

# FACTOR NOTES

BROUGHT TO YOU BY THE SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION

## “STRONGER TOGETHER” FAMILY FEST 2021

FRIDAY, JUNE 25 & SATURDAY, JUNE 26

Summer is just around the corner and with it comes the SWOHF Annual Family Fest. For well over 20 years we have made a weekend of interesting activities and educational programs for our families. This year is no exception albeit a virtual outing. We remain committed to bring Family Fest to you! To kick off the weekend the keynote address will be given by Dr. Stephan Julian, a local speaker and author. He will discuss personality types and families. It is sure to be an insightful glimpse into family dynamics. We will also have a teen breakout session hosted by the Hemophilia Federation of America. This popular breakout game is a huge hit with our teens. In addition, BioMarin will host a family Jeopardy game on Friday evening, that will bring everyone together for an enjoyable session of learning and laughs.

Saturday is scheduled for additional education sessions, interesting speakers, industry partners and more. We will have valuable door prizes (must be present to win) and other fun surprises. Breakout rooms will allow our Industry Partners to connect with you. It isn't too late to register. Sign up today!



2021  
ISSUE #2

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### THANK YOU TO OUR 2021 SPONSORS!



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# The Third National HTC Patient Satisfaction Survey is now open!

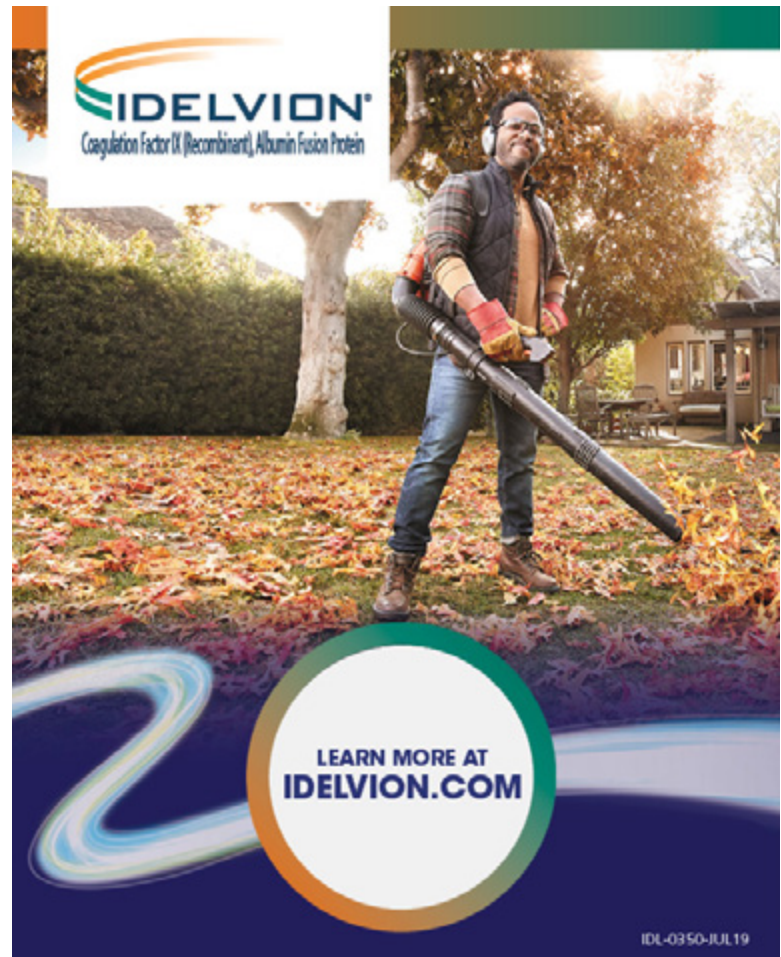
We need your voice and experience to tell us what we're doing right, and areas we need to improve!

Take the survey at [www.htcsurvey.com](http://www.htcsurvey.com) or fill out and return the survey you received in the mail.

**Surveys must be completed by June 30, 2021.**



**Let your voice be heard!  
Take the survey!**





# 1st IN PERSON EVENT — OF 2021 —

from Executive Producer  
ALEX BORSTEIN

## BOMBARDIER BLOOD

Join SWOHF for a special screening!

**THURSDAY, JULY 29, 2021**

THE NEON THEATRE (DOWNTOWN DAYTON)

CHECK OUR WEBSITE FOR MORE INFORMATION!



