CHAPTER *Factors*

SUMMER 2022

Midwest
Hemophilia
Association

Midwest
Hemophilia
Association

CAMP WILDERNESS

+ EST 1991 +

CALLING ALL CAMPERS & VOLUNTEERS!

Camp Wilderness registration is OPEN!

We are so excited for camp this year and are hopeful to have it live, in person at Lake Doniphan Conference & Retreat Center in Excelsior Springs, MO.

We firmly believe in the value of camp and what it provides to youth with bleeding disorders. Please take a moment to fill out the application and register your camper for their best week ever! And of course, Camp Wilderness would not be possible without the many individuals who donate their time to serve as staff volunteers. We invite you to complete the application to volunteer for your best week ever as well!

Camper & Volunteer registrations must be submitted no later than Monday, June 27, 2022.

SCAN TO REGISTER!

CAMPERS: Camp Wilderness will begin on Monday, August 1, 2022
VOLUNTEER STAFF: Camp Wilderness will begin Sunday, July 31, 2022

ALL: Camp Wilderness will end for everyone on Friday, August 5, 2022

SUMMER 2022 • Volume 32 Number 2

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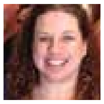
The Midwest Hemophilia Association
1471 W. South St, Suite F, Ozark, MO 65721
PO Box 412866, Kansas City, MO 64141
(816) 479-5900
www.midwesthemophilia.org

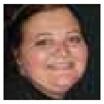
EXECUTIVE DIRECTOR



ANGELA BROWN
angela.brown@midwesthemophilia.org

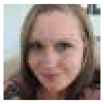
BOARD OF DIRECTORS
2022 OFFICERS

HEATHER INCE
PRESIDENT
hince2013@gmail.com



NORA ANCEL
VICE PRESIDENT
nora.e.ancel@gmail.com

MAREENA SNAREY
TREASURER
treasurer@midwesthemophilia.org

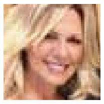


HANNAH BROWN
SECRETARY
hbrown.31622@gmail.com

2022 BOARD MEMBERS

DANIELLE BUCKLAND
dlbuckland19@gmail.com

DAKOTA ROSENFELT
dakotarosenfelt@gmail.com



KIM ROSENFELT
krosenfelt@hotmail.com

CODY YORK
cyork1121@gmail.com

FROM THE EXECUTIVE DIRECTOR

Hooray for summer! Whether you will spend time sunbathing or gardening, enjoying drinks by the pool or going on vacation adventures, I hope you will include MHA in your summer plans! We will be hosting several programs across our coverage area including Community Outreach Programs, Western Kansas Education Day in Dodge City, Trivia Night, and Camp Wilderness!!!

Then before we know it, fall will be here which means it will be time to host our annual golf tournament, Family Education Weekend (aka Family Fun Fair for you who have been around a while), Springfield Education Day, and the fabulous F.A.B. Conference (Females And Bleeding)! All these events and more can be found on our website and social media platforms--Facebook, Twitter, and Instagram! Be sure to check us out! I can't wait to see you there!

As always, it's a pleasure to you! And be sure to drop by the MHA office in Ozark if your summer plans bring you through the area!

Angela Brown
angela.brown@midwesthemophilia.org

2022 Board of Directors meetings are open to the public and scheduled for the following dates: March 26 (KC), May 14 (Ozark), July 16 (Ozark), September 18 (KC), November 12 (Ozark). Changes to these dates may be necessary due to scheduling conflicts and will be updated on our website calendar as soon as they are available.

MHA offers assistance to our community members experiencing financial hardships who live in our geographical coverage area of Kansas and western Missouri and/or for current patients of the Kansas City Regional Hemophilia Treatment Center.

If you or someone you know is experiencing financial hardship, the program guidelines and application form can be found on our website, ***midwesthemophilia.org***, by scanning the QR code.

MHA Financial Assistance

Shop through
amazonsmile
to support Midwest Hemophilia

When you use your existing **Amazon.com** account to shop through AmazonSmile, 0.5% of your eligible purchases will be donated to MHA. AmazonSmile is the same Amazon you know. Same products, same price, same service.

You Shop. Amazon gives.

