# **FACTOR NOTES**

BROUGHT TO YOU BY THE SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

#### **2024 5K REGISTRATION NOW OPEN!**

Join the Southwestern Ohio Hemophilia Foundation on Saturday, September 21 at 10:00 a.m. for our annual

5K Walk/Run for Bleeding Disorder Awareness.





2024 **ISSUE #2** 



Registration/Check-In at 9:00 a.m. Walk/Run Start Time at 10:00 a.m.

Rice Field - Miamisburg Bike Path 2001 Dayton-Cincinnati Rd Miamisburg, Ohio 45342

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The Southwestern Ohio Hemophilia Foundation is hosting the 14th Annual Bleeding Disorder Awareness 5K on September 21 at 10:00 a.m. Registration will begin at 9:00 a.m. Proceeds from the event will go to the Southwestern Ohio Hemophilia Chapter. There will be race awards for the first place male and female in each age category and the You Make a Difference award for the person displaying enthusiasm and commitment to raising awareness.

\$25 Registration fee includes bib, timed finish, and T-shirt. Come be a part of making a difference in the lives of those dealing with blood disorders like hemophilia and Von Willebrand's as we walk or run our way to victory at the BDA 5K Walk/Run!

#### SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

11 West Monument, Suite 605 Dayton OH 45402

(937) 298-8000 www.swohf.org

director@swohf.org





#### **2024 EVENTS**

**SEPT. 21** 5K Bleeding Disorders Awareness Walk/Run

Rice Field, Miamisburg, OH

**OCT. 6** Fall Outing

Young's Dairy Farm, Yellow Springs, OH

NOV. 9 Women's Day Together Educational Program & Lunch

The Golden Lamb, Lebanon, OH



STATE AND NATIONAL ORG EVENTS

**AUGUST 9-11** 

FAMOHIO Columbus, OH

**SEPTEMBER 12-14** 

National Bleeding Disorders Foundation Conference *Atlanta, GA* 

#### **KROGER**

#### Shop at Kroger, Support SWOHF!

Did you know you can support our SWOHF community just by shopping at Kroger? It's easy when you enroll in **Kroger Community** 

Rewards! To get started, sign up at

krogercommunityrewards.com with your Kroger

Plus Card and enter our number #78558 as

your organization. Once you've enrolled, you'll earn rewards for SWOHF every time you shop at Kroger and use your Plus Card!

Kroger is committed to helping our communities grow and prosper. Year after year, local schools, churches and other nonprofit organizations earn millions of dollars through Kroger.









#### 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.

bleedingdisorders.com



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#### AT THE MOVIES

#### sanofi

Featuring Wayne Randy Kathy Warren with Cathy Sharon
Cook Curtis Gerus-Darbison Ingram McAdam Ingram

# Shoulders of Giants

SUPPORTED BY A CONTRIBUTION FROM SONOFI

WWW.ONTHESHOULDERSFILM.COM

RelieveLIMITE



We're so excited to be screening @Believeltd's latest documentary, On the Shoulders of Giants, on August 22nd at 7:00 p.m. at The Neon Theater 130 E. Fifth St. There is no charge for this event, but you must pre-register.

Join us for the untold stories of resilience and courage with 'On The Shoulder of Giants', a captivating documentary celebrating the resilience and courage of our community's legends.

For the first time in history, a generation of people with hemophilia are living past age 50. On the Shoulders of Giants explores the lives of the older generation of hemophilia. We follow blood brother, Wayne Cook's journey as he travels around the country to reunite with fellow blood brothers and sisters in their respective towns, reflecting on lives lost, the joys of family and friends and sharing untold stories of how hemophilia has affected their personal lives today as they age. It's an inspiring heartwarming story of a community's legacy, and their longing to reunite and be there for each other, again.

Supported by a contribution from @Sanofi

Produced by @believeltd

#ontheshouldersofgiants #GiantsHemophiliaFilm



Please note there is no childcare for this event and suggested age for children is 8 and up. The film is approx 50 minutes. Pizza will be provided from Old Scratch and each attendee will receive a soda and a small popcorn. All other Refreshments will be available for purchase.