**SAVE THE DATE**

**FAMILY  
EDUCATION  
WEEKEND**

FAMOHIO

2021

**July 30—August 1, 2021**

Registration for this **VIRTUAL EVENT**  
will open in May 2021

Follow us on Facebook at [www.facebook.com/Famohio](http://www.facebook.com/Famohio)  
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[FAMOhioInfo@gmail.com](mailto:FAMOhioInfo@gmail.com)  
614-344-1075



**SAVE THE DATE!**

**AUGUST 26-28, 2021**

**NHF's Annual Bleeding Disorders Conference** is their signature event and highlights their strong commitment to education. Leading community members and experts on hemophilia and other bleeding disorders come together every year to present the most recent advances, exchange the latest science and discuss the newest clinical applications designed to improve patient care.

Through an extensive lineup of educational sessions for patients, medical provider, chapters, poster and oral communications, state-of-the-art lectures, exhibits and professional networking opportunities, the Conference promotes important advancement for the community.

This year's conference will be fully virtual to ensure the health and safety of all participants.

# Judy Doyle

Patient advocate

## About Judy

Judy is a Novo Nordisk Hemophilia Community Liaison with 18 years of experience supporting those with bleeding disorders. She loves the passion of the hemophilia community to get things done and not let things stand in their way.

## Connect with Judy

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(216) 217-4197



**Hemophilia Community Liaison**  
OH, IN

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# Explore **HEAD-TO-HEAD** Pharmacokinetic (PK) Study Data

See half-life, clearance and other PK data from the crossover study comparing **Jivi**<sup>®</sup> and **Eloctate**<sup>®</sup>

Visit **PKStudies.com** to find out more.

► **Pharmacokinetics** is the study of the activity of drugs in the body over a period of time.

  
antihemophilic factor  
(recombinant) PEGylated-augl  
**LET'S GO**



GO SEEK. GO EXPLORE.  
**GO AHEAD.**

PEOPLE LIKE YOU. STORIES LIKE YOURS.  
Explore more at [HEMLIBRAjourney.com](https://HEMLIBRAjourney.com)



Discover your sense of go. Discover HEMLIBRA.

#### What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

#### What is the most important information I should know about HEMLIBRA?

**HEMLIBRA increases the potential for your blood to clot. People who use activated prothrombin complex concentrate (aPCC; Feiba<sup>®</sup>) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots.**

#### These serious side effects include:

- **Thrombotic microangiopathy (TMA)**, a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs
- **Blood clots (thrombotic events)**, which may form in blood vessels in your arm, leg, lung, or head

Please see Brief Summary of Medication Guide on following page for Important Safety Information, including **Serious Side Effects**.

**HEMLIBRA.**  
emicizumab-kxwh | 300 mg  
injection for subcutaneous use | 78376



**Medication Guide**  
**HEMLIBRA® (hem-lee-bruh)**  
**(emicizumab-kxwh)**  
**injection, for subcutaneous use**

**What is the most important information I should know about HEMLIBRA?**

**HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.**

**HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:**

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
  - confusion
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - stomach (abdomen) or back pain
  - nausea or vomiting
  - feeling sick
  - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - swelling in arms or legs
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - trouble seeing

**If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.**

See **"What are the possible side effects of HEMLIBRA?"** for more information about side effects.

**What is HEMLIBRA?**

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

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

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

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

**How should I use HEMLIBRA?**

**See the detailed "Instructions for Use" that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.**

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.

- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. **Do not** give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

**What are the possible side effects of HEMLIBRA?**

- See **"What is the most important information I should know about HEMLIBRA?"**

**The most common side effects of HEMLIBRA include:**

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

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 HEMLIBRA?**

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 86°F (30°C).
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

**Keep HEMLIBRA and all medicines out of the reach of children.**

**General information about the safe and effective use of HEMLIBRA.**

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

**What are the ingredients in HEMLIBRA?**

**Active ingredient:** emicizumab-kxwh

**Inactive ingredients:** L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,  
1 DNA Way, South San Francisco, CA 94080-4990  
U.S. License No. 1048

HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan

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For more information, go to [www.HEMLIBRA.com](http://www.HEMLIBRA.com) or call 1-866-HEMLIBRA.  
This Medication Guide has been approved by the U.S. Food and Drug Administration.  
Revised: 10/2018



