meaningful and informative conversation ensued. Our hope is that everyone that attended this session walked away with a new understanding of their own insurance situations and with resources for help navigating the process. Thank you to our experts!

FINAL TRIVIA: DID YOU KNOW THAT SPRINGFEST 2023 HAS BEEN SCHEDULED? WE CAN'T WAIT TO SEE YOU AT THE EAGLECREST MARRIOTT HOTEL IN YPSILANTI, MICHIGAN MAY 6 AND 7, 2023!

Further shaped by community feedback, SpringFest included numerous breakout sessions on various topics that included:

- Sessions for teens regarding mental health, communication and consent, gene therapy, as well as a trivia game
- Aging is a popular topic at many educational events, and for SpringFest we had back-to-back sessions to allow more time to explore aspects of aging: care for joint health, dental hygiene, and mental health challenges.
- Relationship challenges including communication and difficult conversations
- Von Willebrand diagnosis and treatment
- Women's empowerment

We wrapped Saturday afternoon with a visit from comedian Leighann Lord who lightened our moods and brought smiles to our faces. Pausing to laugh when you can is so important when things get a little heavy. And laughing with a group of your peers is about as good as it gets!

After additional educational sessions and opportunities to connect, SpringFest concluded Sunday with HFM's annual member's meeting. The ad hoc bylaws committee, chaired by Board Member Kathleen Donohoe, proposed updates to HFM's bylaws that were approved by the board, and subsequently approved by members at the membership meeting. The updated bylaws will be available via www.hfmich.org.

Thank you to each of our members in attendance. Along with our board, you are helping to shape HFM's future. 💧

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Connected. Together.

For me, being a Community Relations and Education (CoRe) Manager for Sanofi is about empowering the hemophilia community by providing a personal connection to education and resources.

Rebecca Gorde
CoRe Manager for
Michigan & Indiana

Stay connected.

248-915-5282

rebecca.gorde@sanofi.com

RareBloodDisorders.com

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PAID CONSUMER OUTREACH

Women's RETREAT



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This year marked the 30th anniversary of HFM's annual Women's Retreat. We were thrilled to acknowledge this special event for women with both an in-person retreat and virtual component. Our objective this year was to provide each attendee with space to focus on themselves, be present for others, share a journey of personal growth, and reflect on their inner beauty.

We had an amazing series of sessions led by Anne Henningfeld, MA, CTRS, that met participants exactly where they were starting from. Each attendee was encouraged to explore their values and reflect on personal hopes. Next, we investigated a variety of flow inducing hobbies and learned how to effectively challenge ourselves within leisure activities to find our own flow. Our third session brought it all together with a care and repair activity showing us that breakage and repair is something to be embraced rather than hidden. Our educational series was further enhanced by sessions that included food and fitness information, women's empowerment, Tai Chi, and self-care acupressure.

We are particularly grateful this year that we were able to come together both in-person and virtually. We thank our wonderful speakers, sponsors, Plymouth Hilton Garden Inn hotel staff, HFM staff, and most notably the women that shared their weekend with us. 💧

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TOOTH TIME

JENNIFER KERNS, BS, RDH

DEAR JENNIFER,

IT SEEMS TO ME THAT THE MORE STRESS I'M UNDER, THE MORE MY MOUTH BLEEDS. DOES STRESS AFFECT OUR MOUTHS OR AM I JUST NOT GETTING MY TEETH CLEAN ENOUGH?

SIGNED,
STRESSED OUT IN MIDLAND

Great question! Stress does play a role in your oral health—in a few different ways! First, if you are limited on time because of all your commitments or you're just purely exhausted by bedtime, you may not be doing the best cleaning job at home. You may also accidentally miss your routine cleaning appointment and be overdue getting some of that deeper debris out from under your gums. Either way,

your gums will begin to bleed with the inflammation from left-over food and bacteria. Make an appointment for a professional cleaning to get all that built up stuff out from under your gums to prevent any permanent damage to the gum fibers that hold your teeth in. Many folks find that leaving their toothbrush in the shower saves time and is an easy reminder. If you can only pick one time of day to brush, make it the bedtime brushing—it's very important to remove any food from your teeth before closing your mouth for the night to prevent permanent damage from occurring while you sleep.

Second, if you are subconsciously taking the stress out on your teeth by grinding or clenching your teeth while you sleep, you may develop some gum attachment loss and will begin to feel sensitivity in those areas. Ask your dentist about getting a bite guard to wear at night; it will prevent putting the stress on your teeth and gums, saving those delicate fibers that support your teeth.

Third, new studies are now showing that stress can actually change the

biology of your mouth and body. When someone is stressed, their immune system is weakened—but now we also know that stress creates an environment for more harmful bacteria to thrive. Stress hormones can change the quality and quantity of your spit as well as the kind of bacteria setting up camp under your gums. Depending on how your body handles the stress and inflammation, you may develop fatigue, canker sores, cold sores, periodontal (gum) disease, your diabetes might not be able to be controlled, your blood pressure may rise, and you may develop more frequent colds.

If you are suffering from any form of stress, please look into the free mobile phone apps and online videos that promote mindfulness—sometimes just a quick 5 minutes of reflection through stretching, meditation, or positive thought can reduce stress and begin to create a healthier mouth and body. My favorite app is Headspace. 💧

Contact Jennifer
231-721-5337
jkerns@nmhsi.org

NEED DENTAL INSURANCE?

