THE WINNING SPIRIT

Summer 2020

EASTERN PENNSYLVANIA
HEMOPHILIA FOUNDATION

41 Counties. 1 Mission.

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. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. HEMLIBRA may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). 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.

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

HEMLIBRA®
emicizumab-kxwh
injection for subcutaneous use | 150 mg/mL

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

For more information, go to 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

HEMLIBRA®
emicizumab-kxwh
injection for subcutaneous use
150 mg/mL

Genentech
A Member of the Roche Group

EASTERN PENNSYLVANIA HEMOPHILIA FOUNDATION

41 Counties. 1 Mission.

Serving the Hemophilia and vWD Community.

National Hemophilia Foundation
for all bleeding and clotting disorders

Proud Member HFA

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800.789.PENN PennMedicine.org

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DIVISION OF HEMATOLOGY

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EASTERN PENNSYLVANIA HEMOPHILIA FOUNDATION

1WALK

1COMMUNITY • 1MISSION

Sunday, October 4, 2020
8:00AM

CREATE A TEAM AND FUNDRAISE TO SUPPORT EPHF PROGRAMS AND SERVICES.

Elmwood Park Zoo

1661 Harding Blvd, Norristown, PA 19401

ELMWOOD PARK ZOO
EVENTS

Festivities include:

- Dance Party
- Face Painting
- Giveaways
- Refreshments
- T-shirts for all registrants
- Animal meet and greet
- Discounts to the carousel, train, and animal feeding
- All day access to the zoo

https://runsignup.com/Race/PA/Norristown/1Walk

CONTACT Kelly McManus on ideas to FUNDRAISE
kellym@hemophiliasupport.org or 484-445-4282

ADVOCACY UPDATE
WORLD HEMOPHILIA DAY

PHILLY LIT IN RED
APRIL 17, 2020

Photo credit Daniel Burke Photo & Video, LLC in partnership with Spark Therapeutics

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

Takeda

ADVOCACY UPDATE
CALL TO ADVOCACY

On Thursday, May 21, 2020, The Eastern and Western PA Hemophilia Foundations hosted a virtual program entitled "Call to Advocacy". We were joined by HTC staff, Milliron and Goodman Government Relations and community members throughout the state. The discussion focused on the Hemophilia Program Line Item and the importance of fighting to keep it, as the money benefits our HTCs. We went through the Advocacy page on the Eastern PA website to show all the tools available to write letters and make phone calls to your state house representatives and senators. There is even a link to the "Find your Legislator" website to see who represents you and their contact information.

We also discussed the Advocacy Ambassador program, which is a grassroots initiative to involve the community in our advocacy efforts. Ambassadors can commit as much time as their busy schedules permit. We are with you every step of the way. Please call or email Curt Krouse if you are interested in becoming an Advocacy Ambassador at (484) 445-4282 or curtk@hemophiliasupport.org.

It is important to have relationships at every level of government to not only protect our access to care, but to also help create awareness for our community. We are proud to share a proclamation from Governor Tom Wolf for World Hemophilia Day on April 17, 2020.

Commonwealth of Pennsylvania

Governor's Office

PROCLAMATION

WORLD HEMOPHILIA DAY
April 17, 2020

WHEREAS, hemophilia is a rare genetic bleeding disorder in which one of the proteins that causes the blood to clot is missing or there is not enough of it to work properly, causing people to bleed longer; and

WHEREAS, without effective blood clotting, cuts and internal injuries have difficulty healing, and internal bleeding into the joints can result in pain and permanent damage; and

WHEREAS, hemophilia is typically a lifelong condition that is primarily treated with infusions of a protein involved in blood clotting; and

WHEREAS, it is estimated that more than 400,000 people worldwide are living with hemophilia; and

WHEREAS, approximately 20,000 people in the United States – and more than 1,000 people in the commonwealth – are living with hemophilia; and

WHEREAS, hemophilia is found in all populations; and

WHEREAS, people living with hemophilia, and those caring for and serving them, are strongly united in advocating for access to treatment and care.