This event is brought to you by Southwestern Ohio Hemophilia Foundation www.swohf. org serving those with bleeding disorders in the Greater Dayton community with support from our Industry Partner Sanofi.

# OHIO BLEEDING DISORDERS COUNCIL

The community came together in April to meet with local lawmakers in Columbus to share the importance of issues pertinent to the bleeding disorders community. If you're are interested in becoming an advocate, please contact the SWOHF office director@swohf.org







#### Ohio Bleeding Disorders Council







#### **30 YEARS FOR HFA**

Thirty years ago, among the tragedy of the bad blood crisis, the bleeding disorders community came together. Not only did our community fiercely advocate for a safe blood supply for all Americans, but we formed organizations determined to carry on the fight.

HFA was one such organization and we're proud to celebrate their 30-year anniversary in 2024! In those 30 years, advances in treatment have helped the community largely shift from "surviving" to "thriving," and HFA's purpose of serving the community into this new phase continues.









### When the temperature rises above 86°F Esperoct® has you covered

The EHL product with the highest storage temperature for the longest time

#### Be prepared with

#### **Proven protection** against bleeds in adults and adolescents

• 1.2 overall bleeds per year<sup>b</sup>

EHL=extended half-life.

<sup>a</sup>For up to 3 months.

**High factor levels** from one dose to the next in adults and adolescents<sup>c</sup>

- At or above 3% trough level for 100% of the timed
- At or above 5% trough level for 90% of the time<sup>e</sup>

b175 previously treated patients with severe hemophilia A received Esperoct® 50 IU/kg every 4 days for 76 weeks based on median annualized bleed rates shown. cTrough level goal is 1% for prophylaxis.

<sup>d</sup>Data shown are from a study where 175 previously treated adolescents and adults received routine prophylaxis with Esperoct<sup>®</sup> 50 IU/kg every 4 days for 76 weeks. Pre-dose factor activity (trough) levels were evaluated at follow-up visits. Mean trough levels for adolescents (12-<18 years) were 2.7 IU/dL. <sup>e</sup>Steady-state FVIII activity levels were estimated in 143 adults and adolescents using pharmacokinetic modeling.

#### What is Esperoct®?

Esperoct® [antihemophilic factor (recombinant), glycopegylated-exei] is an injectable medicine to treat and prevent or reduce the number of bleeding episodes in people with hemophilia A. Your healthcare provider may give you Esperoct® when you have surgery

• Esperoct<sup>®</sup> is not used to treat von Willebrand Disease

#### **IMPORTANT SAFETY INFORMATION**

#### Who should not use Esperoct®?

 You should not use Esperoct<sup>®</sup> if you are allergic to factor VIII or any of the other ingredients of Esperoct<sup>®</sup> or if you are allergic to hamster proteins

#### What is the most important information I need to know about Esperoct®?

- Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center
- Call your healthcare provider right away or get emergency treatment right away if you get any signs of an allergic reaction, such as: hives, chest tightness, wheezing, dizziness, difficulty breathing, and/or swelling of the face

#### What should I tell my healthcare provider before using Esperoct®?

- Before taking Esperoct®, you should tell your healthcare provider if you have or have had any medical conditions, take any medicines (including non-prescription medicines and dietary supplements), are nursing, pregnant or planning to become pregnant, or have been told that you have inhibitors to factor VIII
- Your body can make antibodies called "inhibitors" against Esperoct®, which may stop Esperoct® from working properly. Call your healthcare provider right away if your bleeding does not stop after taking Esperoct®

#### What are the possible side effects of Esperoct®?

 Common side effects of Esperoct<sup>®</sup> include rash or itching, and swelling, pain, rash or redness at the location of infusion

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

Discover more at **Esperoct104.com**.



Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.

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#### **esperoct**®

antihemophilic factor (recombinant), glycopegylated-exei

#### esperoct<sup>®</sup>

antihemophilic factor (recombinant), glycopegylated-exei

#### Brief Summary information about ESPEROCT® [antihemophilic Factor (recombinant), glycopegylated-exei]

This information is not comprehensive.