If you are uninsured or underinsured with your dental coverage, we may be able to help. We understand that our community faces challenges obtaining dental care to meet unique and individual needs. HFM has partnered with Cascade Hemophilia Consortium to offer free dental insurance to those who need it.

QUESTIONS?

Contact Lisa Clothier, LMSW, ACSW, LCSW, Outreach and Community Education Manager, at lclothier@hfmich.org or 734.961.3512

You can find the application here: www.hfmich.org/dental-health

In order to be eligible for this program you must:

- Have a bleeding disorder
- Be a Michigan resident
- Have no dental insurance or only Children's Special Health Care Services
- However, if you have Medicare, Medicaid, or an employer based private insurance plan you may be eligible for limited-time coverage based on special circumstances – these exceptions are limited and determined on a case-by-case basis. Please call us for more information. 💧

**To maintain your coverage, you must visit the dentist two times during the calendar year for regular teeth cleanings.*

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DO YOU HAVE A DENTAL QUESTION
WEIGHING ON YOUR MIND? CONFUSED
ABOUT YOUR DENTAL CARE? EMAIL
LISA CLOTHIER WITH YOUR QUESTIONS!
LCLOTHIER@HFMICH.ORG



*Pictured left to right:
Jason Rogers,
Gwyn Hulswit,
David Hart*

ADVANCED ADVOCACY TRAINING

JASON ROGERS, HFM BOARD MEMBER

In June, I had the opportunity to participate in the National Hemophilia Foundation's Advanced Chapter Advocacy Training in Washington D.C. I participated together with HFM Associate Director, Gwyn Hulswit, and fellow Board Member, David Hart.

The training provided detailed advocacy training and in-depth discussions on policy affecting the bleeding disorders community. As high-cost specialty drugs receive critical review by insurance companies, we were reminded that it is absolutely imperative that members of the bleeding disorders community work with their local chapters to share their stories and provide information about barriers to access to care.

This was the first time NHF offered this training and topics included insurance trends and barriers to care, stakeholder support, virtual advocacy

platforms, Medicaid and regulatory advocacy, gene therapy updates and public policy considerations. We also heard from a Congressional Hill staffer who reminded us of the importance of meeting with legislative staff and clearly expressing our asks. In addition to hearing from advocacy experts, we were also given the chance to participate in breakout discussions where advocates from different states, and with varying ranges of experience, were assigned to small groups to discuss advocacy strategies, opportunities, and lessons learned.

All of Michigan's participants commented on how refreshing it was to hear from other states and realized how great a position Michigan is already in with our advocacy work. I am thankful for the opportunity to support HFM's advocacy work and look forward to bringing ideas and lessons learned to future efforts! ♦

LANSGING DAYS

SARAH PROCARIO

On Tuesday, March 22 and Wednesday, March 23, 2022, thirty-one Michigan bleeding disorders advocates joined HFM for our legislative advocacy event, Lansing Days. On Tuesday evening, patient advocates participated in legislative advocacy training at the Kellogg Hotel and Conference Center and practiced telling their personal stories.

On Wednesday, our group of bleeding disorders advocates traveled to the capital to meet with twenty-seven state legislator offices to share bleeding disorders education and to discuss two issues important to the community.

Advocates asked legislators to continue funding Children's Special Health Care Services, a program within the Michigan Department of Health and Human Services that provides coverage for bleeding disorders treatment when all else fails. Constituents also shared information on copay accumulator adjustment programs and the financial impact they have on Michigan patients who rely on copay assistance to access their necessary medications. We thanked House members for voting yes on HB 4353, a copay accumulator reform

bill, and asked Senators to support HB 4353 and urge the Senate Health Policy and Human Services Committee to schedule a hearing.

We were pleased to join together again in-person for such an important cause. We look forward to following up with the offices we met with during our Lansing Days event and continuing to work towards passing HB 4353. 💧

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COMMUNITY MEMBER FEATURE

JENNIFER TEPER

The Lansing Days experience was second to none.

Walking into the capital in our red shirts made me feel I was an empowered State of Michigan citizen. Going into the legislative offices, I realized my voice was speaking on behalf of the entire bleeding disorders community. I was not only representing myself, as a patient, but family members, caregivers, and medical and support staff that treat patients.

Meeting with government officials, HFM not only gave me the knowledge on the issues, but also amplified my voice and opportunity to convey the importance of supporting HB 4353, along with continued funding of Children's Special Health Care Services. Until cures are found for all bleeding disorders, I plan on continuing my participation in and support of HFM, its programming, and advocacy work.

I thank HFM for doing what you do, helping me find my voice to speak out, and welcoming me with open arms. I look forward to many more Lansing Days as well as other in person and online events. 💧

Pictured: Kory Stamper, Jennifer Teper





HEMOPHILIA A IS A PIECE OF THEM. NOT ALL OF THEM.

ADYNOVATE® has a simple, twice-weekly dosing schedule on the same 2 days every week that can help personalize treatment, so your patients have more time to spend doing the other things that also make them who they are.^{1,2}

*In clinical trials, ADYNOVATE demonstrated the ability to help patients prevent bleeding episodes using a prophylaxis regimen.