THEREFORE, I, Tom Wolf, Governor of the Commonwealth of Pennsylvania, do hereby proclaim April 17, 2020, as WORLD HEMOPHILIA DAY. I strongly encourage all citizens to increase their awareness of hemophilia diagnosis and treatment.

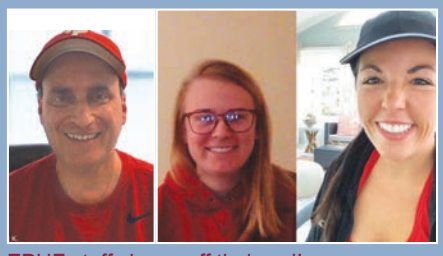
GIVEN under my hand and the Seal of the Governor, at the City of Harrisburg, this seventeenth day of April two thousand twenty, the year of the commonwealth the two hundred forty-fourth.

TOM WOLF
Governor

MORE PHOTOS FROM WORLD HEMOPHILIA DAY

Every year on World Hemophilia Day, Monsignor McHugh School honors one of their own, Callie Padilla. It doesn't matter if the students and their families are near or far, they wear red to show their support for Callie and others in the bleeding disorders community.

Board Member Tom DiCamillo and his family got into the spirit!



EPHF staff shows off their red!

SCHOLARSHIP SPOTLIGHT

JAMES WALKER

FROM ARCHBALD, PA

GRADUATING SENIOR, PENN STATE UNIVERSITY

WHAT IS YOUR MAJOR AT PENN STATE UNIVERSITY?

Mechanical Engineering

WHAT ARE YOUR PLANS AFTER GRADUATION?

I will be working as a Project Engineer with Paradigm, a construction company in D.C. that builds apartment complexes. I interned with them during the summer of 2019 and I am excited to return as a full-time employee.

WHAT HAS BEEN YOUR FAVORITE EXPERIENCE IN COLLEGE?

My favorite college experience at Penn State was being an Engineering Ambassador for the past two years. This organization was my family at school. We would go on outreach trips to K-12 schools in the area and we would present various engineering topics to students. After the presentations, we would do a fun, engaging activity with them. I really loved working with the people in this organization and seeing the excitement on students faces when they were having fun learning about engineering.

In this professional organization, I was also a tour guide that would show new incoming students the campus and everything the College of Engineering has to offer. These tours were always wonderful and there was nothing better than to hear from students or their parents that they chose Penn State because of me. I love Engineering Ambassadors and I will forever miss my family at PSU.

HOW HAS THE CORONAVIRUS AFFECTED YOUR SENIOR YEAR?

The pandemic has made life as a college student extremely difficult. Engineering can't all be taught online because a lot of the work is hands on. We must make the best of the situation. Even though it has been difficult, I will finish strong and graduate in May.

The worst thing about having school online is the number of events and other things we had taken away from us. Spring semester senior year is the time where you relax and spend time with the friends you will have to say goodbye to. We couldn't do this. We abruptly had to transition online which changed everything. Our graduation is postponed, sports events are canceled, banquets, outreach, clubs, and so many other fun worthwhile activities are all gone.

All those things are terrible and sad, but the worst thing by far is the memories that we will not get to make. School passes by extremely fast because every minute of every day there is something going on. The hardest part is not being there for that and finishing online. It is just not the same and it is sad. I love Penn State and I guess this pandemic gives me all the reason to go back for every football game in the fall and tailgate with my friends and family. WE ARE!!!

CONGRATS TO OUR OTHER GRADUATING SENIORS

Omar Esquivias
Penn State University

Tate Hutchinson
St. Joseph's University

Evan Kerstetter
Pennsylvania College of Health Science

Melanie Matthews
King's College

Jennifer Perez
Temple University

Coping With Hemophilia as a Family:

Suggestions for Managing the Family Dynamic

For more information, visit b2byourvoice.com to download *Hemophilia B: A Family Perspective.*

This content is brought to you by Pfizer.

