KHFHemospher

2024 Kentucky Unite Walk

The 11th Annual KHF Unite Walk once again did not disappoint. This Walk and Community Event celebrates the fundraising efforts of our walkers and walk teams. Twelve teams from across Kentucky and several individual walkers participated in our eleventh annual Walk at E. P. "Tom" Sawyer State Park.

The weather was perfect for a walk in the park. Colorful Halloween decorations awaited our walkers on this gorgeous day in October. The aroma of hot dogs and hamburgers soon filled the air to the backdrop of children's laughter and the DJ's Halloween music.

After the walk, participants enjoyed freshly grilled hot dogs and hamburgers prepared by Eric Marcum, board president, and Travis Price, long-term volunteer. Pumpkin painting, pinatas, balloon animals, trick or treat candies, and the costume contest entertained the many kids who came with their families.













The highlight of the walk celebration was the awards ceremony. Top teams were Team Tag and Trey's Turtles from Bowling Green in 1st place with \$7,025; Team Levi from Cynthiana in 2nd place with \$2,085; and Team XL from Louisville in 3rd place with \$1,520. Each of the top three winning team captains received an inscribed glass award. All top three team members received a medal and a commemorative KHF to-go cup.



Special News

Study Suggests Patients Preferences Evolving Along with Treatments

In recent years, the arrival of novel hemophilia treatments that are effective and less burdensome to administer have opened up new possibilities for the consumers of these therapies. This begs the question – How might this evolving landscape be impacting treatment preferences for people with hemophilia?



Investigators sought answers to this question in a new study, "Patient and Caregiver Preferences for Haemophilia Treatments: A Discrete-Choice Experiment," which was published in the journal Haemophilia. The study was informed by a literature review and a survey open to adult males with hemophilia age 18 years and older, and caregivers of teen/adult males with hemophilia age 17 years or younger.

The surveys, which were submitted online from February to April 2022, generated a sample of 151 affected adults and 151 caregiver respondents. Each respondent evaluated hypothetical hemophilia treatment profiles defined by six attributes via a discreet choice experiment (DCE). The DCE was used by the authors to quantify preferences and learn more about trade-offs individuals consider when making decisions about available treatments.

Respondents answered questions based on six attributes: number of annual spontaneous bleeds; ability to live a more active lifestyle; how a medicine is prepared/administered; frequency of administration; risk of an inhibitor; risk of hospitalization due to treatment side-effects.

The burdens of treatment administration (intravenous and subcutaneous) and storage were also explored through a best-worst (BWS) scaling exercise, used to assess an individuals' priorities. It captures extremes including best and worst items, most and least important factors, biggest and smallest influences.

"In the BWS exercise, adult respondents and caregivers had overall similar preferences regarding the burden of treatment administration features, reported the investigators "Both samples found frequent and longer IV infusions most burdensome and a Sub-Q injection every 2 months least burdensome."

DCE results indicated that both adult patients and caregivers preferred treatments that enabled a more active lifestyle and are associated with a lower inhibitor risk. Notably, both groups valued an active life more than reducing spontaneous bleeds.

that both adult patients and caregivers preferred treatments that enabled a more active lifestyle and are associated with a lower inhibitor risk.

"These findings suggest that adults with haemophilia and caregivers of children with haemophilia are willing to make tradeoffs for potential improvements in lifestyle not offered by clotting factor concentrates, bypass agents or activated factor VIII mimetics," explained the authors.

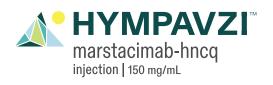
The paper also acknowledged limitations. The sample generated from the survey included English speakers exclusively and respondents were predominantly white, highly educated. In addition, the survey was only available online, which would exclude individuals/families who do not have internet.

The authors posit that this study underscores the importance of a shared decision-making (SDM) approach to hemophilia care. Through SDM, healthcare providers and patients/caregivers may arrive at decisions that factor in the current treatment landscape and individual preferences.

Citation

Garcia VC, Mansfield C, Pierce A, Leach C, Smith JC, Afonso M. Patient and caregiver preferences for haemophilia treatments: A discrete-choice experiment. Haemophilia. 2024 Jan 10. doi: 10.1111/hae.14928. Epub ahead of print. PMID: 38198352.