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No actual patients depicted.

ADYNOVATE twice-weekly prophylaxis prevented or reduced the number of bleeds²

ADYNOVATE was proven in 2 pivotal clinical trials to prevent or reduce the number of bleeding episodes in children and adults when used regularly (prophylaxis)²

- **Children Under 12 Years:** This study evaluated the efficacy of ADYNOVATE twice-weekly prophylaxis and determined the ability to treat bleeding episodes for 6 months in 66 children under 12 years old who received 40–60 IU/kg of ADYNOVATE prophylaxis treatment
 - During the 6-month study in children under 12, those receiving twice-weekly prophylaxis treatment experienced a median[†] overall ABR[‡] of 2.0
 - 0 bleeds in 38% (25 out of 66 patients) during 6 months on twice-weekly prophylaxis

[†]Median is defined as the middle number in a list of numbers arranged in numerical order.

[‡]ABR=annualized bleed rate, the number of bleeds that occur over a year

[§]Per-protocol patients were assigned to the prophylactic group and treated with their originally assigned dose for the entire duration of the study.

ADYNOVATE Important Information

Indications and Limitation of Use

ADYNOVATE is a human antihemophilic factor indicated in children and adults with hemophilia A (congenital factor VIII deficiency) for:

- On-demand treatment and control of bleeding episodes
- Perioperative management
- Routine prophylaxis to reduce the frequency of bleeding episodes

ADYNOVATE is not indicated for the treatment of von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

CONTRAINDICATIONS

Prior anaphylactic reaction to ADYNOVATE, to the parent molecule (ADVATE® [Antihemophilic Factor (Recombinant)]), mouse or hamster protein, or excipients of ADYNOVATE (e.g. Tris, mannitol, trehalose, glutathione, and/or polysorbate 80).

WARNINGS & PRECAUTIONS

Hypersensitivity Reactions

Hypersensitivity reactions are possible with ADYNOVATE. Allergic-type hypersensitivity reactions, including anaphylaxis, have been reported with other recombinant antihemophilic factor VIII products, including the parent molecule, ADVATE. Early signs of hypersensitivity reactions that can progress to anaphylaxis may include angioedema, chest tightness, dyspnea, wheezing, urticaria, and pruritus. Immediately discontinue administration and initiate appropriate treatment if hypersensitivity reactions occur.

- **Adolescents and Adults 12 Years and Older:** This study evaluated the efficacy of ADYNOVATE in a 6-month study that compared the efficacy of a twice-weekly prophylactic regimen with on-demand treatment and determined hemostatic efficacy in the treatment of bleeding episodes in 137 patients. These adolescents and adults were given either ADYNOVATE prophylaxis twice-weekly at a dose of 40–50 IU/kg (120 patients) or on-demand treatment with ADYNOVATE at a dose of 10–60 IU/kg (17 patients). The primary study goal was to compare ABR[†] between the prophylaxis and on-demand treatment groups²
 - 95% reduction in median overall ABR [41.5 median ABR with on-demand (17 patients) vs 1.9 median ABR with prophylaxis (120 patients)]
 - 0 bleeds in 40% (40 out of 101 per-protocol[§] patients) during 6 months on twice-weekly prophylaxis

WARNINGS & PRECAUTIONS (continued)

Neutralizing Antibodies

Formation of neutralizing antibodies (inhibitors) to factor VIII can occur following administration of ADYNOVATE. Monitor patients regularly for the development of factor VIII inhibitors by appropriate clinical observations and laboratory tests. Perform an assay that measures factor VIII inhibitor concentration if the plasma factor VIII level fails to increase as expected, or if bleeding is not controlled with expected dose.

ADVERSE REACTIONS

The most common adverse reactions (≥1% of subjects) reported in the clinical studies were headache, diarrhea, rash, nausea, dizziness and urticaria.

Please see the following page for the Brief Summary of the ADYNOVATE Full Prescribing Information.

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

References: 1. Valentino LA. Considerations in individualizing prophylaxis in patients with haemophilia A. *Haemophilia*. 2014;20(5):607-615. 2. ADYNOVATE Prescribing Information.

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**ADYNOVATE [Antihemophilic Factor (Recombinant) PEGylated]
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BRIEF SUMMARY: Consult the Full Prescribing Information for complete product information.

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INDICATIONS AND USAGE

ADYNOVATE is a human antihemophilic factor indicated in children and adults with hemophilia A (congenital factor VIII deficiency) for:

- On-demand treatment and control of bleeding episodes
- Perioperative management
- Routine prophylaxis to reduce the frequency of bleeding episodes

Limitation of Use

ADYNOVATE is not indicated for the treatment of von Willebrand disease.

CONTRAINDICATIONS

ADYNOVATE is contraindicated in patients who have had prior anaphylactic reaction to ADYNOVATE, to the parent molecule (ADVATE), mouse or hamster protein, or excipients of ADYNOVATE (e.g. Tris, mannitol, trehalose, glutathione, and/or polysorbate 80).

WARNINGS and PRECAUTIONS

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Monitoring Laboratory Tests

- Monitor plasma factor VIII activity by performing a validated one-stage clotting assay to confirm the adequate factor VIII levels have been achieved and maintained.
- Monitor for the development of factor VIII inhibitors. Perform the Bethesda inhibitor assay to determine if factor VIII inhibitor is present. If expected factor VIII activity plasma levels are not attained, or if bleeding is not controlled with the expected dose of ADYNOVATE, use Bethesda Units (BU) to determine inhibitor levels.

