

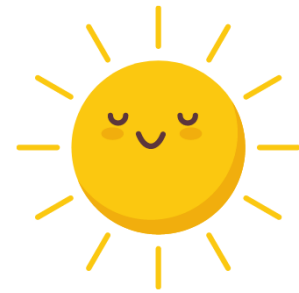


# WEST VIRGINIA CHAPTER NATIONAL HEMOPHILIA FOUNDATION

## SUMMER E-NEWSLETTER 2021

### In this newsletter you'll find:

- Upcoming Events
- Changes in WVNHF Staff
- Registration and RSVP details for Family Camp
- Eligibility Requirements for a Free iPad
- Registration for the Unite for Bleeding Disorders Walk
- Info on our New Dental Program
- Easter Cookie Decoration Recap
- How to Request Financial Assistance



### Save the Date!

#### August:

- Family Camp - August 20-22, 2021 @ Camp Twin Creeks
- National Bleeding Disorders Conference - August 26-28, 2021 (Virtual)

#### October:

- Unite for Bleeding Disorders Walk - October 16, 2021 (Virtual)

#### November:

- Annual Education Retreat- November 13-14, 2021 @Stonewall Resort

#### December:

- Factor & Frost - TBD @ Elkins

Check out our [Events Calendar](#) or [Facebook](#) for up-to-date info and registrations for events.

# ADVERTISEMENT



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

See half-life, clearance and other PK data from the crossover study comparing **Jivi®** and **Eloctate®**.

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

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

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**Jivi**  
antihemophilic factor  
(recombinant) PEGylated auct  
**LET'S GO**

# Goodbye Fernando



In case you missed it, WVNHF Executive Director Fernando Andrzejewski, left the chapter this April. He had this to say:

"Dear West Virginia bleeding disorders community,

After much thought, emotion, and discussion with my family, I bid farewell as the Executive Director of the West Virginia Chapter of the National Hemophilia Foundation, as I am resigning effective April 23rd to start a new chapter in my professional career. Through my near two years at the West Virginia Chapter, I have grown and learned more than I have ever thought I would in a short period of time.

I will cherish my tenure as the Executive Director and am honored to have worked for such an amazing organization that has made a profound impact on me both personally and professionally. Please know my decision to resign was not made lightly and I will continue to support and be involved with the West Virginia Chapter activities moving forward. The chapter has experienced tremendous growth over the past few years and has never been stronger, due in large part to the amazing volunteer advocates, community members, and donors.

Over the past two years, I have seen first-hand how amazing and supportive this community is and I am lucky to be a part of it. I am excited about my future and the future of the West Virginia Chapter of the National Hemophilia Foundation, and I look forward to being part of that success as a volunteer, community member, and true believer of the work being accomplished."

Fernando was a passionate advocate for those in the community and will definitely be missed.

## Meet Chelsea Hilty Program Director

Hello everyone,

I'm happy to be writing to you as the new Program Manager for the WV Chapter. I'm originally from central Pennsylvania but spent the last ten years living in Pittsburgh after moving there to attend the University of Pittsburgh. I got my degree in Environmental Studies, but wasn't sure what I wanted to do with it.



After a few internships I realized my true passion was in nonprofit work and I have been in that sector ever since, usually doing event planning and education.

I moved to West Virginia when my husband was accepted into WVU's Pharmacy Program. I spend as much time as I can outside and feel lucky that West Virginia has a lot to offer in that arena. I like going to concerts, reading, and painting.

My role here is to help develop programs to fit the community's needs, and to make sure they run smoothly. It's been a few crazy months, especially with Fernando's departure, but I've really enjoyed the work so far. What I am most excited about are the upcoming events because I can't wait to meet everybody!

I want to assure you all that I'm working hard with several other NHF staff members to ensure our chapter continues to grow. I'm really interested in learning more about what types of programs people want to see and I want to help in any way that I can, so if you have questions, ideas, or anything else please let me know.

-Chelsea

## ADVERTISEMENT



There are ways  
to help you

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**AFFORD YOUR  
HEMOPHILIA A  
MEDICINE.**

**LEARN  
MORE >**

### Registration for Family Camp is Now Open!

Family Camp is a place to have fun, connect with other people in the bleeding disorders community, and make memories. It's free to participate. We hope to see you there!