Learn more or get started today!
Go to: https://smile.amazon.com

QUICK NOTES

World Hemophilia Day Celebration

In April, MHA celebrated World Hemophilia Day at the Bristol Seafood Grill in Kansas City with fun, fellowship, and food. Danielle Kempker, Sanofi's Community Relations and Education Manager, highlighted the importance of joint health as well as local & global community support.

During the program, attendees rotated through three different activities that demonstrated the impact of joint damage. Each station used materials that limited range of motion in joints then required them to attempt basic daily tasks such as walking, writing, and grasping. One particular station involved wearing cuffs on both elbows then attempting to unscrew a jar lid and buttoning up a shirt.

One participant commented, "I didn't realize how hard simple tasks could be for my [family member] who has joint damage and now limited range of motion from so many elbow bleeds."

The group also discussed the impact they have with each other to encourage joint health. The program ended with a give-back activity that included writing encouraging notes for those diagnosed with bleeding disorders living in other countries where access to care and/or treatment may not be as easily available. Cards will be sent to individuals through a partnership with Save One Life.

Above and right, MHA members participate in World Hemophilia Day held at Bristol Seafood Grill in Kansas City.

NHF's BDC in Houston on August 25-27

Join the fun at the NHF's 74th Annual Bleeding Disorders Conference (BDC) this summer in Houston, Texas! From August 25-27, you'll be able to reconnect with your community, learn in sessions designed just for you, and more! For those unable to travel, the conference also features a virtual registration option. However, you choose to attend, you don't want to miss this year's event! Register the whole family at hemophilia.org/bdc.

Trivia Night Fundraiser Coming in August! Gather the smartest and wisest people you know and join MHA for a fun night of refreshments, drinks, and trivia! Prizes awarded for 1st, 2nd, & 3rd place teams.
$25/individual or $125 per team of 6.
Register online at www.midwesthemophilia.org/events/

Mental Health First Aid Training

Angela Brown, MHA Executive Director, along with other HFA Board Members participated in a Mental Health First Aid program which included 2 hours of online pre-work, several hours of in-person training during symposium, and post-training test to receive certification. The MHFA training provided participants with knowledge regarding common mental health conditions, how to identify when someone is struggling emotionally and how to communicate with someone in despair. A list of resources are provided on MHA's website under the resource tab.

Above, HFA Board Members joined a Mental Health First Aid program, held during HFA's Symposium in Texas.

Below, kids have fun at the Wichita Education Day held on May 21.

Wichita Education Day

Community members from Wichita and the surrounding area attended Wichita Education Day at the Drury Plaza Hotel Broadview on May 21st where Dr. Lauren Amos, Hematologist from Children's Mercy Hemophilia Treatment Center, presented a program called, "On the Horizon," which included information about ongoing research and potential future treatments for Hemophilia A, Hemophilia B, and von Willebrand disease. Attendees then experienced hands-on practice of kinesiology taping with Amy Becker, physical therapist, also from the HTC. Attendees received lunch and tickets to Exploration Place. Thank you to everyone who attended!

Community Outreach Programs Continue

Community Outreach Programs continue to be a great way to connect with friends and families with bleeding disorders. Check out these photos from events held in Wichita (Chicken N' Pickle) and Kansas City (Top Golf) where attendees heard from event sponsors, enjoyed a meal, and had some fun playing together. Thank you to our sponsors: Octapharma, Brothers Healthcare, CSL Behring, and Optum Rx.

Be sure to visit *midwesthemophilia.org* to find a Community Outreach Program in your area and follow us on Facebook, Twitter, & Instagram!

CALENDAR OF EVENTS

JULY

19	Community Outreach Program: Kansas City

AUGUST

1-5	Camp Wilderness
9	Trivia Night Fundraiser
25-27	NHF BDC: Houston, TX

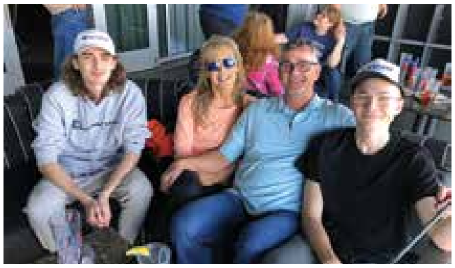
SEPTEMBER

16	24th Annual Golf Tournament
17-18	Family Education Weekend (FEW)

OCTOBER

6	Community Outreach Program: Wichita
14-16	FAB (Females And Bleeding) Conference
18	Community Outreach Program: Joplin
22	Springfield Education Day
27	Community Outreach Program: Kansas City

Below and right, MHA members connect with friends and families of others with bleeding disorders during the Community Outreach Programs held in Wichita and Kansas City.