Hemophilia Affects the Whole Family

Despite improvements in the medical management of bleeding disorders, raising a child living with hemophilia still affects the lives of everyone in the family. It's important to address the needs of caregivers and family members as well as acknowledge how a diagnosis of hemophilia alters family dynamics.[1]

Hemophilia is a complex disorder that requires treatment for a lifetime. If hemophilia is new to the family, feelings of uncertainty about coping with day-to-day management can occur. In particular, infusing factor may initially be upsetting to the child and stressful for the caregiver who is experiencing challenges with the process.[1]

> "One thing we learned was that growing up is a learning process for all children, whether they have hemophilia or not."
>
> — Jill L.
>
> Mother of 2 sons with hemophilia B

Discipline and Limits

It's important for parents and other caregivers to support one another in the daily care of the child, including talking about emotions and overcoming hemophilia-related challenges together.[2] Some of these challenges can include providing discipline and setting limits. Parents and caregivers are often advised to address these issues in the same way they would for children who are not diagnosed with a bleeding disorder.

Some suggestions from the National Hemophilia Foundation that may help in caring for a child with hemophilia include[3]:

- Praise your child when he or she reports a bleed to a caregiver
- Reinforce that having a bleeding disorder that requires treatment is not a punishment
- Openly discuss the potential effects of behavior and activities
- Never punish your child for having a bleed

One major concern that parents or caregivers may face is knowing when a child is having a bleed. In some cases, bleeds can be tricky to identify, as a child may exhibit one or more of the following signs or symptoms of a muscle bleed[4]:

- Holding a part of the body in an awkward position or reluctance to use that part of the body
- Complaining of pain or a tingly sensation in the injured area
- The injured area feels warm, swollen, and/or firm to the touch

It's important to recognize that caring for a child with hemophilia may create changes to which the family must become accustomed. Lifestyle modifications are a part of living with hemophilia, and sometimes these changes extend to the entire family. However, these adjustments represent opportunities for positive change through learning and self-awareness.[5]

References: **1.** Beeton K, Neal D, Watson T, Lee CA. Parents of children with haemophilia—a transforming experience. *Haemophilia.* 2007;13(5):570-579. **2.** Wiedebusch S, Pollmann H, Siegmund B, Muthny FA. Quality of life, psychosocial strains and coping in parents of children with haemophilia. *Haemophilia.* 2008;14(5):1014-1022. **3.** National Hemophilia Foundation. Steps for Living website. Discipline. www.stepsforliving.hemophilia.org/first-step/family-life/discipline. Accessed July 12, 2019. **4.** Rivard G-E, Blanchette V, Hilliard P, Mulder K, Zourikian N. Management of bleeds. In: *All About Hemophilia: A Guide for Families.* Montréal, Québec: Canadian Hemophilia Society; 2010: 4-1–4-32. **5.** Cassis FRMY. *Psychosocial Care for People With Hemophilia.* Montréal, Québec: World Federation of Hemophilia; 2007.

PP-HEM-USA-1226

September 2019

Pfizer

BECOME A MEMBER OF EPHF

Membership is free. Please visit our website and fill out an online form even if you currently receive our emails and newsletters. In the future, membership will be needed to take advantage of all the wonderful programs and services offered by the Foundation. The form can be found on our website, hemophiliasupport.org, by clicking on the Membership tab.

WE ARE PROUD MEMBERS


Michkel Davis


Ekawati Phiong


Frank Lentini


Hajar Abusief

Member Spotlight

Jaqueline Torres

HOW WAS YOUR FRESHMAN YEAR OF COLLEGE? WHAT IS YOUR MAJOR?

My freshman year at the Community College of Philadelphia was phenomenal as I am majoring in Healthcare. My first semester was a bit challenging because the environment and atmosphere were very different from high school. The second semester was more of a roller coaster. I had four classes as a full-time student but now with a part-time job as well. I found this was a bit too much. I was feeling tremendous stress and my mental health was not correct. I asked myself how I could do my best in school. I ended up dropping one course. I felt relief that I did that and soon everything was back on track and I was doing great. I met with the members of the Eastern Pennsylvania Hemophilia Foundation. They helped me a lot with making some great decisions while offering me wonderful opportunities. I am so excited. I began working out in between my classes and met two great girlfriends. Even though, due to Covid-19, we transferred to online classes, which was not my preference, I tried my very best to end the school year on a positive note. I finished the first semester with all A's and a B and the second semester with all A's. Despite all my difficulties during my first year, it was a marvelous experience. I look forward to Fall 2020.