This synopsis of an article published in a peer-reviewed journal has been provided by the National Bleeding Disorders Foundation.



For routine prophylaxis in patients 12 years and older with hemophilia A or B without inhibitors



Scan the QR code to sign up for updates at **HYMPAVZI.com**

NOW APPROVED



*Your first dose (loading dose) of HYMPAVZI is 300 mg (two 150 mg injections). Then you will inject a weekly (maintenance) dose consisting of 1 or 2 injections as prescribed by your healthcare provider. If more than one injection is required to deliver a complete dose, administer each injection at a different injection site.

What is HYMPAVZI?

HYMPAVZI is a prescription medicine used to prevent or reduce the frequency of bleeding episodes in adults and children 12 years of age and older with hemophilia A without factor VIII inhibitors or hemophilia B without factor IX inhibitors

It is not known if HYMPAVZI is safe and effective in children younger than 12 years old.

IMPORTANT SAFETY INFORMATION

Important: Before you start using HYMPAVZI, it is very important to talk to your healthcare provider about using factor VIII and factor IX products (products that help blood clot but work in a different way than HYMPAVZI). You may need to use factor VIII or factor IX medicines to treat episodes of breakthrough bleeding during treatment with HYMPAVZI. Carefully follow your healthcare provider's instructions regarding when to use factor VIII or factor IX medicines and the prescribed dose during your treatment with HYMPAVZI.

Before using HYMPAVZI, tell your healthcare provider about all of your medical conditions, including if you:

- have a planned surgery. Your healthcare provider may stop treatment with HYMPAVZI before your surgery. Talk to your healthcare provider about when to stop using HYMPAVZI and when to start it again if you have a planned surgery.
- have a severe short-term (acute) illness such as an infection or injury.
- are pregnant or plan to become pregnant. HYMPAVZI may harm your unborn baby.

Females who are able to become pregnant:

- Your healthcare provider will do a pregnancy test before you start your treatment with HYMPAVZI.
- You should use effective birth control (contraception) during treatment with HYMPAVZI and for at least 2 months after the last dose of HYMPAVZI.
- Tell your healthcare provider right away if you become pregnant or think that you may be pregnant during treatment with HYMPAVZI.
- are breastfeeding or plan to breastfeed. It is not known if HYMPAVZI passes into your breast milk.



Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, and herbal supplements.

What are the possible side effects of HYMPAVZI? HYMPAVZI may cause serious side effects, including:

- blood clots (thromboembolic events). HYMPAVZI may increase the
 risk for your blood to clot. Blood clots may form in blood vessels in
 your arm, leg, lung, or head and can be life-threatening. Get medical
 help right away if you develop any of these signs or symptoms of
 blood clots: swelling or pain in arms or legs; redness or discoloration
 in your arms or legs; shortness of breath; pain in chest or upper back;
 fast heart rate; cough up blood; feel faint; headache; numbness in
 your face; eye pain or swelling; trouble seeing
- allergic reactions. Allergic reactions, including rash and itching have happened in people treated with HYMPAVZI. Stop using HYMPAVZI and get medical help right away if you develop any of the following symptoms of a severe allergic reaction: swelling of your face, lips, mouth, or tongue; trouble breathing; wheezing; dizziness or fainting; fast heartbeat or pounding in your chest; sweating

The most common side effects of HYMPAVZI are injection site reactions, headache, and itching.

These are not all the possible side effects of HYMPAVZI. Call your doctor for medical advice about side effects. You may report side effects to the FDA at 1-800-FDA-1088.

Please see Important Facts about HYMPAVZI on the next page or at www.HYMPAVZI.com



IMPORTANT FACTS

Important information: Before you start using HYMPAVZI, it is very important to talk to your healthcare provider about using factor VIII and factor IX products (products that help blood clot but work in a different way than HYMPAVZI). You may need to use factor VIII or factor IX medicines to treat episodes of breakthrough bleeding during treatment with HYMPAVZI. Carefully follow your healthcare provider's instructions regarding when to use factor VIII or factor IX medicines and the prescribed dose during your treatment with HYMPAVZI.

What is HYMPAVZI used for?

HYMPAVZI is a prescription medicine used to prevent or reduce the frequency of bleeding episodes in adults and children 12 years of age and older with hemophilia A without factor VIII inhibitors or hemophilia B without factor IX inhibitors.