YOUR EXPERIENCE 20 20+ YEARS* MATTERS

BeneFix®
Coagulation Factor IX (Recombinant)
Room Temperature Storage

*BeneFix was approved February 11, 1997.

EXPERIENCE MATTERS

BeneFix is FDA approved for **once-weekly prophylaxis** and **on-demand use** to fit your dosing needs—from the only recombinant factor IX supporting individuals with hemophilia B for more than 20 years.*

Not actual patients.

- **More than 20 years* of experience—**the first recombinant treatment for individuals with hemophilia B
- **Designed with viral safety in mind.** More than 150 quality control tests are done on each batch of BeneFix
- **The convenience of the BeneFix Rapid Reconstitution (R2) Kit** with a range of vial sizes
- **Ask your doctor about BeneFix dosing** options to meet your needs

*FOR **ONCE-WEEKLY** PROPHYLAXIS AND **ON-DEMAND** USE*

What Is BeneFix?

BeneFix, Coagulation Factor IX (Recombinant), is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Your doctor might also give you BeneFix before surgical procedures.

BeneFix is **NOT** used to treat hemophilia A.

Important Safety Information

- BeneFix is contraindicated in patients who have manifested life-threatening, immediate hypersensitivity reactions, including anaphylaxis, to the product or its components, including hamster protein.
- Call your health care provider right away if your bleeding is not controlled after using BeneFix.
- Allergic reactions may occur with BeneFix. Call your health care provider or get emergency treatment right away if you have any of the following symptoms: wheezing, difficulty breathing, chest tightness, your lips and gums turning blue, fast heartbeat, facial swelling, faintness, rash, or hives.
- Your body can make antibodies, called "inhibitors," which may stop BeneFix from working properly.
- If you have risk factors for developing blood clots, such as a venous catheter through which BeneFix is given by continuous infusion, BeneFix may increase the risk of abnormal blood clots. The safety and efficacy of BeneFix administration by continuous infusion have not been established.
- Some common side effects of BeneFix are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness, and rash.

Please see the Brief Summary for BeneFix on the next page.

PP-BEN-USA-0642

December 2021

Pfizer

BeneFIX®

Coagulation Factor IX (Recombinant)

Room Temperature Storage

Rx only

Brief Summary

See package insert for full Prescribing Information. This product's label may have been updated. For further product information and current package insert, please visit www.Pfizer.com or call our medical communications department toll-free at 1-800-438-1985.

Please read this Patient Information carefully before using BeneFIX and each time you get a refill. There may be new information. This brief summary does not take the place of talking with your doctor about your medical problems or your treatment.

What is BeneFIX?

BeneFIX is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Your doctor might also give you BeneFIX before surgical procedures.

BeneFIX is **<u>NOT</u>** used to treat hemophilia A.

What should I tell my doctor before using BeneFIX?

Tell your doctor and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal medicines.

Tell your doctor about all of your medical conditions, including if you:

- have any allergies, including allergies to hamsters.
- are pregnant or planning to become pregnant. It is not known if BeneFIX may harm your unborn baby.
- are breastfeeding. It is not known if BeneFIX passes into the milk and if it can harm your baby.

How should I infuse BeneFIX?

The initial administrations of BeneFIX should be administered under proper medical supervision, where proper medical care for severe allergic reactions could be provided.

See the step-by-step instructions for infusing in the complete patient labeling.

You should always follow the specific instructions given by your doctor. If you are unsure of the procedures, please call your doctor or pharmacist before using.

Call your doctor right away if bleeding is not controlled after using BeneFIX.

Your doctor will prescribe the dose that you should take.

Your doctor may need to test your blood from time to time.

BeneFIX should not be administered by continuous infusion.

What if I take too much BeneFIX?