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**Genentech**  
A Member of the Roche Group

# CONGRATULATIONS 2021 GRADUATES!

## APPLY FOR SCHOLARSHIP

The **Brad Miller Memorial Scholarship** has been created to commemorate and remember an exceptional young man from the bleeding disorder community. Brad was born with severe hemophilia in 1979, a time when hemophilia treatment was less refined and many treatment products were ultimately found to be unsafe. These and other life issues contributed to the many challenges experienced by this scholarship's namesake. Throughout his 29 years, Brad held his head high and did his very best to live each day fully. Brad's immediate and extended family members supported him during his short life and continue to be active volunteers and mentors for the bleeding disorder community. Through this scholarship, Brad and his family's spirit of living and dedication to giving will continue to honor Brad and the entire bleeding disorder community for many years to come.

The SWOHF board and the members of the scholarship committee acknowledge the many challenges students face during their journey to complete a post-secondary educational program or beyond. It is hoped that the financial assistance

provided by the Brad Miller Memorial Scholarship of \$1,000 will help recipients continue their quest for knowledge and the attainment of their dreams.

The Brad Miller Memorial Scholarship is open to any person with a bleeding disorder diagnosis, i.e., hemophilia, von Willebrand disease or other inherited bleeding disorders, who receive treatment at Dayton Children's Hemostasis and Thrombosis Center. The applicant must be seeking post-secondary education at a university/college or technical school or be enrolled in a graduate school program.

The scholarship application and supporting documents must be submitted by July 12, 2021. The decision by the scholarship committee will be announced by July 30, 2021. Payment will be made directly to the student's university/college or technical school.

For more information about the application process, check our website for a list of requirements and to download the application form. The completed application and all supporting documentation should be submitted via email to [joy@swohf.org](mailto:joy@swohf.org) by July 12, 2021.







# JUNE FOR JOINT HEALTH™

Brought to you by NHF and Sanofi Genzyme

## JUNE IS JOINT HEALTH MONTH!

Healthy joints are critical to safeguard our mobility as we age. Below are a few simple steps to assist in joint health care: *Always contact your doctor before beginning a physical activity or exercise program. Do not stretch if a joint or muscle has had a recent bleed or is swollen, warm, or painful.*

-Did you know that 80% of bleeds occur in your joints, and most of those bleeds go undetected, which may play a role in joint damage?

Clinical studies have shown that conditioning, stretching, exercising and the right treatment may help to improve health, reduce joint bleeds, and resolve target joints. As Always, talk to your healthcare team before starting any physical activity.

A good way to care for our joints is to keep them and your muscles, ligaments, and bones strong and stable.

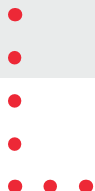


### STAY ACTIVE

Movement reduces stiffness in our joints. Low impact exercise such as swimming, stretching, and walking can enable joints to stay mobile.

### STAY STRONG

Strength building exercises builds muscles that keep joints safe and mobile. Core exercises for the abdomen, chest, and back provide a solid base for support and stability.

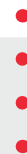


### MAINTAIN A HEALTHY WEIGHT AND DIET

Avoid extra stress and pressure on knees, ankles, and hips by pursuing healthy weight and diet goals.

### POSTURE MINDFULNESS

Proper posture can reduce injury to muscles surrounding our joints.



### JOINT PARTNERSHIP

The National Hemophilia Foundation and Sanofi Genzyme are committed to building awareness about the crucial function activity plays in improving joint health in the hemophilia community. If you have questions send an email at [handi@hemophilia.org](mailto:handi@hemophilia.org)

When it comes to your hemophilia A treatment

# Move beyond the threshold<sup>a</sup>

Esperoct<sup>®</sup> can give you high factor levels for longer.<sup>b</sup>

**Extend half-life beyond the standard** 22-hour average half-life in adults<sup>c</sup>

## FOR ADULTS AND ADOLESCENTS

### Switching made easy with a standard 50 IU/kg dose every 4 days

-50% fewer infusions if you previously infused every other day

-40% fewer infusions if you previously infused 3x a week

### High factor levels

At or above 3%  
for 100% of the time<sup>d,e</sup>

At or above 5%  
for 90% of the time<sup>d,f</sup>

### Flexible on the go

The ONLY extended half-life product that can be stored up to 104°F<sup>g</sup>

Please see Brief Summary for complete storage instructions.