It is not known if HYMPAVZI is safe and effective in children younger than 12 years old.

What should I tell my healthcare provider before using HYMPAVZI?

Tell your healthcare provider about all your medical conditions, including if you:

- have a planned surgery. Talk to your healthcare provider about when to stop using HYMPAVZI and when to start it again if you have a planned surgery.
- have a severe short-term (acute) illness such as an infection or injury.
- are pregnant or plan to become pregnant. HYMPAVZI may harm your unborn baby.

Females who are able to become pregnant:

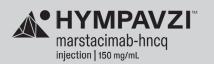
- Your healthcare provider will do a pregnancy test before you start your treatment with HYMPAVZI.
- You should use effective birth control (contraception) during treatment with HYMPAVZI and for 2 months after the last dose of HYMPAVZI.
- Tell your healthcare provider right away if you become pregnant or think that you may be pregnant during treatment with HYMPAVZI.
- are breastfeeding or plan to breastfeed. It is not known if HYMPAVZI passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, and herbal supplements.

How should I use HYMPAVZI?

See the detailed "Instructions for Use" that comes with your HYMPAVZI for information on how to inject a dose of HYMPAVZI, and how to properly throw away (dispose of) used HYMPAVZI prefilled syringe or HYMPAVZI prefilled pen.

- Use HYMPAVZI exactly as prescribed by your healthcare provider.
- Your healthcare provider will provide information on the treatment of breakthrough bleeding during your treatment with HYMPAVZI. Do not use HYMPAVZI to treat breakthrough bleeding.



What warnings should I know about HYMPAVZI?

HYMPAVZI may cause serious side effects, including:

- blood clots (thromboembolic events). HYMPAVZI may increase the risk for your blood to clot in blood vessels in your arm, leg, lung, or head and can be life-threatening. Get medical help right away if you develop any of these signs or symptoms of blood clots:
 - swelling or pain in arms
 - or legs

back

- redness or discoloration in your arms or legs
- shortness of breathpain in chest or upper
- o fast heart rate
- o cough up bloodo feel faint
- o teel taint
- headachenumbness in your face
- eye pain or swelling
- o trouble seeing
- allergic reactions. Allergic reactions, including rash and itching have happened in people treated with HYMPAVZI.
 Stop using HYMPAVZI and get medical help right away if you develop any of the following symptoms of a severe allergic reaction:
 - swelling of your face, lips, mouth, or tongue
 - trouble breathing

wheezing

- o dizziness or fainting
- fast heartbeat or pounding in your chest
- sweating

The most common side effects of HYMPAVZI are injection site reactions, including:

- itching
- redness
- swelling
- bruising
- hardening
- pain

Headache and itching were also common side effects. A serious side effect of swelling in the legs happened in one patient in the clinical trial.

These are not all of the possible side effects of HYMPAVZI. Call your doctor for medical advice about side effects. For more information, ask your doctor.

This information is not comprehensive. How to get more information:

- Talk to your health care provider or pharmacist
- Visit www.HYMPAVZI.com to obtain the FDA-approved product labeling
- Call 1-888-HYMPAV-Z

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.



More News



2024 Kentucky Unite Walk

Continued

The top three individual fundraisers also received an inscribed glass award. The recipients were Monica Poynter in 1st place with \$5,200; Levi & Hunter Hill in 2nd place with \$2,060; and Diane Hardman

in 3rd place with \$1,295. We greatly applaud and appreciate the tremendous

fundraising efforts conducted by these teams and extend our utmost thanks to them as well as to the other teams and walkers.

We also thank our sponsors who contributed so generously to our fundraising total. They were Silver Level sponsors CSL Behring and Novo Nordisk; Bronze Level sponsors Biomatrix, PhRMA, Sanofi, and Takeda; and Kilometer Sponsor Republic Bank & Trust Company. We also thank our staff and volunteers who contributed so much to the Walk's success. They were Madison Bowles, Lindsay Martin, Eric Marcum, Travis Price, Pam Price, Milton Kamala, Connie Thacker and Kayden, Laura Webb, and Patrick and Jennifer Dunegan. The Walk raised a total of \$28,257 for KHF's programs and services for Kentucky's bleeding disorders community.