ADVERSE REACTIONS

The most common adverse reactions ($\geq 1\%$ of subjects) reported in the clinical studies were headache, diarrhea, rash, nausea, dizziness and urticaria.

Clinical Trials Experience

Because clinical trials are conducted under widely varying conditions, adverse reaction rates observed in the clinical trials of a drug cannot be directly compared to rates in clinical trials of another drug and may not reflect the rates observed in practice.

The safety of ADYNOVATE was evaluated in 365 previously treated patients (PTPs) and previously untreated patients (PUPs) with severe hemophilia A (factor VIII less than 1% of normal), who received at least one dose of ADYNOVATE in 6 completed multi-center, prospective, open label clinical studies and 1 ongoing clinical study. The total number of infusions within the safety database is 74487. Following are the adverse reactions reported during clinical studies.

Adverse reactions reported for ADYNOVATE as shown by Percent of Subjects, Number of subjects (%), n (N=365). Reported adverse reactions are listed by MedDRA Preferred Term. Diarrhea (6.8%, n=25), Nausea (2.2%, n=8), Ocular Hyperaemia (0.8%, n=3), Hypersensitivity^a (0.5%, n=2), Headache (11.2%, n=41), Dizziness (1.9%, n=7), Rash (2.7%, n=10), Urticaria (1.9%, n=7), Drug Eruption (0.3%, n=1), Flushing (0.27%, n=1), Eosinophil Count Increased (0.5%, n=2), Infusion Related Reaction (0.5%, n=2).

^aThe event of hypersensitivity was a mild transient non-serious rash, occurring in one 2-year old patient who had developed a previous rash while on ADYNOVATE.

Two cases of acute pancreatitis, with no precipitating cause identified in one case, were reported in adults during an extension study of the clinical trial which evaluated 216 subjects. Administration of ADYNOVATE continued and both cases resolved.

Immunogenicity

Clinical trial subjects were monitored for neutralizing (inhibitory) antibodies to FVIII. Of the 6 completed clinical trials in previously treated patients (PTPs), in the randomized controlled trial comparing different dosing regimens of ADYNOVATE, one previously treated patient developed a transient low titer FVIII inhibitor at 0.6 BU while receiving more frequent dosing with ADYNOVATE.

In a continuation study with ADYNOVATE, one patient developed a transient low titer (0.6 BU) FVIII inhibitor. Repeat testing did not confirm the presence of inhibitor. Both of these subjects continued treatment without change in the dose of ADYNOVATE.

Immunogenicity also was evaluated by measuring the development of binding IgG and IgM antibodies against factor VIII, PEGylated (PEG)-factor VIII, PEG and Chinese hamster ovary (CHO) protein using validated ELISA assays.

Persistent treatment-emergent binding antibodies against FVIII, PEG-FVIII or PEG were not detected. Out of 365 subjects, thirty-six subjects in total showed pre-existing antibodies to factor VIII (n=5), PEG-factor VIII (n=31) and/or PEG (n=6) prior to the first exposure to ADYNOVATE. Twenty-four subjects who tested negative at screening developed transient antibodies against factor VIII (n=10), PEG-FVIII (n=16) and/or PEG (n=3) at one or two consecutive study visits. Antibodies were transient and not detectable at subsequent visits. Two subjects showed positive results for binding antibodies at study completion or at the time of data cutoff. Binding antibodies that were detected prior to exposure to ADYNOVATE, that transiently developed during the trial or were still detectable at study completion or data cutoff could not be correlated to any impaired treatment efficacy or altered PK parameters. There was no causal relationship between observed adverse events and binding antibodies except in one subject where a causal relationship cannot be ruled out based on available data. No subject had pre-existing or treatment-emergent antibodies to CHO protein.

From an ongoing study in previously untreated patients <6 years with severe hemophilia A, 9 cases of FVIII inhibitor development associated with treatment with ADYNOVATE were reported.

The detection of antibodies that are reactive to factor VIII is highly dependent on many factors, including: the sensitivity and specificity of the assay, sample handling, timing of sample collection, concomitant medications and underlying disease. For these reasons, comparison of the incidence of antibodies to ADYNOVATE with the incidence of antibodies to other products may be misleading.

USE IN SPECIFIC POPULATIONS

Pregnancy: Risk Summary

There are no data with ADYNOVATE use in pregnant women to inform a drug-associated risk. Animal reproduction studies have not been conducted with ADYNOVATE. It is unknown whether ADYNOVATE can cause fetal harm when administered to a pregnant woman or can affect reproduction capacity. In the U.S. general population, the estimated background risk of major birth defect and miscarriage in clinically recognized pregnancies is 2-4% and 15-20%, respectively.

Lactation: Risk Summary

There is no information regarding the presence of ADYNOVATE in human milk, the effect on the breastfed infant, or the effects on milk production. The developmental and health benefits of breastfeeding should be considered along with the mother's clinical need for ADYNOVATE and any potential adverse effects on the breastfed infant from ADYNOVATE or from the underlying maternal condition.