## Safety Proven across 5 studies, the largest and longest EHL clinical trial program

<sup>a</sup>Of 1% trough factor levels for standard half-life (SHL) products in adults and adolescents.

<sup>b</sup>Compared with SHL products.

<sup>c</sup>Data shown are from 42 adults who received a pharmacokinetic (PK) assessment around the first Esperoct<sup>®</sup> 50 IU/kg dose.

<sup>d</sup>Trough level goal is 1% for prophylaxis.

<sup>e</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.

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>f</sup>Steady-state FVIII activity levels were estimated in 143 adults and adolescents using pharmacokinetic modeling.

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

### What is Esperoct<sup>®</sup>?

Esperoct<sup>®</sup> [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<sup>®</sup> when you have surgery

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

### IMPORTANT SAFETY INFORMATION

#### Who should not use Esperoct<sup>®</sup>?

- 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<sup>®</sup>?

- 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<sup>®</sup>?

- Before taking Esperoct<sup>®</sup>, 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<sup>®</sup>, which may stop Esperoct<sup>®</sup> from working properly. **Call your healthcare provider right away if your bleeding does not stop after taking Esperoct<sup>®</sup>**

#### What are the possible side effects of Esperoct<sup>®</sup>?

- 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 [Esperoct.com](https://www.esperoct.com).



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

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**esperoct<sup>®</sup>**

*antihemophilic factor (recombinant),  
glycopegylated-exei*



# esperoct<sup>®</sup>

antihemophilic factor (recombinant), glycopegylated-exei

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

This information is not comprehensive.

- Talk to your healthcare provider or pharmacist
- Visit [www.novo-pi.com/esperoct.pdf](http://www.novo-pi.com/esperoct.pdf) to obtain FDA-approved product labeling
- Call 1-800-727-6500

## Patient Information

### ESPEROCT<sup>®</sup> [antihemophilic factor (recombinant), glycopegylated-exei]

**Read the Patient Information and the Instructions For Use that come with ESPEROCT<sup>®</sup> 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<sup>®</sup> after reading this information, ask your healthcare provider.

### **What is the most important information I need to know about ESPEROCT<sup>®</sup>?**

**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<sup>®</sup> so that your treatment will work best for you.

### **What is ESPEROCT<sup>®</sup>?**

ESPEROCT<sup>®</sup> 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<sup>®</sup> 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<sup>®</sup> when you have surgery.

### **Who should not use ESPEROCT<sup>®</sup>?**

You should not use ESPEROCT<sup>®</sup> if you

- are allergic to Factor VIII or any of the other ingredients of ESPEROCT<sup>®</sup>
- 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<sup>®</sup> might not be right for you.

### **What should I tell my healthcare provider before I use ESPEROCT<sup>®</sup>?**

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<sup>®</sup>?**

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

ESPEROCT<sup>®</sup> is given as an infusion into the vein.

You may infuse ESPEROCT<sup>®</sup> 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<sup>®</sup> 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<sup>®</sup>.**

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<sup>®</sup> or even a different product to control bleeding. Do not increase the total dose of ESPEROCT<sup>®</sup> to control your bleeding without consulting your healthcare provider.

### **Use in children**

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

### **If you forget to use ESPEROCT<sup>®</sup>**

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<sup>®</sup>**

Do not stop using ESPEROCT<sup>®</sup> 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<sup>®</sup>?**

Always take ESPEROCT<sup>®</sup> 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<sup>®</sup> than recommended, tell your healthcare provider as soon as possible.

### **What are the possible side effects of ESPEROCT<sup>®</sup>?**

#### **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<sup>®</sup>, which may stop ESPEROCT<sup>®</sup> 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<sup>®</sup>. 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<sup>®</sup> dosage strengths?**

ESPEROCT<sup>®</sup> 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<sup>®</sup>?**

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

Protect from light. Do not freeze ESPEROCT<sup>®</sup>.

ESPEROCT<sup>®</sup> 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<sup>®</sup> may be kept at room temperature (not to exceed 86°F/30°C) for up to 12 months, **or** up to 104°F (40°C) for no longer than 3 months.

If you choose to store ESPEROCT<sup>®</sup> 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<sup>®</sup> should appear clear and colorless without visible particles.

The reconstituted ESPEROCT<sup>®</sup> should be used immediately.