2025 KHF Activities Calendar

June 9 Play a Round for a Cure Golf Scramble, Glen Oaks Country Club, Prospect

July 20-24 Camp Discovery for Children and Teens, Cedar Ridge Camp,

Sept. 13 Summer Family Event/Annual Education Meeting, Louisville

Oct. 18 KHF Unite for Bleeding Disorders Walk at E. P. "Tom" Sawyer State Park, Middletown

Nov. 30 Year-End Family Event, German-American Club, Louisville

Nov-Dec Poinsettia Fundraiser - November and December, office pick-ups and deliveries

Event News

Annual Education Meeting – Summer Family Event

This event is our major education forum every year in late summer/early fall. Speakers presented cutting edge information pertinent to all attending bleeding disorders families. In 2024, topics were "Bleeding Disorders Care – Past, Present, and Future," "Bleeds: How to Recognize and Respond," and "Stop Waiting: Six Principles of Empowerment. Exhibitors engaged with our community and informed them of available products and services. Breakfast and lunch provided welcome interludes.

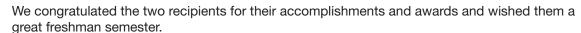
Children's activities and door prizes rounded out the event. KHF recognized outgoing board members, Patrick Dunegan and Travis Price. Travis also received the award of outstanding volunteer for thirteen years of exceptional volunteer service and leadership as a KHF Camp Counselor. The membership elected officers for FY 24/25. They are Eric Marcum, President, Andrew Hartmans, VP/Treasurer, and Aisha Irvin, Secretary, and they welcomed Trevor Black as a new director on the KHF board. Young Leader Awards were presented for demonstrated exceptional leadership to Taylor Currie, Elijah Eke, Sam Johnson, Quinn Jackson, Marissa Johns, Izzi Woods, and Jackson Woods.



2024 Fall Scholarships

We awarded two \$500 Scholarships for post-secondary education. The Herb Schlaughenhoupt, Jr. Memorial Scholarship was awarded to Emily Wolf from Union, Kentucky. She graduated from Boone County's Randall K. Cooper High School and was on her school's Honor Roll all four years of high school, received multiple awards, was active in school clubs, and led several school councils. She is a freshman at the University of Kentucky with a major in Marketing and expecting to graduate with a degree in Business Administration.

The Theodore (Ted) L. Forcht Memorial Scholarship was awarded to Kensey Marie Clayton. She graduated from Bethlehem High School in Bardstown and was on her school's Honor Roll all four years of high school as well. She was active in soccer and basketball and held multiple leadership positions in school clubs and councils. She is a freshman at the University of Kentucky Lewis Honors College majoring in Finance and expecting to graduate with a degree in Finance and a Minor in International Business.







Gettin' in the Game

The 2024 Gettin' in the Game Junior Championship sponsored by CSL Behring took place in Henderson, Nevada. Children and teens from across the country gathered to compete in the disciplines of baseball, basketball, golf, and swimming.

KHF nominated two Kentucky boys, Nikolai Smith from Shepherdsville and Elias Lowrie from Bowling Green. They both stretched their wings in the baseball competition and had a "ball" doing so!



Event News



Poinsettia Fundraiser

We thank our faithful volunteers for helping us with our annual poinsettia fundraiser! With their help, we were able to sell more than 900 plants during the holiday season. Our primary supporters of this fundraiser are Louisville and southern Indiana churches and businesses as well as churches in Owensboro, Lebanon Junction, Shelbyville, and Lexington. We extend our gratitude to all supporters, especially Mr. & Mrs. Terry Forcht for their generous contribution and Republic Bank & Trust Company for the sizable order. Many

thanks as well to our volunteers who promoted this fundraiser and took orders from family members, friends, co-workers, neighbors, and fellow church members. They are Brandy Fox, Emily Kinnard, Sharon McMahan, Sadalia Sturgill, Eric Marcum, Deborah Hitt, Myra Loeser, Gail Yates, and April Zimmerman for placing orders. Proceeds from the poinsettia fundraiser benefit our programs and services for Kentucky's bleeding disorders community.