Pediatric Use

Safety and efficacy studies have been performed in 91 previously treated, pediatric patients age 1 year to <18 years who received at least one dose of ADYNOVATE as part of routine prophylaxis, on-demand treatment of bleeding episodes, or perioperative management. Adolescent subjects age 12 to <18 (n=25) were enrolled in the adult and adolescent safety and efficacy trial, and subjects <12 years of age (n=66) were enrolled in a pediatric trial. The safety and efficacy of ADYNOVATE in routine prophylaxis and the treatment of bleeding episodes were comparable between children and adults. Pharmacokinetic studies in children (<12 years) have demonstrated higher clearance, a shorter half-life and lower incremental recovery of factor VIII compared to adults. Because clearance (based on per kg body weight) has been demonstrated to be higher in children (<12 years), dose adjustment or more frequent dosing based on per kg body weight may be needed in this population.

Geriatric Use

Clinical studies of ADYNOVATE did not include subjects aged 65 and over.

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CONGRATULATIONS TO HFM'S 2022 SCHOLARSHIP RECIPIENTS SAMANTHA DYE & ISMAEL JABER

Samantha and Ismael expressed deep gratitude upon receiving their \$2,500 academic scholarship.

"THIS SCHOLARSHIP MEANS
A LOT TO ME AND I'M SO
GRATEFUL TO HAVE THE HFM
COMMUNITY BY MY SIDE."

ISMAEL JABER



"I AM PROUD TO BE A MEMBER
AND REPRESENT THIS COMMUNITY
THAT STRIVES TO HELP OTHERS
WITH BLEEDING DISORDERS."

SAMANTHA DYE



Ismael's scholarship was decided prior to election to the Board of Directors.

**THANK YOU TO HFM'S SCHOLARSHIP
COMMITTEE MEMBERS FOR VOLUNTEERING
THEIR TIME TO THE COMMUNITY!**

LAURA OLSON, HFM OFFICE MANAGER

ALICE CAKEBREAD, LLMSW, UNIVERSITY OF MICHIGAN HTC SOCIAL WORKER

RACHEL MILLER, COMMUNITY MEMBER

Michelle Leona Cecil, M.P.A.

Patient advocate

About Michelle

Michelle is a Novo Nordisk Hemophilia Community Liaison who lives with a bleeding disorder. She is passionate about supporting people in the community and helping them take full advantage of the trusted products of Novo Nordisk.

Connect with Michelle

VQMC@novonordisk.com
(614) 674-0147

Hemophilia Community Liaison
Great Lakes (MI and WI)



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IMPROVING THE MOMENT

STEVE EDWARDS, LMSW, SOCIAL WORKER, MICHIGAN STATE UNIVERSITY CENTER FOR BLEEDING AND CLOTTING DISORDERS

HOW IS YOUR STRESS LEVEL? HOW STRESSED HAVE YOU BEEN IN THE LAST WEEK? OR YESTERDAY? OR RIGHT NOW? SAFE-SPACE VISUALIZATION IS A TECHNIQUE THAT YOU CAN USE TO IMAGINE A SOOTHING SPACE IN YOUR MIND. VISUALIZING A SAFE SPACE CAN CAUSE YOU TO ACTUALLY RELAX, AS YOUR BRAIN AND BODY OFTEN CANNOT TELL THE DIFFERENCE BETWEEN WHAT YOU IMAGINE AND WHAT IS ACTUALLY HAPPENING TO YOU!

THE FOLLOWING SAFE SPACE EXERCISE CAN BE EXPERIENCED IN DIFFERENT WAYS. YOU MAY READ IT AND REMEMBER IT, RECORD YOURSELF READING THE DIRECTIONS, OR READ THEM ALOUD TO YOURSELF AND THEN CLOSE YOUR EYES, ALLOWING YOURSELF TO EXPERIENCE WHAT YOU HAVE CREATED. ♡

BREATHE

To begin, sit in a comfortable chair with your feet flat on the floor and your hands resting comfortably, either on the arms of the chair or in your lap. Close your eyes. Take a slow, long breath in through your nose. Feel your belly expand like a balloon as you breathe in. Hold it for five seconds: 1, 2, 3, 4, 5. Then release it slowly through your mouth. Feel your belly collapse like a balloon losing its air. Repeat two times. Then begin to take slow, long breaths without holding them, and continue to breathe smoothly for the rest of this exercise.

IMAGINE

Now, with your eyes closed, imagine that you enter your safe place using all your

senses to ground yourself in the scene. Your safe space can be literally any place at all! A favorite vacation spot, an imaginary world from a book or TV show, or something that you have invented entirely. The possibilities are limitless.

SIGHT

First, look around using your imaginary sense of sight. What does this place look like? Is it daytime or nighttime? Is it sunny or cloudy? Notice the details. Are you alone or are there other people or animals? What are they doing? Choose something soothing to look at. Then continue looking for a few seconds using your imaginary sense of sight.

HEARING

Next, use your imaginary sense of hearing. What do you hear? Do you hear other people or animals? Do you hear music? Do you hear the wind or the ocean? Choose something soothing to hear. Then listen for a few seconds using your imaginary sense of hearing.

SMELL

Now use your imaginary sense of smell. If you're inside, what does it smell like? Does it smell fresh? Do you have a fire burning that you can smell? Or, if you're outside, can you smell the air, the grass, the ocean, or the flowers? Choose to smell something soothing in your scene. Then take a few seconds to use your imaginary sense of smell.