Call your doctor if you take too much BeneFIX.

What are the possible side effects of BeneFIX?

Allergic reactions may occur with BeneFIX. Call your doctor or get emergency treatment right away if you have any of the following symptoms:

wheezing

difficulty breathing

chest tightness

turning blue
(look at lips and gums)

fast heartbeat

swelling of the face

faintness

rash

hives

Your body can also make antibodies, called "inhibitors," against BeneFIX, which may stop BeneFIX from working properly.

Some common side effects of BeneFIX are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness and rash.

BeneFIX may increase the risk of thromboembolism (abnormal blood clots) in your body if you have risk factors for developing blood clots, including an indwelling venous catheter through which BeneFIX is given by continuous infusion. There have been reports of severe blood clotting events, including life-threatening blood clots in critically ill neonates, while receiving continuous-infusion BeneFIX through a central venous catheter. The safety and efficacy of BeneFIX administration by continuous infusion have not been established.

These are not all the possible side effects of BeneFIX.

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

How should I store BeneFIX?

DO NOT FREEZE the BeneFIX kit. The BeneFIX kit can be stored at room temperature (below 86°F) or under refrigeration. Throw away any unused BeneFIX and diluent after the expiration date indicated on the label.

Freezing should be avoided to prevent damage to the pre-filled diluent syringe.

BeneFIX does not contain a preservative. After reconstituting BeneFIX, you can store it at room temperature for up to 3 hours. If you have not used it in 3 hours, throw it away.

Do not use BeneFIX if the reconstituted solution is not clear and colorless.

What else should I know about BeneFIX?

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

If you would like more information, talk with your doctor. You can ask your doctor or pharmacist for information about BeneFIX that was written for healthcare professionals.

This brief summary is based on BeneFIX® [Coagulation Factor IX (Recombinant)] Prescribing Information LAB-0464-14.0, revised September 2021.

PP-BEN-USA-0643

December 2021

Pfizer


ELOCTATE®
[Antihemophilic Factor
(Recombinant), Fc Fusion Protein]
JOIN THE CONVERSATION.
LEARN ABOUT ELOCTATE.

First Ever MEN'S RETREAT

By John Carleton

On May 13th, twenty-three men representing Midwest Hemophilia and Gateway Hemophilia gathered at Margaritaville at Lake of the Ozarks for the first ever men's retreat. The weekend was filled with informational meetings and a lot more. On Friday evening we all gathered and spent the time networking and getting acquainted. Since we had two chapters represented many of the participants were meeting for the first time. From the noise level and laughter, I think we all bonded very well.

Saturday morning Angela Brown, MHA's Executive Director, Bridget Tyrey, GHA's Executive Director, and Julie Golla, Senior Account Manager for BioMarin, welcomed the attendees. At that point the ladies departed and the program began. Our first speaker was Bill Berger, social worker with the treatment center at Washington University in St. Louis. The presentation centered around mental health and combined related specific issues presented by Bill with small round table discussions mixed in. The topic proved to be timely and very interesting.

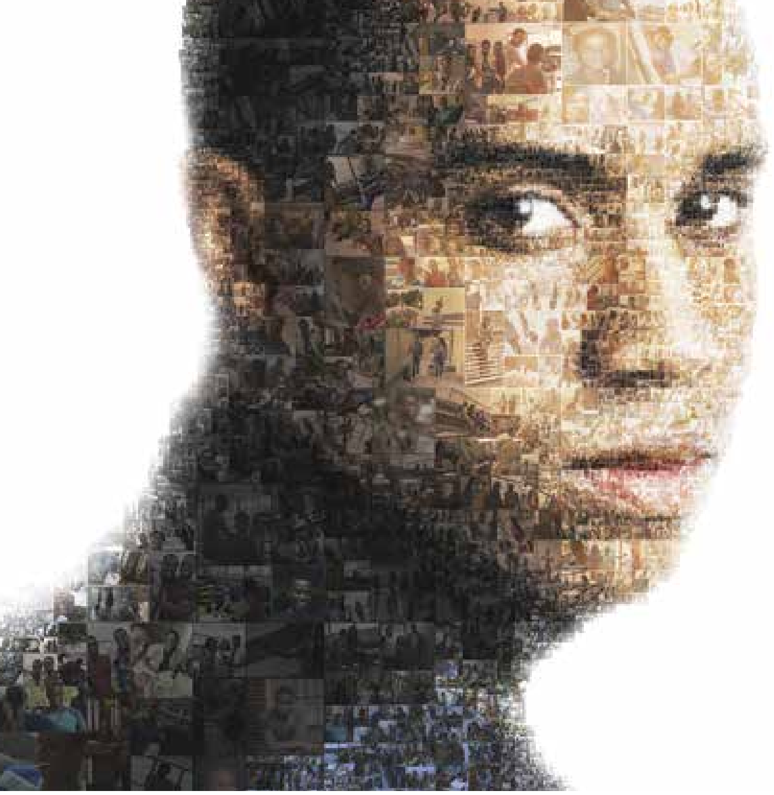
After lunch Dr. Osman Khan, a treatment center physician in Oklahoma City, made a presentation on the current status of gene therapy. After the presentation we were treated to a Jeopardy formatted game on the information we had just learned. The game and presentation were fun and informative.