Year-End Family Event

The Year-End Family Event is a time for bleeding disorders families to get together at the German-American Club in Louisville and celebrate the season. Everyone enjoyed the festive atmosphere and the children's growing excitement. Bake contest, "ugly" tie contest, silent auction, door prizes, gifts for kids by Santa Claus and Mrs. Claus, DJ Axel's music, and delicious hors d'oeuvres prepared by Chef John Taylor contributed to a special holiday celebration.





Tira Miller won the 29th Annual Bake Contest with her Pumpkin Cupcakes topped with Cream Cheese Frosting. She selected the large, two-section crockpot as her well-deserved prize. The winners of the "Ugly Tie Contest" were Emily Beard, 1st place, Nathaniel Beard, 2nd place, and 3rd place was shared by Adeline Beard and Kari Grever. These creative individuals all received a gift card for their unique contest entries.

We thank our exhibitors who sponsored this event and who helped make this wonderful celebration possible. They were Biomatrix, CSL Behring, InfuCare, Novo Nordisk, Optum Rx, Paragon Healthcare, and Sanofi. Many thanks also to our staff and day-of-event volunteers who were essential to the event's success. They were Madison Bowles, Samantha Johnson, Patrick and Jennifer Dunegan, Connie Thacker, Pam Price, Shannon Johns, and Milton Kamala.

2025 Spring Scholarship Award

KHF extends congratulations to its 2025 spring semester scholarship recipient! Marissa Johns of Shepherdsville was awarded the \$500 Betty Meadors Mattingly Memorial Scholarship. Marissa is on a pre-med tract at the University of Louisville majoring in Neuroscience. She expects to graduate in May 2026 and has her sights set on attending Medical School. Marissa is a member of the National Bleeding Disorders Foundation's National Youth Leadership Institute and a valued counselor at KHF's Camp Discovery. The deadline to apply for a 2025 fall semester scholarship is July 15, 2025. Contact KHF for the application form at info@kyhemo.org.



More News

2024/2025 Donations

July 2024 - February 2025

We thank the following individuals and companies for their generous support!

Donor, \$4,000

Sanofi

Donors, \$3,000+

Forcht Group Professional Services for Poinsettias Siskin Steel & Supply for Unite Walk Donors, \$2,000+

Levi & Hunter Hill for Unite Walk LTC ® John & Patricia Tharp

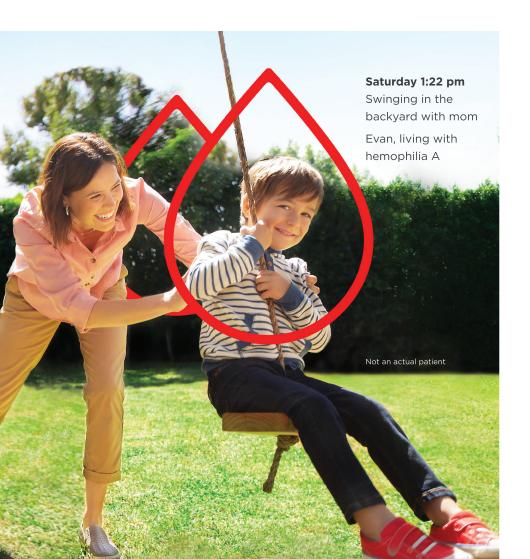
Donors, \$750 - 1,000

National Bleeding Disorders Foundation for Unite Walk (KHF Award) Takeda



Donors, \$500+

Constellation for Unite Walk William Gamble for Unite Walk Pam Howard for Unite Walk



WE'RE IN THIS TOGETHER.

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.

bleeding disorders.com



Copyright © 2020 Takeda Pharmaceutical Company Limited. All rights reserved. TAKEDA and the TAKEDA logo are trademarks or registered trademarks of Takeda Pharmaceutical Company Limited. US-NON-0136v1.0 03/20 Alhemo® is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children 12 years of age and older with hemophilia A with Factor 8 inhibitors or hemophilia B with Factor 9 inhibitors. It is not known if Alhemo® is safe and effective in people using Alhemo® while receiving ongoing immune tolerance induction. It is not known if Alhemo is safe and effective for hemophilia A and B with and without inhibitors in children younger than 12 years of age.

Reimagined bleed protection is now within your reach

First and only prophylaxis treatment in a prefilled, subcutaneous pen for people who have hemophilia B with inhibitors or hemophilia A with inhibitors





Royal lives with hemophilia B with inhibitors, uses Alhemo®, and is an employee of Novo Nordisk.