- · Talk to your healthcare provider or pharmacist
- Visit www.novo-pi.com/esperoct.pdf to obtain FDA-approved product labeling
- Call 1-800-727-6500

#### Patient Information ESPEROCT®

[antihemophilic factor (recombinant), glycopegylated-exei]

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

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

#### What is the most important information I need to know about ESPEROCT®?

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

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

#### What is ESPEROCT®?

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

ESPEROCT® is used to treat and prevent or reduce the number of bleeding episodes in people with hemophilia A.

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

#### Who should not use ESPEROCT®?

You should not use ESPEROCT® if you

- are allergic to Factor VIII or any of the other ingredients of ESPEROCT®
- if you are allergic to hamster proteins

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

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

#### What should I tell my healthcare provider before I use ESPEROCT®?

You should tell your healthcare provider if you:

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

#### **How should I use ESPEROCT®?**

Treatment with ESPEROCT® should be started by a healthcare provider who is experienced in the care of patients with hemophilia A.

ESPEROCT® is given as an infusion into the vein.

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

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

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

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

#### Use in children

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

#### If you forget to use ESPEROCT®

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

#### If you stop using ESPEROCT®

Do not stop using ESPEROCT® without consulting your healthcare provider.

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

#### What if I take too much ESPEROCT®?

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

#### What are the possible side effects of ESPEROCT®?

#### Common Side Effects Include:

- · rash or itching
- swelling, pain, rash or redness at the location of infusion

#### Other Possible Side Effects:

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

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

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

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

#### What are the ESPEROCT® dosage strengths?

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

Cap Color Indicator	Nominal Strength
Red	500 IU per vial
Green	1000 IU per vial
Gray	1500 IU per vial
Yellow	2000 IU per vial
Black	3000 IU per vial

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

#### **How should I store ESPEROCT®?**

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

Protect from light. Do not freeze ESPEROCT®.

ESPEROCT® can be stored in refrigeration at 36°F to 46°F (2°C to 8°C) for up to 30 months until the expiration date stated on the label. During the 30 month shelf life, ESPEROCT® may be kept at room temperature (not to exceed 86°F/30°C) for up to 12 months, <u>or</u> up to 104°F (40°C) for no longer than 3 months.

If you choose to store ESPEROCT® at room temperature:

- Record the date when the product was removed from the refrigerator.
- . Do not return the product to the refrigerator.
- Do not use after 12 months if stored up to 86°F (30°C) or after 3 months if stored up to 104°F (40°C) or the expiration date listed on the vial, whichever is earlier.

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

#### **After Reconstitution:**

The reconstituted (the final product once the powder is mixed with the diluent) ESPEROCT® should appear clear and colorless without visible particles.

The reconstituted ESPEROCT® should be used immediately.

If you cannot use the reconstituted ESPEROCT® immediately, it must be used within 4 hours when stored at or below 86°F (30°C) or within 24 hours when stored in a refrigerator at 36°F to 46°F (2°C to 8°C). Store the reconstituted product in the vial.

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

#### What else should I know about ESPEROCT® and hemophilia A?

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

Revised: 10/2019

ESPEROCT® is a trademark of Novo Nordisk Health Care AG.

For Patent Information, refer to: http://novonordisk-us.com/patients/products/product-patents.html

#### More detailed information is available upon request. Available by prescription only.

Manufactured by: Novo Nordisk A/S Novo Allé

DK-2880 Bagsværd, Denmark

For information about ESPEROCT® contact: Novo Nordisk Inc. 800 Scudders Mill Road Plainsboro, NJ 08536, USA 1-800-727-6500