TOUCH

Next, notice if you can feel anything with your imaginary sense of touch. What are you sitting or standing on in your scene? Can you feel the wind? Choose to touch something soothing in your scene. Then take a few seconds to use your imaginary sense of touch.

TASTE

Last, use your imaginary sense of taste. Are you eating or drinking anything in this scene? Choose something soothing to taste. Then take a few seconds to use your imaginary sense of taste.

Now take a few more seconds to explore your safe place using all of your imaginary senses. Recognize how safe and relaxed you feel here. Look around one last time to remember what it looks like. Remember that you can come back to this place in your imagination whenever you need to feel safe and relaxed. Now keep your eyes closed and return your focus to your breathing. Again, take some slow, long breaths in through your nose and exhale through your mouth. Then, when you feel ready, open your eyes and return your focus to the room.

Your safe space can be literally any place at all! A favorite vacation spot, an imaginary world from a book or TV show, or something that you have invented entirely. The possibilities are limitless.

Source: *The Dialectical Behavioral Therapy Skills Workbook: Practical DBT Exercises for Learning Mindfulness, Interpersonal Effectiveness, Emotion Regulation and Distress Tolerance* by Matthew McKay, Jeffrey Brantley, and Jeffrey Wood.



Connected to you.

As Community Relations & Education Managers, our work with the hemophilia community is deeply personal. It unites us in our efforts to help educate and support you and your family.



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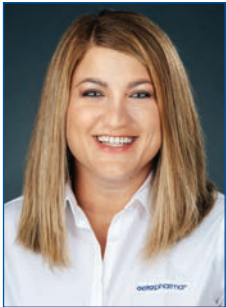
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Resources for patients and caregivers, including free trial and co-pay assistance, educational materials, and community connection.

**Join the program at www.factorway.com
or call 1-855-498-4260.**

CRAIG'S CRUISERS COMMUNITY NIGHT

HFM's return to in-person Community Nights was too fun much to fit into just one evening! We hosted two fantastic nights in June filled with laughter and joy at Craig's Cruisers in Grand Rapids. After attendees devoured a delicious dinner buffet, we were joined by staff members from Helen DeVos Children's Hospital to guide us through a variety of relaxation techniques. Thank you to Allison Postma, Jayme Sturuss, and Liz James for sharing your wisdom and practical tools with us! Attendees then had an opportunity to interact with our sponsors, before venturing off to explore a multitude of fun and engaging activities. The competition was palpable as families battled it out in the laser tag arena, raced go-karts, and enjoyed a round of mini-golf.

Others took to the giant arcade to win tickets for prizes. The atmosphere was light-hearted, energetic, and folks were eager to connect with each other. HFM staff were ecstatic to witness old connections being re-kindled and new friendships blossom. We are grateful to have had the opportunity to provide a safe and fun outing for the community! 📍

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IMPORTANT SAFETY INFORMATION

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IDELVION is administered by intravenous injection into the bloodstream, and can be self-administered or administered by a caregiver. Do not inject IDELVION without training and approval from your healthcare provider or hemophilia treatment center.

Tell your healthcare provider of any medical condition you might have, including allergies and pregnancy, as well as all medications you are taking. Do not use IDELVION if you know you are allergic to any of its ingredients, including hamster proteins. Tell your doctor if you previously had an allergic reaction to any FIX product.

Stop treatment and immediately contact your healthcare provider if you see signs of an allergic reaction, including a rash or hives, itching, tightness of chest or throat, difficulty breathing, lightheadedness, dizziness, nausea, or a decrease in blood pressure.

Your body can make antibodies, called inhibitors, against Factor IX, which could stop

IDELVION from working properly. You might need to be tested for inhibitors from time to time. IDELVION might also increase the risk of abnormal blood clots in your body, especially if you have risk factors. Call your healthcare provider if you have chest pain, difficulty breathing, or leg tenderness or swelling.

In clinical trials for IDELVION, headache and dizziness were the only side effects occurring in more than 1% of patients (1.8%), but are not the only side effects possible. Tell your healthcare provider about any side effect that bothers you or does not go away, or if bleeding is not controlled with IDELVION.

Please see full prescribing information for IDELVION, including patient product information.

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You can also report side effects to CSL Behring's Pharmacovigilance Department at 1-866-915-6958.

* Hemophilia FIX Market Assessment.
Third-Party Market Research.

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VWD SYMPOSIUM

JUNE 11, 2022

LEARNING AS A COMMUNITY

A DAY OF LEARNING AND CAMARADERIE

We were walking on sunshine at HFM's 2022 von Willebrand Disease Symposium which took place virtually on Saturday, June 11. We had 35 individuals join us throughout the day, attending from all over the state of Michigan along with experts from across the nation. Attendees received a curated VWD conference box which contained scrumptious snacks, a portfolio for taking notes, sponsor items, and fun in the sun sunscreen and beach towels!

Before the learning and resource sharing began, we took time to connect as a community. We were introduced to veteran HFM program attendees as well as VWD Symposium newcomers. As we explored our commonalities and unique interests, we learned many of us enjoy a bowl of mac n' cheese as our comfort food of choice (ice cream and chocolate weren't far behind).