NO vials



Needles provided separately and may require a prescription in some states.

*Store in refrigerator before first use. After first use, Alhemo® can be stored at room temperature below 86 °F (30 °C) or in a refrigerator at 36 °F to 46 °F (2 °C to 8 °C) for up to 4 weeks.

IV=intravenous.

Important Safety Information

What is the most important information I should know about Alhemo®?

- It is important to follow the daily dosing schedule of Alhemo® to stay protected against bleeding. This is especially important during the first 4 weeks of treatment to make sure a correct maintenance dose is established. Use Alhemo® exactly as prescribed by your healthcare provider (HCP). Do not stop using Alhemo® without talking to your HCP. If you miss doses or stop using Alhemo®, you may no longer be protected against bleeding
- Your HCP may prescribe bypassing agents during treatment with Alhemo®. Carefully follow your HCP's instructions regarding when to use on-demand bypassing agents, and the recommended dose and schedule for breakthrough bleeds

Do not use Alhemo® **if you** are allergic to concizumab-mtci or any of the ingredients in Alhemo®.

Before using Alhemo®, tell your HCP about all of your medical conditions, including if you:

- Have a planned surgery. Your HCP may stop treatment with Alhemo® before your surgery. Talk to your HCP about when to stop using Alhemo® and when to start it again if you have a planned surgery
- ${}^{\bullet}$ Are pregnant or plan to become pregnant. It is not known if Alhemo ${}^{\circledcirc}$ may harm your unborn baby

Females who are able to become pregnant

- Your HCP may do a pregnancy test before you start treatment with Alhemo®.
- You should use an effective birth control (contraception) method during treatment with Alhemo® and for 7 weeks after ending treatment. Talk to your HCP about birth control methods that you can use during this time
- Are breastfeeding or plan to breastfeed. It is not known if Alhemo® passes into your breast milk. Talk to your HCP about the best way to feed your baby during treatment with Alhemo®

Tell your HCP about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Know the medicines you take. Keep a list of them to show your HCP and pharmacist when you get a new medicine.

How should I use Alhemo®?

- Change (rotate) your injection site with each injection. **Do not** use the same site for each injection
- To determine the right maintenance dose for you, your HCP will do a blood test to check the amount of Alhemo® in your blood. Your HCP may do additional blood tests during treatment with Alhemo®
- Do not share your Alhemo® pens and needles with another person, even if the needle has been changed. You may give another person an infection or get an infection from them
- If you miss a dose of Alhemo® during the first 4 weeks of treatment, contact your HCP right away. Your HCP will tell you how much Alhemo® to inject

What are the possible side effects of Alhemo®?

Alhemo® may cause serious side effects, including:

- Blood clots (thromboembolic events). Alhemo® may cause blood clots to form in blood vessels, such as in your arms, legs, heart, lung, brain, eyes, kidneys, or stomach. You may be at risk for getting blood clots during treatment with Alhemo® if you use high or frequent doses of factor products or bypassing agents to treat breakthrough bleeds, or if you have certain conditions. Get medical help right away if you have any signs and symptoms of blood clots, including: swelling, warmth, pain, or redness of the skin; headache; trouble speaking or moving; eye pain or swelling; sudden pain in your stomach or lower back area; feeling short of breath or severe chest pain; confusion; numbness in your face; and problems with your vision
- Allergic reactions. Alhemo® can cause allergic reactions, including redness of the skin, rash, hives, itching, and stomach-area (abdominal) pain. Stop using Alhemo® and get emergency medical help right away if you develop any signs or symptoms of a severe allergic reaction, including: itching on large areas of skin; trouble swallowing; wheezing; pale and cold skin; dizziness due to low blood pressure; redness or swelling of lips, tongue, face, or hands; shortness of breath; tightness of the chest; and fast heartheat

The most common side effects of Alhemo® include: bruising, redness, bleeding, or itching at the site of injection, and hives.

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



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Ready to discover more?

Ask your doctor about Alhemo® or visit **Alhemo.com** by scanning the QR Code





Brief Summary of information about Alhemo® (concizumab-mcti) injection

Rx Only

This information is not comprehensive.