**AUGUST  
20-22**

MARLINTON, WV

**WEST VIRGINIA  
NATIONAL HEMOPHILIA FOUNDATION**

**FAMILY  
CAMP**

[Register Here](#)

## Virtual Connectivity Initiative

If you live in one of the following counties, **you may be eligible for a free iPad** through our West Virginia Virtual Connectivity Initiative. The initiative was designed to make it easier to connect with doctors via telemedicine and attend remote chapter events, like the upcoming Unite Day Walk.

People who live in these counties may qualify: Boone, Cabell, Kanawha, Lincoln, Logan, Mason, Mingo, Putnam, and Wayne. Contact us for more info!

## Unite for Bleeding Disorders Walk



Last year was our biggest walk to date! We want to build on that momentum by having another virtual walk this year, making participation easy no matter where you live. The walk is a great community event that increases awareness for bleeding disorders, and all the money we raise will stay at the WV chapter. This funds chapter programs like camp and the education retreat, and sustains our education, support, and advocacy services. With your help we can make this year even better than the last!

[Register Here](#)

# ADVERTISEMENT

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<sup>°F</sup><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.

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

<sup>h</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](http://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®

**antihemophilic factor (recombinant), glycopegylated-exei**

## Brief Summary information about ESPERECT® [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

### ESPERECT® [antihemophilic factor (recombinant), glycopegylated-exei]

**Read the Patient Information and the Instructions For Use that come with ESPERECT® 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 ESPERECT® after reading this information, ask your healthcare provider.

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

**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 ESPERECT® so that your treatment will work best for you.

### What is ESPERECT®?

ESPERECT® 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.

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

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

### Who should not use ESPERECT®?

You should not use ESPERECT® if you

- are allergic to Factor VIII or any of the other ingredients of ESPERECT®
- 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 ESPERECT® might not be right for you.

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

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 ESPERECT®?

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

ESPERECT® is given as an infusion into the vein.

You may infuse ESPERECT® 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 ESPERECT® 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 ESPERECT®.**

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 ESPERECT® or even a different product to control bleeding. Do not increase the total dose of ESPERECT® to control your bleeding without consulting your healthcare provider.

### Use in children

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

### If you forget to use ESPERECT®

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 ESPERECT®

Do not stop using ESPERECT® 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 ESPERECT®?

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

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

#### 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 ESPERECT®, which may stop ESPERECT® 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 ESPERECT®. 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 ESPERECT® dosage strengths?

ESPERECT® 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 ESPERECT®?

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

Protect from light. Do not freeze ESPERECT®.

ESPERECT® 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, ESPERECT® 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 ESPERECT® 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) ESPERECT® should appear clear and colorless without visible particles.

The reconstituted ESPERECT® should be used immediately.

If you cannot use the reconstituted ESPERECT® 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 ESPERECT® and hemophilia A?

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

Revised: 10/2019

ESPERECT® 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 ESPERECT® contact:

Novo Nordisk Inc.

800 Scudders Mill Road

Plainsboro, NJ 08536, USA

1-800-727-6500

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US19ESP00168 December 2019



Annual Meeting, Education Weekend, Annual Retreat? Whatever you call it, it's back!



## West Virginia Dental Program

The WV Dental Program is an idea we are piloting with the goal of improving oral health care for members of our community. Through a partnership between the chapter, our local hemophilia treatment centers and the West Virginia Oral Health Coalition, we are developing a network of dental care providers throughout the region. Our plan is for dentists who join the network to receive additional training in how to better care for patients with bleeding disorders and will enable them to work with the HTC's to make patient specific treatment plans. We hope that this will relieve some of the stress associated with visiting the dentist and will encourage members of the community to seek more preventative oral healthcare treatments.

## Easter Cookie Decoration



This Spring we partnered with the Central Ohio Chapter to connect with families for a virtual cookie decorating event. Thanks to CSL Behring, we were able to send cookies and supplies directly to people's homes.

During the event participants were able to catch up with friends and spend family time having fun together. The children especially loved a craft that involved staying up late and eating lots of sugar.

## WVNHF Financial Assistance Program

The Financial Assistance program is part of the West Virginia Chapter of the National Hemophilia Foundation's continuing effort to improve the quality of life of individuals and families affected by bleeding disorders by providing financial support. The Financial Assistance program is supported by generous contributions from individuals, foundations, and corporations committed to the bleeding disorders community.

[Click Here for Info](#)