Talking about our favorite comfort foods served as a seamless transition into our first session on medical marijuana

as a tool to manage pain. This session, sponsored by the National Hemophilia Foundation, explored the history of marijuana and what people with bleeding disorders should know about utilizing marijuana as part of one's pain treatment plan. We had a round robin session with our industry sponsors, then were joined by a panel of experts for our VWD Q&A lunch talk. Our panel of experts included Meera Chitlur, MD, Roshni Kulkarni, MD, and Magdalena Lewandowska, MD, CACP. It was an incredible conversation as panelists shared their knowledge and experiences while answering questions from attendees. It was a beneficial session for all, as attendees and panelists learned about VWD across the lifespan, new treatments, and tips for managing one's symptoms.

The afternoon breakout sessions addressed a variety of topics including aging with a bleeding disorder, how to prepare for the unexpected, psychosocial challenges of living with a bleeding disorder, and resources and

support for caregivers. The Hemophilia Federation of America sponsored our final session of the day as Bekah Heckathorne, RN, BSN, presented on the challenges of managing a mild bleeding disorder. Much gratitude to the speakers, sponsors, and HFM staff who came together to make this year's VWD Symposium an informative and enjoyable experience! Thank you to all of our attendees for your participation, sharing of knowledge and resources, and desire to invest in each other's wellness and learning journey. We appreciate you all! 💧

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SPRING TEEN RETREAT

Michigan teens look forward to HFM's annual Spring Teen Retreat as a way to connect and strengthen relationships, and it serves as a great opportunity to come together between the HFM holiday party and Camp Bold Eagle. This year's virtual Spring Teen Retreat focused on age-appropriate mental health conversations, emotional literacy, and differentiating between emotions and feelings. Conversations about expanding our vocabulary to accurately describe how we are feeling were integrated into online games and opened the door to sharing and self-reflection.

With a group of eight participants for this year's retreat, every teen fully participated and engaged with one another through conversation and fun. Creating safe spaces to allow open dialogue about mental health is always so important, especially now with all the changes and challenges we have faced over the last few years. Thank you to all the teens who participated in this year's Spring Retreat! We celebrate all the many ways we come together to support each other as a community and as individuals. 💙

THANK YOU TO GENENTECH FOR SPONSORING
HFM'S SPRING TEEN RETREAT.

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DAYS FOR GIRLS



HFM's Days for Girls Ypsilanti, MI team began in 2015 with a goal to provide menstruators around the world with reusable menstrual health kits and education. We further defined our mission in 2019 with the support of our partnership with Save One Life ***to equip women and girls in bleeding disorders communities around the world to manage their menstrual health, leading to freedom and independence.***

Prior to 2020 we distributed kits and provided education to women in bleeding disorders communities in the Philippines, Uganda, Kenya, and India. During the pandemic, we have been unable to send completed kits

to more communities, as travel has been greatly impacted. However, in 2021 we were able to supply women in India with 100 extra liners through a purchase from a local DfG Enterprise in India.

We are excited to return to in-person team workdays this summer and are looking for volunteers to join us! There are many volunteer jobs available and sewing experience is not necessary.

Thank you to Genentech for their support as we renew our work.

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For more information about volunteer opportunities with our Ypsilanti, MI DfG Team, please contact Shari Luckey: sluckey@hfmich.org

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CENTER OF CARE: QUALITY IMPROVEMENT

SAMANTHA L. CASSISI, MS, CGC,
CERTIFIED GENETIC COUNSELOR,
MICHIGAN STATE UNIVERSITY

In healthcare, quality improvement is the organized way to systematically make clinic flow and patient care better. It is a team-based approach that includes review of current processes, and errors are seen as opportunities to learn. In a multidisciplinary clinic such as a hemophilia treatment center (HTC), providers and staff from all specialties, such as nurse staff and physicians to genetic counselors and dental hygienists, meet to discuss clinic. The goal is to develop the clinic's current procedures and enhance the patient experience through implementing plans for improvement and studying the results of these changes. It is focused on patient-centered care and can increase patient understanding and improve patient outcomes. Quality improvement is achieved through four specific stages which include planning, implementation, studying, and action. This "Plan-Do-Study-Act" model, or PDSA, is a "trial-and-learning" method to test changes quickly to see how they work in a clinic. In this way, quality improvement is an integral part of development of best practices.

An HTC should always be growing and trying new things to improve patient care. Michigan State University is currently focusing on improving the patient experience around transition. Transition is often seen as the period between childhood and adulthood, where many changes occur in a person's life. However, transition is more than one moment in our lives. For example, children transition schools, adults start new jobs, people get married and buy new homes. All these situations can be considered periods of transition. When we expand our definition of transition, we can fully capture the patient experience throughout the entirety of their life, and we create opportunities to improve that experience.

Michigan State University is currently in the implementation phase of transition-related quality improvement. As a multidisciplinary clinic, there is a unique opportunity to address transition from many directions. Each specialty has chosen at least two transition-related topics related to their field of study to engage in with the patient throughout their life. For example, nursing staff is assuring that patients across all age groups understand their diagnosis and treatment plan, with the depth of their knowledge increasing in each age group. The genetic counselor has chosen to work on helping patients feel confident discussing and understanding their family history, with young children discussing their immediate family's health and older patients discussing their entire family history. These targets and achievements are recorded in the patient's chart, and patients are encouraged to keep reaching new goals.