- Talk to your healthcare provider or pharmacist
- Visit www.novo-pi.com/alhemo.pdf to obtain FDA-approved product labeling
- Call 1-888-668-6732

What is the most important information I should know about Alhemo®?

- It is important to follow the daily dosing schedule of Alhemo® to stay
 protected against bleeding. This is especially important during the first 4
 weeks of treatment to make sure a correct maintenance dose is established. Use Alhemo® exactly as prescribed by your healthcare provider. **Do not** stop using Alhemo® without talking to your healthcare provider. If you miss doses, or stop using Alhemo®, you may no longer be protected against bleeding.
- Your healthcare provider may prescribe bypassing agents during treatment with Alhemo®. Carefully follow your healthcare provider's instructions regarding when to use on-demand bypassing agents, and the recommended dose and schedule for breakthrough bleeds.

See "How should I use Alhemo®?" for more information on how to use

What is Alhemo®?

Alhemo® is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children 12 years of age and older with hemophilia A with factor VIII inhibitors or hemophilia B with factor IX

It is not known if Alhemo® is safe and effective in people using Alhemo® while receiving ongoing Immune Tolerance Induction (ITI).

It is not known if Alhemo® is safe and effective for hemophilia A and B with and without inhibitors in children younger than 12 years of age.

Do not use Alhemo® if you are allergic to concizumab-mtci or any of the ingredients in Alhemo®

Before using Alhemo®, tell your healthcare provider about all of your medical conditions, including if you:

- have a planned surgery. Your healthcare provider may stop treatment with Alhemo® before your surgery. Talk to your healthcare provider about when to stop using Alhemo® and when to start it again if you have a planned surgery.
- are pregnant or plan to become pregnant. It is not known if Alherno® may harm your unborn baby. Females who are able to become pregnant
 - Your healthcare provider may do a pregnancy test before you start treatment with Alhemo®.
 - o You should use an effective birth control (contraception) during treatment with Alhemo® and for 7 weeks after ending treatment. Talk to your healthcare provider about birth control methods that you can use during this time.
- are breastfeeding or plan to breastfeed. It is not known if Alhemo® passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby during treatment with Alhemo®

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Know the medicines you take. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I use Alhemo®?

- Use Alhemo® exactly as prescribed by your healthcare provider.
- Your healthcare provider will provide instructions for stopping (discontinuing) your current treatment when switching to Alhemo®.
- Iniect Alhemo® 1 time a day.
- Your healthcare provider should show you or your caregiver how to use Alhemo® before you use it for the first time.
- Alhemo® is given as an injection under the skin (subcutaneous injection) by you or a caregiver.
- Ask your healthcare provider if you need to use a different injection technique. For example, children and people who are lean may need to inject into a pinched fold of skin to avoid injecting too deep (into the muscle).
- Change (rotate) your injection site with each injection. **Do not** use the same site for each injection.
- You will inject a larger dose (a loading dose) of Alhemo® on your first day of treatment. Then your healthcare provider will prescribe a dose to inject 1 time a day until your maintenance dose is established.
- To determine the right maintenance dose for you, your healthcare provider will
 do a blood test to check the amount of Alhemo® in your blood. Your healthcare provider may do additional blood tests during treatment with Alhemo
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.

How should I use Alhemo®? (cont'd)

- Your healthcare provider will provide information on the treatment of breakthrough bleeding during your treatment with Alhemo®
- Do not share your Alhemo® pens and needles with another person, even if the needle has been changed. You may give another person an infection or get an infection from them
- If you miss a dose of Alhemo® during the first 4 weeks of treatment, contact your healthcare provider right away. Your healthcare provider will tell you how much Alhemo® to inject.
- If you miss a dose of Alhemo® after your daily maintenance dose is established:

 - For 1 missed dose, continue your normal daily dose.
 For 2 to 6 missed doses, give 2 doses as soon as you remember. Then continue your normal daily dose the next day.
 For 7 or more missed doses, contact your healthcare provider right away as
 - you will need to receive a new loading dose before continuing your normal daily dose
 - o If you are unsure about how much to Alhemo® to inject, contact your healthcare provider.