After a break we did what we termed a "give back" event. All of the attendees participated in an activity where we packed gift bags for the homeless. All of the supplies and bags were purchased with a grant from Thrivent Financial. Thrivent is the financial arm of the Lutheran Church. Each attendee then took three of the bags with them to distribute to the homeless in their area. The men also did a little closet clearing before coming for the weekend. The donated cloths were collected and given to the City Union Mission in Warsaw, MO.

Late Saturday afternoon we were treated to an hour and half cruise on Lake of the Ozarks on a 75-foot Tropic Island boat. Many of the men had not been on the lake before and it provided a scenic view and time to network. To say we had a good time would not be adequate.

Our last "official" activity of the weekend was the Saturday evening Chili cook-off competition. The men were divided into teams of three and given a station with a cookpot and utensils. A large table on one side of the room had an amazing assortment of "fixins" that could be combined to make the champion chili. Thirty minutes later the chili was judged for Best Chili, Best Presentation and Most Unique. Once awards were presented, we shared our chili for dinner. According to the event evaluations this was our most popular activity.

Sunday morning each man had a breakfast voucher to use at the resort. At that point we all headed home in our various directions. BioMarin was our sponsor for the weekend and provided speakers, funding and support in numerous ways. I cannot thank Julie and the BioMarin team enough. I think our first ever Men's Retreat was successful and left the men wanting to return again next year.


No actual patients depicted.

ADYNOVATE
[Antihemophilic Factor (Recombinant), PEGylated]
REAL LIFE. REAL BLEED PROTECTION.*

AdynovateRealLife.com

HEMOPHILIA A IS A PIECE OF YOU.

NOT ALL OF YOU.

ADYNOVATE® is a treatment that can be personalized to fit your lifestyle so you have more time to spend doing the other things that also make you, you. It has a simple, twice-weekly dosing schedule on the same 2 days every week.[1,2]

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

ADYNOVATE twice-weekly prophylaxis prevented or reduced the number of bleeds[2]

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[2]
  - 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
- **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 groups[2]
  - 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

[†] 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

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 mouse 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, diarrhea, rash, nausea, dizziness, and hives. 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.

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

US-ADY-0351v1.0 08/21

Takeda

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 breast-feeding because ADYNOVATE may not be right for you.

How should I use ADYNOVATE?

ADYNOVATE is given directly into the bloodstream.

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

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

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

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

How should I use ADYNOVATE? (cont'd)

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

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

You should tell your healthcare provider if you:

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

What are the possible side effects of ADYNOVATE?

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

What else should I know about ADYNOVATE and Hemophilia A?

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

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

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADYNOVATE. The FDA-approved product labeling can be found at www.ADYNOVATE.com or 1-877-TAKEDA-7.

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.

Patented: see www.takeda.com/en-us/patents/

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Issued 06/2021

Takeda

Congratulations

TO OUR 2022 GRADUATES

Jadynn Andereck

PARENT NAME: Shane & Janet Andereck

GRADUATED FROM: Hoisington High School

FUTURE PLANS: Welding

MESSAGE TO GRADUATE: "Super proud of you and excited to see what your future holds" ~Mom & Dad

Jesse Hancock

PARENT NAME: Carol Hancock

GRADUATED FROM: Northwest High School

FUTURE PLANS: Attending Friends University on an art scholarship to study graphic design.