The project has the potential to continue to grow and is able to address transition-related topics at many stages in a patient's life. Another benefit is that all specialties can be involved and address their specific area of study. Specialties have chosen their areas of education with help from the National Hemophilia Foundation's transition guidelines. The chosen transition goals are SMART goals, which are goals that are specific, measurable, achievable, relevant, and time bound.

Quality improvement is an important aspect to any clinic's continued growth. Taking the time to meet and discuss patient care and clinic flow is imperative to the success of a hemophilia treatment center. Not only that but sharing these developments with other HTCs allows for greater growth in patient understanding, patient treatment, and clinic flow. 📌



WE'RE IN THIS TOGETHER.

Friday 6:26 pm

Sharing stories by the campfire with friends

Isaac, living with hemophilia B

Not an actual patient

Let's make today brilliant.

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

 bleedingdisorders.com | 

TOLEDO ZOO COMMUNITY NIGHT

Families from across Michigan took a VIP behind the scenes trip to the Toledo Zoo Aquarium for our virtual Community Night and visited with sharks, stingrays, and jellies (and learned why they are no longer called jellyfish!). Sea creatures and colorful fish swam about as our zookeeper tour guide shared fun and fascinating facts and answered all our questions. While there were no whales, we had a whale of a time with the underwater views! It was an amazing look at all the many things that live beneath the water and great fun to learn more about their lives and environment.

After saying goodbye to all the marvelous creatures at the aquarium, we had a fun sprinkle of additional animal education by learning about service animals, who they are, what they can do, and how we should treat them. We even learned about miniature horses that are service animals and the difference between service animals and emotional support animals. Kids and adults talked about their favorite animals and as we said goodbye, we promised to see each other (and our pets!) again soon. 💧

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Exploring the science behind gene therapy research

Gene therapy research has the potential to bring an entirely new option to people with specific genetic conditions. Many gene therapies are in clinical trials to evaluate the possible risks and benefits for a range of conditions, including hemophilia. HemDifferently is here with gene therapy education, providing accurate information on the basics and beyond.

What questions do you have? Get them answered. Explore gene therapy at **HemDifferently.com**

No gene therapies for hemophilia have been approved for use or determined to be safe or effective.

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AGING PROGRAM SERIES

HFM is excited to announce that the National Hemophilia Foundation and the Hemophilia Alliance Foundation have awarded grants for new programming to address the needs of those with bleeding disorders in our community who are aging. Our 2021 Community Assessment identified this gap in current services and education. These grant funds, as well as a charitable contribution from Genentech, will allow for the addition of new sessions addressing the challenges of aging with bleeding disorders and HFM will launch a virtual multi-week educational initiative in the first quarter of 2023. More details will be available later this year.

We are grateful for the support and look forward to addressing this unmet need in the Michigan community. 💧

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 **NATIONAL HEMOPHILIA FOUNDATION**
for all bleeding disorders

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CAMP RETURNS TO PIONEER TRAILS

As campers and counselors arrived at HFM's Camp Bold Eagle/Pioneer Trails, there was a sense of returning home. While we know that camp is not the place it's the people—a sentiment that provided comfort and hope when we transitioned to Camp Bold Eagle at Home—there were feelings of joy and familiarity as HFM's camping programs gathered in-person again.



HFM's camping programs empower children with bleeding disorders to live a life of freedom and independence by providing safe yet challenging experiences. The home of Camp Bold Eagle since 1994, Pioneer Trails' rustic cabins clustered on the hill alongside the grassy fields and shady woods, and the picturesque waterfront of Big Blue Lake, create the beautiful backdrop for the adventures that await all campers.

We were so happy to see new and returning campers experience the joys of in-person camp like a morning dip in the lake (our Polar Bear tradition), shooting a bullseye during archery, sleeping away from home, and learning about medical independence with our amazing health center. We were especially excited to bring a new camp program to the community. Eagles Nest Family Camp introduced young children with bleeding disorders who haven't been to camp in-person before and their families to the Camp Bold Eagle experience. We can't wait for these now experienced campers to join us again next year!

HFM enacted a thorough COVID policy, including vaccination requirements, COVID testing prior to arrival, and mask usage, when necessary, to ensure a safe camping experience for all. We appreciate the community's support in helping us safely transition back to our in-person camping programs. 🍓



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UPCOMING 2022 EVENTS

September 9-11

Old Beagle

Pioneer Trails

In-person

September 22

Medicare 101

Virtual

September 24

Unite Walk SE Michigan

Kensington Metropark

In-person

September 27

Ruby Connection:

Financial Wellness 101

Virtual

October 7-9

**National Conference for
Women and Teens with
Hemophilia and Rare
Factor Deficiencies**

The Westin Detroit

Metropolitan Airport

In-person and virtual

October 21-22

Upper Peninsula Retreat

Marquette, MI

In-person

November 4-6

**Bleeder and a Buddy
Teen Retreat**

In-person

November 11

**Community Night:
Incredible Mo's**

Grawn, MI

In-person

Date TBA

End of the Year

Community Gathering

Troy High School

In-person

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OTHER UPCOMING HFM EVENTS,
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