What are the possible side effects of Alhemo®? Alhemo® may cause serious side effects, including:

- Blood clots (thromboembolic events). Alhemo® may cause blood clots kidneys, or stomach. You may be at risk for getting blood clots during treatment with Alhemo® if you use high or frequent doses of factor products or bypassing agents to treat breakthrough bleeds, or if you have certain conditions. Get medical bela risk for user if you have certain conditions. help right away if you have any signs and symptoms of blood clots, including: o feeling short of breath or
 - o swelling, warmth, pain, or redness of the skin headache
 - severe chest pain o confusion
 - o trouble speaking or moving • eye pain or swelling
- o numbness in your face o problems with your vision
 - o sudden pain in your stomach or lower back area
- Allergic reactions. Alhemo® can cause allergic reactions, including redness
 of the skin, rash, hives, itching, and stomach-area (abdominal) pain. Stop using Alhemo® and get emergency medical help right away if you develop any signs or symptoms of a severe allergic reaction, including:
 o itching on large areas of skin reduced neith right aw o redness or swelling of lips, tongue.
 - o trouble swallowing

 - wheezingpale and cold skin
- face, or hands
- o shortness of breath tightness of the chest

o dizziness due to low blood pressure of fast heartbeat The most common side effects of Alhemo® include:

• bruising, redness, bleeding, or itching at the site of injection hives These are not all the possible side effects of Alhemo®.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store Alhemo®?

 Before first use:

 Store unused Alhemo® pens in the refrigerator between 36°F to 46°F (2°C to

 8°C)

· After first use:

- Store the Alhemo® pen in the refrigerator between 36°F to 46°F (2° to 8°C) or at room temperature below 86°F (30°C) for up to 28 days.
- Write the date of first use in the space provided on the carton.
- o Throw away (discard) the Alhemo® pen 28 days after first opening even if some medicine is left in the pen.
- Store Alhemo® with the cap on and keep it in the original carton to protect from liaht.
- Do not store Alhemo[®] in direct sunlight and keep away from direct heat.
- When stored in the refrigerator, do not store the pen directly next to the cooling element (the part that cools the refrigerator).
- · Do not freeze Alhemo®
- Do not use Alhemo[®] if it has been frozen or if it has been stored above 86°F

Keep Alhemo® and all medicine out of the reach of children.

More detailed information is available upon request.

Available by prescription only

For information contact: Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536, USA, 1-888-668-6444 Manufactured by: Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, NJ 08536 U.S. License No. 1261

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More News

2024/2025 Donations

Continued

Donor, \$425

David Wayne

in honor of Waneta (Nita) Wayne-Zehnder

Donors, \$300+

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for Unite Walk

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for Summer Camp

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for Andy Rogers

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Donors, up to \$49

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for Unite Walk

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for Poinsettias

Ashlee M. Wolf

In Memory

Gone from our sight but never our memories; gone from our touch but never our hearts... May their memory be a blessing!

Winter 2024/2025

Dr. Joseph H. Cieslak

Action Research Team

Dr. David Blount

Mike & Carter Rae Carpenter

Dr. Suzanne & Mr. John Hoekstra

Members of the Riley School of Irish Music

Dr. & Mrs. Richard A. Pape

Kathleen Salter

Dr. Thad Schulten

Susan Sketch

Fred Vamos

Jim & Jane Weiss

Summer/Fall 2024

Ann Boyd

Louis & Debbie Rowe

Robert Heightchew, Jr.

Harley & Jean Smallwood

Mary Marasa

Kathy & Rick Eigelbach

Kenlie Place Patio Home Association

Gary Wayne Meadows

Grandma, Sharon, Sheila, & Warren

Employees of the Kentucky Medical Association

Patrick T. & Elizabeth A. Padgett



Do The Five

Follow these steps to prevent or reduce complications of bleeding disorders

- 1. Get an annual comprehensive checkup at a hemophilia treatment center.
- 2. Get vaccinated Hepatitis A and B are preventable.
- 3. Treat bleeds early and adequately.
- 4. Exercise to protect your joints.
- 5. Get tested regularly for blood-borne infections.

To find out more about the National Prevention Program developed by the National Hemophilia Foundation in collaboration with the Centers for Disease Control and Prevention (CDC), click on www.hemophilia.org or call toll-free 800-42-HANDI.



<u>Like us on Facebook</u> and keep up-to-date on all **KHF** activities and events.

KHF does not give medical advice or engage in the practice of medicine. KHF under no circumstances recommends particular treatments for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.







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