If you cannot use the reconstituted ESPEROCT<sup>®</sup> 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<sup>®</sup> and hemophilia A?**

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

Revised: 10/2019

ESPEROCT<sup>®</sup> 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.

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# REMEMBERING AYMAN EL-SHEIKH, MD



The Southwestern Ohio Hemophilia Foundation (SWOHF) staff and members send sincere sympathy to the family, patients, colleagues, and friends of Ayman El-Sheikh, MD. Dr. El-Sheikh was the medical director of the hematology and oncology department at Dayton Children's from 2015 until his untimely death in February of this year from complications of Covid-19. Board certified in pediatrics and pediatric hematology and oncology, Dr. El-Sheikh, was especially interested in blood and marrow transplants, solid tumor treatment, education, and research.

Respected scholar, dedicated physician, skilled clinician, brilliant teacher, and strong advocate are just a few of the attributes used to describe this exceptional man. Advancing the hematology department in order to improve medical care and treatments for the pediatric patient was always in forefront for Dr. El-Sheikh. In addition to achieving a cure Dr. El-Sheikh was also very interested in the comfort of his young patients and interacted with them in a way to put them at ease. The smile on Dr. El-Sheikh's face mirrored the smile on the patient's face as together they chose the perfect stickers after a visit!



As an accomplished scholar, Dr. El-Sheikh spoke seven languages. When a newly immigrated Arabic speaking family came for their first hemophilia visit, Dr. El-Sheikh conducted the visit in their own language. "His warm welcome opened the door for a very successful relationship with this family. He always looked for what he could do to help those around him and supported the hemophilia team in caring for patients." according to Jordan Wright, MD, director of the hemophilia program.

Collaborative efforts are on-going between the SWOHF and Dayton Children's to design and provide a physical memorial to honor Ayman El-Sheikh, MD. **He will be missed and his legacy of kindness will be displayed for future generations!**



# A **ONCE-WEEKLY** TREATMENT OPTION FOR HEMOPHILIA B.



HOW DOES  
THIS FACTOR IN?

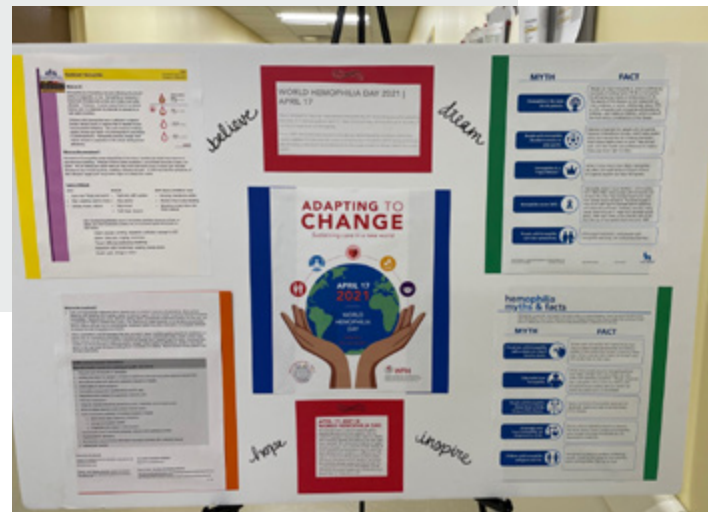
To find out about a prescription  
option, talk to your doctor or visit  
**[OnceWeeklyForHemophiliaB.com](https://www.OnceWeeklyForHemophiliaB.com)**

# INCREASING AWARENESS

## HTC CELEBRATES WORLD HEMOPHILIA DAY

In order to celebrate World Hemophilia Day on April 17th, Dayton Children's HTC provided education on Hemophilia to the hospital staff using fun and tasty cookies from AmyCakes in Miamisburg, Ohio. We realized that due to the great treatment options our patients have available, that hospital knowledge regarding Hemophilia needed a boost. We passed out cookies with tidbits of information

about Hemophilia to Hematology/Oncology staff, hospital administrators and Residents from units. A poster presentation will be displayed in a main corridor for a couple weeks to give talking points on Hemophilia and handouts were provided with cookies. This education was provided using grant funds from Cascade.





# HTC CORNER



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]



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**SWOHF**  
SOUTHWESTERN OHIO  
HEMOPHILIA FOUNDATION

## CONTACT US



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

### 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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