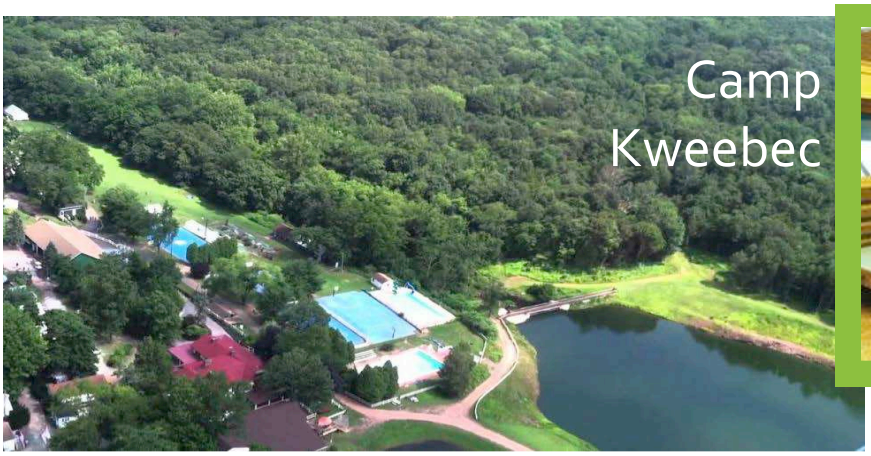
WHAT DO YOU LIKE TO DO WHEN YOU ARE NOT IN SCHOOL?

I love to do a variety of things. I attend therapy to talk about my life, and it's a great feeling to receive feedback. I love to paint. I go out to my backyard or to a beautiful park on a great weather day and paint. It is a way to relax my body. I also love to read poetry. I love to work out and do meditation. It is a way to distract myself from all stress and relax my mind. Besides all of that, I enjoy family get togethers. We play a variety of games, color, sing, cook and have a great time.

Eastern PA Hemophilia Foundation

2020 Family Camp

September 18 –20



There is no cost for this event.

We are going back to Camp Kweebec this September. Nestled on 186 acres in Montgomery County, Camp Kweebec is the perfect site for a weekend family event. The camp has nice, clean cabins that are bright and airy and elevated off the ground with bathrooms.

We will have delicious family-style food throughout the weekend. The camp has tennis, basketball and volleyball courts, soccer and baseball fields, and boating. There will also be a full arts and crafts program and a special live reptile show and dance party on Saturday night. In case of inclement weather, there are many indoor areas that will accommodate our group with fun activities.

Get registration information on our website: https://www.hemophiliasupport.org
Contact Lindsay Frei at lindsayf@hemophiliasupport.org or (484) 445-4282.

EASTERN PENNSYLVANIA HEMOPHILIA FOUNDATION

41 COUNTIES. **1** MISSION.

Annual Meeting

Tuesday, October 13, 2020

The Hilton Hotel
4200 City Avenue, Philadelphia, Pennsylvania

5:30 PM EXHIBIT HALL OPEN
Meet representatives from pharmaceutical companies and specialty pharmacies to learn about their products and services.

7:00 PM DINNER & PROGRAM

Get registration information on our website: https://www.hemophiliasupport.org
Contact Lindsay Frei at lindsayf@hemophiliasupport.org or (484) 445-4282.

REMARKS BY:

Ruben Rhoades, MD
Thomas Jefferson University Hospital

Sharon Meyers
PRESIDENT & CEO
Hemophilia Federation of America

David Buono, Jr.
SENIOR ADVISOR TO THE COMMISSIONER
PA Insurance Department

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

Not an actual patient.