Isabella Richards

PARENT NAME: Phillip & Christina Patterson

GRADUATED FROM: Iola High School

FUTURE PLANS: Attending Pittsburg State University to major in Nursing

MESSAGE TO GRADUATE: "We love you Isabella dn we are so proud of you and your accomplishments. We can't wait to see what the future holds for you."

Brady Stockwell

PARENT NAME: Ed & Sharla Stockwell

GRADUATED FROM: Mill Valley High School

FUTURE PLANS: Attending Kansas State University to study Wildlife Biology

MESSAGE TO GRADUATE: "Congratulations on your high school graduation Brady! You have made us so proud and we're excited to see you follow your dreams. Best of luck in college!" ~Dad & Mom

FAB 2022

October 14-16, 2022

Margaritaville
494 Tan Tara Estate Drive
Osage Beach, MO 65065

MHA will co-host a Women's Retreat with Gateway Hemophilia Association, Nebraska Chapter of NHF, and Hemophilia of Iowa,for women 18 and older with a bleeding disorder, carriers, and a parent/guardian of a person with a bleeding disorder.

Attendees must be a member and live in MHA's service area of Kansas and western Missouri. Registration deadline is Sept. 9, 2022. Contact info@midwesthemophilia.org with any questions.

REGISTER NOW AT
www.midwesthemophilia.org

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A Texas-Sized FAMILY REUNION

by Martin Addie

How would one describe a symposium? Google defines it as a conference or meeting to discuss a particular subject. HFA referred to it as a Texas Sized Family Reunion. Catching up with old friends, actually meeting those that you only knew from all the online meetings of the Covid era and making new ones here. I almost forgot hugs and handshakes with those that were comfortable with them. Oh, we also had a lot of conversations and meetings that corralled and herded us to consider many aspects of surviving and thriving with hemophilia. Being that it covered four days I won't make this take 4 days to read, your welcome.

Let's not forget the exhibit hall where the sponsors encouraged us to learn about their products, and services. Encouragement involved lots of candy/chocolate and related goodies, did you know there were so many product choices these days? Did I mention Chocolate? I missed that in the virtual conferences.

My mom took me to my first symposium in the early 70's before we started home care in Wisconsin where I grew up, at least physically, some might argue that I haven't fully matured yet. In those days factor was new, Mom would have been fascinated to see all the changes, especially the hope that comes with these treatment options. It excites me that there were younger men and kids that had hemophilia, but you may not have noticed as many didn't have the telltale signs of joint damage like a fused knee or ankle or arms that don't straighten all the way all because of better treatments that are available. I was born near the end of the 50's my parents were told because of hemophilia I may not live past my teens.

A bit of history makes the present seem even sweeter in a lot of ways, yet in others our history has many painful memories besides the physical. Zander Masser had a presentation about his dad based on a book he wrote called, Unburying My Father, telling and sharing his father's professional photos, his dad Randy passed from Aids-related illness in 2000. It is a moving story about his path after his dad's passing. You can learn more at *https://www.randymasserphoto.com/* We got to visit with Zander and his mom there were many things that we have in common in our lives.

There was also a celebration of life to read the names and see photos of many of our community that have passed.

It was a full agenda with many sessions for different interests, for young families, older guys, women/girls with bleeding disorders. Friday night there was a big feed, with games and a DJ, dancing and adult beverages if you were so inclined. It looked like everyone enjoyed the evening, and the symposium.

Our hotel was on the Riverwalk, not far from the Alamo (not the car rental). Several of the MHA group took the boat tour on the river, that was quite nice.

If you haven't been to a symposium, hold on …. Wait for it… guess what, they are planning another in April 2023 in sunny Florida!

From Advocacy Ambassadors Newsletter...

Missouri Senate Bill 1031

Our work continues on Senate Bill 1031 (SB 1031), which remains stalled in the Senate Insurance & Banking Committee. We have made great progress coalition building with other patient organizations in Missouri, as you can see from the updated "one-pager" attached. We are now looking to continue strenghtening our postition throughout the rest of this year and regroup with a stronger position in the 2023 legislative session.