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#### CASINO NIGHT













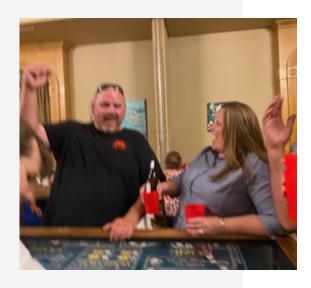














OLD SCRATCH PIZZA

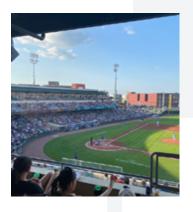


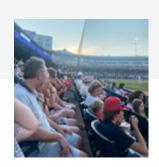
#### **FAMILY FEST**



Family Fest 2024 is officially in the books. Once again we chose Scene 75 as the starting place to bring the bleeding disorders community together for fun and education. Pat Torrey from Gut Monkey was our keynote speaker. His insight into how we manage our mindsets provided us with just the right challenge. Mindsets can determine how we live and adapt. Having the attitude of accepting failure as a growth opportunity. In so many areas of life we try and try again! We haven't mastered it yet....This attitude of grit and determination will serve us all well including learning to manage a bleeding disorder.

The rest of the weekend was dedicated to fun -- playing games at Scene 75 and rooting for the Dayton Dragons! A hometown victory in the ninth inning! It couldn't have been more exciting.











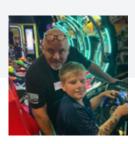


























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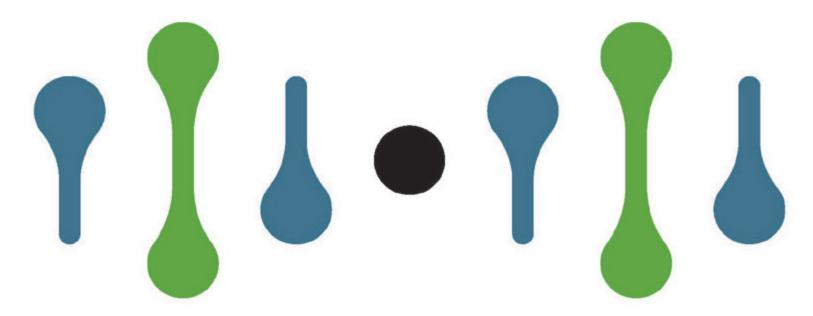




# BEQVEZ fidanacogene elaparvovec-dzkt

Suspension for intravenous infusion  $1 \times 10^{13} \text{ vg/mL}$ 

## Now Approved



Scan QR code for more information or visit www.BEQVEZ.com



#### **NEW TO 5K?**

#### FOLLOW THESE TIPS:

- Warm up by stretching before every walk
- Walk consistently and gradually increasing your speed
- Add intervals of higher-intensity walking to your workouts
- Walk longer distances to build up endurance
- Wear appropriate footwear for walking

#### TIPS TO INCREASE DONATIONS AND RAISE ADDITIONAL FUNDS TO SWOHF THROUGH THE 5K:

- Create a team to join you in your 5K. This could be friends, family, other groups or sporting teams that you are affiliated with.
- Get the word out through social media posts, emails, texts. Announce that you are preparing for the SWOHF 5K and ask local businesses, friends and family to support you with donations.
- Take time to explain the importance of education and awareness of bleeding disorders. If you can explain the reason, often it is the simple ask of, "Please join me" that will convince someone to support or participate.

#### **INSPIRATIONAL QUOTES ON PHILANTHROPY:**

- 1. "No one has ever become poor by giving." Anne Frank
- "To give away money is an easy matter and in any man's power. But to decide to whom to give it, and how large and when, and for what purpose and how, is neither in every man's power nor an easy matter."
   Aristotle
- 3. "You have not lived today until you have done something for someone who can never repay you."

   John Bunyan
- 4. "The best way to find yourself is to lose yourself in the service of others." Mahatma Gandhi
- 5. "We make a living by what we get, but we make a life by what we give." Winston Churchill
- 6. "The greatest gift you can give someone is your time, because when you give your time, you are giving a portion of your life that you will never get back." *Unknown*
- 7. "The smallest act of kindness is worth more than the grandest intention." Oscar Wilde
- 8. "Generosity consists not the sum given, but the manner in which it is bestowed." Mahatma Gandhi
- 9. "I have found that among its other benefits, giving liberates the soul of the giver." Maya Angelou
- 10. "The measure of a life, after all, is not its duration, but its donation." Corrie Ten Boom

#### SUMMER, SUN, AND SAFETY

Summer has officially started and with that comes the perfect time to discuss safety as related to your bleeding disorder. This year we are going to discuss the "why" behind wearing a Medical ID bracelet. Along with Play-Doh, Yahtzee, Barbie and Elvis Presley, Medical ID jewelry has been around since the 1950s! Though the primary purpose of communicating important medical information (when the wearer was unable to speak for themselves) has not changed, the actual design and sophistication has seen many changes and upgrades.