ADVATE has over 15 years of treatment experience in the real world and provides clinically proven bleed protection* for patients with hemophilia A.[1]

ADVATE
[Antihemophilic Factor (Recombinant)]

REAL LIFE. REAL BLEED PROTECTION.*

AdvateRealLife.com

takeda AD

Prophylaxis with ADVATE prevented bleeds[1]

- ADVATE was proven in a pivotal clinical trial to prevent or reduce the number of bleeding episodes in children and adults when used regularly (prophylaxis)
- The efficacy of ADVATE was studied in a multicenter, open-label, prospective, randomized, 2-arm controlled trial of 53 previously treated patients with severe to moderately severe hemophilia A. Two different ADVATE prophylaxis regimens (standard, 20–40 IU/kg every 48 hours, or pharmacokinetic-driven, 20–80 IU/kg every 72 hours) were compared with on-demand treatment. Patients underwent 6 months of on-demand treatment before 12 months of prophylaxis
  - 98% reduction in median annualized bleeding rate (ABR) from 44 to 1 when 53 patients in the clinical study switched from on-demand to prophylaxis
  - 0 bleeds in 42% (22/53) of patients during 1 year on prophylaxis

ADVATE Important Information

What is ADVATE?

- ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia).
- ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A. Your healthcare provider (HCP) may give you ADVATE when you have surgery.
- ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADVATE?

Do not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

Tell your HCP if you are pregnant or breastfeeding because ADVATE may not be right for you.

What should I tell my HCP before using ADVATE?

Tell your HCP if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADVATE passes into your milk and if it can harm your baby.

What should I tell my HCP before using ADVATE? (continued)

- Are or become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What important information do I need to know about ADVATE?

- You can have an allergic reaction to ADVATE. Call your HCP right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.
- Do not attempt to infuse yourself with ADVATE unless you have been taught by your HCP or hemophilia center.

What else should I know about ADVATE and Hemophilia A?

- Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADVATE from working properly. Talk with your HCP to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

What are possible side effects of ADVATE?

- Side effects that have been reported with ADVATE include: cough, headache, joint swelling/aching, sore throat, fever, itching, unusual taste, dizziness, hematoma, abdominal pain, hot flashes, swelling of legs, diarrhea, chills, runny nose/congestion, nausea/vomiting, sweating, and rash. Tell your HCP about any side effects that bother you or do not go away or if your bleeding does not stop after taking ADVATE.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see Important Facts about ADVATE on the following page and discuss with your HCP.

For Full Prescribing Information, visit www.ADVATE.com.

Reference: 1. ADVATE Prescribing Information.

Takeda

ADVATE
[Antihemophilic Factor (Recombinant)]

Important facts about

ADVATE [Antihemophilic Factor (Recombinant)]

This leaflet summarizes important information about ADVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADVATE. If you have any questions after reading this, ask your healthcare provider.

What is the most important information I need to know about ADVATE?

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

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

What is ADVATE?

ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia). The product does not contain plasma or albumin. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A.

Your healthcare provider may give you ADVATE when you have surgery. ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

Who should not use ADVATE?

You should not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

Tell your healthcare provider if you are pregnant or breastfeeding because ADVATE may not be right for you.

How should I use ADVATE?

ADVATE is given directly into the bloodstream.

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

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

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

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

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

You should tell your healthcare provider if you:

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

What are the possible side effects of ADVATE?

You can have an allergic reaction to ADVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Side effects that have been reported with ADVATE include:

cough	headache	joint swelling/aching
sore throat	fever	itching
unusual taste	dizziness	hematoma
abdominal pain	hot flashes	swelling of legs
diarrhea	chills	runny nose/congestion
nausea/vomiting	sweating	rash

Tell your healthcare provider about any side effects that bother you or do not go away

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

What else should I know about ADVATE and Hemophilia A?

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

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

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADVATE. The FDA-approved product labeling can be found at www.ADVATE.com or 1-877-825-3327.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Patented: see https://www.shire.com/legal-notice/product-patents

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HTC SPOTLIGHT

THIS INTERVIEW WAS CONDUCTED WITH MICHELLE DOLT, MSN, RN, CRNP. MICHELLE IS THE NURSE PRACTITIONER AT THE ST. CHRISTOPHER'S HOSPITAL FOR CHILDREN HEMOPHILIA TREATMENT CENTER.

WHERE ARE YOU ORIGINALLY FROM?