We can't encourage this enough. Now is the time to sign up for the Missouri Bleeding Disorders Coalition's Capital Canary Network (previously called "Phone2Action). Simply text MOBDADVOCATE to 52886. This will allow us to send you prewritten messages you can send to your legislators right from your phone to help advocate for this cause. The more voices they hear, the better chance we have of getting this important legislation passed. With a united voice we can raise public awareness of bleeding disorders and shape public policy that improves the quality of life for all. Your voice and our mission are linked together. Our success as a grassroots organization depends on your advocacy.

NHF's Washington Days

Missouri constituents from MHA and GHA chapters meet with Senator Josh Hawley's Legislative Aide Tyler Fagan (below) and Senator Roy Blunt's Legislative Aide Senn Boswell (right) during NHF's virtual Washington Days held in March.

Make All Copays Count

Copay Accumulator Adjustment Programs: Why They Are Increasing Costs to Patients and the Health Care System

The Problem: Copay Accumulator Adjustment Programs (CAAPs)
Patients with complex and chronic illnesses often rely on copay assistance programs to afford the specialty medications essential to their health. These funds from nonprofit organizations and manufacturers help patients afford their treatments—medications that rarely have generic alternatives. Click here to learn more.

Increasingly, health insurance companies are using "**copay accumulator adjustment programs**" which exclude copay assistance payments from counting toward a patient's annual deductible or out-of-pocket maximum. In effect, the insurer demands double payment of out-of-pocket costs: first from copay assistance and then again from patients.

Copay accumulator adjustment programs harm patients by undermining access to life-saving prescription drugs, making it more difficult for people living with chronic illnesses to adhere to a treatment plan.

What's the story in Missouri?
Copay accumulator adjustment programs are on the rise. An analysis of the 2022 Missouri ACA plans found that **CAAPs are present in 8 out of 9 plans.** With CAAPs in place, patients can end up on the hook for out-of-pocket costs (up to the full amount of their out-of-pocket maximum, potentially as high as $8,700/person or $17,400/family in 2022!). CAAPs also increase overall health care spending because patients cannot afford their prescribed preventative care and end up with advanced medical issues.

Missouri Health Plan	CAAP Present?
Aetna	Yes
Ambetter/Celtic (Centene)	Yes
Anthem	Yes
Blue KC	Yes
Cox	Yes
Medica	Yes
Oscar	Yes
SSM/WellFirst	Yes
Cigna	No

The AIDS Institute, "Discriminatory Copay Policies Undermine Coverage for People with Chronic Illness" (2022)

A recent study conducted by the National Hemophilia Foundation found that 69% of patients who depend on financial assistance to afford their medications make less than $40,000 a year.

And until we ban co-pay accumulator policies, these vulnerable patients will struggle to afford their essential medications. Read more

Policy Solution: Ensure All Copays Count
Missouri legislators can help patients afford critical treatments by ensuring all payments – made by or on behalf of patients – are counted toward the patients' deductibles and out-of-pocket maximums:

- Patients should not be punished for utilizing copay assistance for treatments they need to control their complex and chronic conditions.
- So far, 12 states (AR, AZ, CT, GA, IL, KY, LA, NC, OK, TN, VA, WV) and Puerto Rico have protected patients by passing legislation to ensure all copays count.
- SB 1031 would protect Missouri patients by requiring insurers to count copay assistance payments toward patient deductibles and out-of-pocket maximums. Please support SB1031

Missouri All Copays Count Coalition

Gateway Hemophilia Association
Midwest Hemophilia Association
HFA Hemophilia Federation of America
Cancer Action Network American Cancer Society
MS National Multiple Sclerosis Society
Spondylitis Association of America
Lupus and Allied Diseases Association, Inc.
National Psoriasis Foundation
American Diabetes Association
Arthritis Foundation
GCA Gaucher Community Alliance
National Eczema Association
HIV+HEP Policy Institute
Susan G. Komen
Chronic Disease Coalition
AIMED Alliance
AfPA Alliance for Patient Access
Chronic Care Policy Alliance
IDF Immune Deficiency Foundation
Allergy & Asthma Network
Missouri Oncology Society
National Hemophilia Foundation for all bleeding disorders
CSRO
ALS Association
ASCO Association for Clinical Oncology
msaa Improving Lives Today! Multiple Sclerosis Association of America