We were able to connect with first responders from around the greater Dayton Area including: police, fire, rescue, care flight, and emergency room staff (including Dayton Children's and others) to discuss medical alerts/IDs related to their position in public safety. We learned a lot from these conversations which all reiterated the importance to always wear your medical alerts. It is suggested that greater than 95% of first responders check for medical alert/ID bracelets, the number of first responders checking for medical alert/id necklaces is significantly less at around only 68%. When questioned about Medical ID tattoos none of those asked looked for or knew about Medical ID tattoos which leads us to believe this is not yet a strong recommendation for aiding in your safety and prompt care.

#### SOME DIRECT QUOTES RECEIVED FROM LOCAL FIRST RESPONDERS WHEN ASKED IF THEY CONSIDER MEDICAL IDS TO BE HELPFUL:

"Yes! Any alert or medical information you can obtain is helpful to ensure proper care." (local police department)

"Definitely! Medical Alert bracelets have a history, and first responders are conditioned to look for them. Wearing such items can improve time and efficiency in providing critical care when every second counts." (another local police department)

"Though we are not the first providers to arrive on scene, this information is obtained by the ground staff and reported to us in hand-off report; our staff may also look for IDs when doing an assessment." (Care flight spokesperson) "Medical ID bracelets save time and ultimately save lives." (local first responder)

"We do check for medical IDs during triage, but medical alert tattoos are not something common and therefore are likely to be missed." (local emergency room staff)

"In times of emergencies panic can set in and it can be difficult for loved ones to organize their thoughts. Often the first to arrive on scene, police officers try to relay as much information as possible to medics while enroute or upon arrival."

In closing, your HTC team continues to encourage all persons with bleeding disorders to wear a Medical ID. Wearing them may aid in you getting the emergent, critical, and sometimes lifesaving care you need. For more tips regarding safety and emergency preparedness, please visit https://stepsforliving.hemophilia.org and type the word "emergency" or "safety" in the search box.

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#### **MEDICAL IDs**

In collaboration with Dayton Children's HTC, SWOHF has recently switched to a new provider for our Medical ID's. We are happy to announce our partnership with American Medical ID. They offer a great variety of quality products at a discount to Chapters. Additionally, their Customer Service is exceptional, their shipping is fast and their prices are significantly less than MedicAlert (our previous supplier).

Free products are included with every order: An emergency medical ID card, a small ID charm and an exclusive engraved rectangular "InCase" phone ID that easily attaches to your cellphone case or any flat object, such as a suitcase, briefcase or laptop.

SWOHF is grateful for grant funding and donations that facilitate these purchases on behalf of our Greater Dayton Bleeding Disorders Community. So when you go to the HTC for your next visit, you can view sample products available and complete a form to request a new bracelet or necklace according to Chapter guidelines.



[Phone not included]

#### **CONTACT US**



DO WE HAVE YOUR EMAIL? DON'T MISS OUT ON PROGRAM UPDATES.



11 WEST MONUMENT, SUITE 605 DAYTON, OH 45402



937-298-8000

WE WANT TO HEAR FROM YOU!

#### **MISSION STATEMENT**

SWOHF helps improve the quality of life for those affected by hemophilia, von Willebrand disease, and other bleeding disorders by providing support education, networking, advocacy, and services to individuals, their families and the community.

#### **EXECUTIVE DIRECTOR**

Joy Linder, joy@swohf.org

#### **DISCLAIMER**

The material provided in Factor Notes is for your general information only. SWOHF does not give medical advice or engage in the practice of medicine. SWOHF under no circumstances recommends particular treatment for specific individuals, and in all cases recommends that you consult your physician or treatment center before pursuing any course of treatment.

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