NHLBI Grant Supports Scientific Research to Enhance Hemophilia A Gene Therapies

A group of investigators are embarking on a new research program designed to unpack some of the outstanding fundamental questions associated with current approaches to gene therapy for hemophilia A. While multiple gene therapies are currently in various stages of preclinical or clinical studies there remain concerns relevant to the biological nuances affecting long term safety and efficacy.

The new program, which is being supported by a $12 million grant from the National Heart Lung and Blood Institute (NHLBI), represents a multi-institutional effort to ultimately help improve these therapies. It will be led by Roland Herzog, PhD, at the Indiana University (IU) School of Medicine.

Herzog is the Director of IU's Gene and Cell Therapy Program. He was also a recipient of NHF's Career Development Award from 2000-2003, for his funded project "Immunology of Liver-Derived Expression of Factor IX from AAV Vectors."

"Several companies have taken this forward into clinical trials, and in some of these trials, the patients initially looked like they were cured," said Herzog, who is the Riley Children's Foundation Professor of Immunology. "But what they all have in common is that they need to deliver a lot of the virus in order to get the desired results, and over time clotting factor levels started to decline. So, it's clear that we need to further study the biology of this phenomenon."

According to an IU School of Medicine press release this program will include three major projects, with investigators conducting molecular-level analysis of key components in liver-directed gene therapy, including human liver cells and factor VIII (FVIII) viral vectors. Herzog and his colleagues hope to garner new insights that can ultimately lead to lower levels of cellular toxicity and "improved longevity of FVIII production" in individuals who are treated with gene therapy for hemophilia A.

> **"My hope is that our studies will help the field as a whole move toward curing hemophilia A."**
>
> ***— Roland Herzog, PhD***
> ***Director of Gene and Cell Therapy Program, Indiana University School of Medicine***

"This is an incredibly significant and urgent medical question, and it requires the synergy of multiple groups with different expertise to come together and solve a problem that they wouldn't be able to solve on their own," said Herzog. "My hope is that our studies will help the field as a whole move toward curing hemophilia A."

Source: Indiana University School of Medicine news release dated March 8, 2022

24TH ANNUAL MHA GOLF TOURNAMENT

DATE + VENUE

SEPTEMBER 16, 2022
CHECK-IN 7AM

Winterstone Golf Course
17101 E. Kentucky Road
Independence, MO 64058

REGISTER online at
www.midwesthemophilia.org/events

For questions, contact Adam Noel at adam.noelkc@gmail.com or the MHA office at 816-479-5900

Register for Family Education Weekend!

September 17-18, 2022
Marriott KC Overland Park

You don't want to miss Family Education Weekend 2022! MHA is continually striving to better serve you because having a bleeding disorder has an impact on all aspects of life. FEW is an opportunity for you to share and learn valuable information that can help you manage you and/or your family member's bleeding disorder. With all that in mind, MHA's annual meeting will have a keynote speaker, breakouts, exhibits, childcare, youth, and teen programs, raffles, and plenty of time for fun!

Midwest Hemophilia Association
FAMILY EDUCATION Weekend
Connecting the Bleeding Disorder Community
SEPTEMBER 17-18, 2022

Visit www.midwesthemophilia.org to register!

Registration closes Thursday, August 18, 2022 at midnight.

MOVING? NEW ADDRESS?

Update your contact information by visiting *MidwestHemophilia.org* and clicking on the "Become a Member" tab. Once complete, click JOIN and you're done!

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Dedication and Personal Support

Pfizer Rare Disease | RARE DISEASE PATIENT AFFAIRS

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

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"I've helped organize patient educational programs for over 10 years—I enjoy creating interactions and sharing knowledge in the community."

My work is guided by:

Compassion—Listening to your needs and addressing questions and concerns that you may have

Commitment—Educating you about Pfizer's tools and resources, including the Pfizer Community Connections Program, the HemMobile® app for logging bleeds and infusions, B2B materials, and more

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

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