I was born in Moscow, Pennsylvania which is a small town in the Northeast in Lackawanna County. The population is around 2,000 people. I moved to the Philadelphia area when I was in 5th grade. My mom was working as a private investigator at that time and was transferred to the area. A lot of my family has moved from that area, but I do still have a couple of aunts, uncles, and cousins there.

HOW LONG HAVE YOU WORKED AT ST. CHRISTOPHER'S HOSPITAL HEMOPHILIA TREATMENT CENTER?

I started officially working at SCHC HTC in June of 2018. But I came with a long history of collaboration with them, as detailed in the next question.

HOW DID YOU BECOME INTERESTED IN BLEEDING DISORDERS?

Back in 2003, I received a post card in the mail from a home care company called Pediatric Services of America looking for nurses. When I went to interview, the nursing director was the daughter of my 8th grade teacher and we bonded quite quickly. I started working there initially as a per diem nurse as I had a full-time job on the pediatric unit at Abington hospital. Most of the patients I was treating had a bleeding disorder. I was going to their home, schools, camps, and offices for factor infusions. In 2005, I started working for PSA full-time. In 2011, I decided to further my education and pursued my MSN and pediatric nurse practitioner degree. I started working as a NP at St. Christopher's in 2013 in the short procedure unit and in 2018, I was notified that the NP position was available in hematology and I jumped at the opportunity.

WHAT DO YOU THINK ARE THE BIGGEST SOCIAL ISSUES FACING PEOPLE WITH BLEEDING DISORDERS?

One of the biggest social issues facing the pediatric population is some of the restrictions on activities. Several of our patients ask on multiple occasions about playing football and wrestling. These are sports we don't encourage even for our non-bleeding disorder patients due to risk of head injury. We also don't endorse parties and attendance at the trampoline parks. These have become very popular in recent years. These parks have a about a 55% injury rate. We try to refocus families on activities and sports they can participate in and encourage them to live healthy, active, fulfilling lives while trying not to focus on what they CAN'T do.

WHAT KIND OF RESOURCES DOES THE HTC PROVIDE FOR PATIENTS, OUTSIDE OF MEDICAL CARE?

We assist with finding school scholarships, referrals for camps, and support groups.

HOW HAS THE RELATIONSHIP WITH THE EASTERN PA HEMOPHILIA FOUNDATION HELPED YOU TO BETTER SERVE YOUR PATIENTS?

The Foundation has always been very supportive of us and our needs. Most recently they supported a project to improve the appearance of our clinic by adding new artwork to all our clinic rooms. The artist also painted some ceiling tiles which were placed in our phlebotomy room and waiting area. A cheerful environment helps reduce fears felt by the children while in the clinic setting, especially when they know phlebotomy will occur.

WHAT IS YOUR FAVORITE PART OF YOUR JOB?

There are a couple things. I love the education piece, being able to attend conferences, meeting people from different treatment centers, and bringing updated information back to our patients. Another bonus is seeing some of the patients I used to treat when I worked home care all GROWN up. I also believe it was helpful for them to have a familiar face in clinic.

WHAT DO YOU LIKE TO DO IN YOUR SPARE TIME?

I like to take my dog for walks in the park. In the nice weather, my husband and I like to explore different bike trails and towns. But I would say I enjoy traveling the most, as often as possible. I have traveled to many places in the US and abroad, including Spain, France, Italy, Ireland, Denmark and Africa.

September 15, 2020

EASTERN PENNSYLVANIA HEMOPHILIA FOUNDATION

Golf Classic

Join us and take in the beauty of the RiverCrest Golf Course with native grasses, rock walls, cascading waterfalls and deep ravines challenging players of all skill levels. Enjoy their award-winning food and let their team of professionals deliver a day of great golf, fun and camaraderie.

Perry Parker, who has played in the PGA Tour, Three US Opens, Australian Legends Tour, and European Senior Tour, will hold a free adult clinic from 10:00–11:00am. From 11:00–12:30pm, he will analyze your swing on the driving range.

- Buffet Lunch at 11:45AM
- Shotgun Start at 1:00PM
- Cocktail and Buffet Dinner to Follow
- Drone Drop, Closest to Pin, Putting Contest, and more

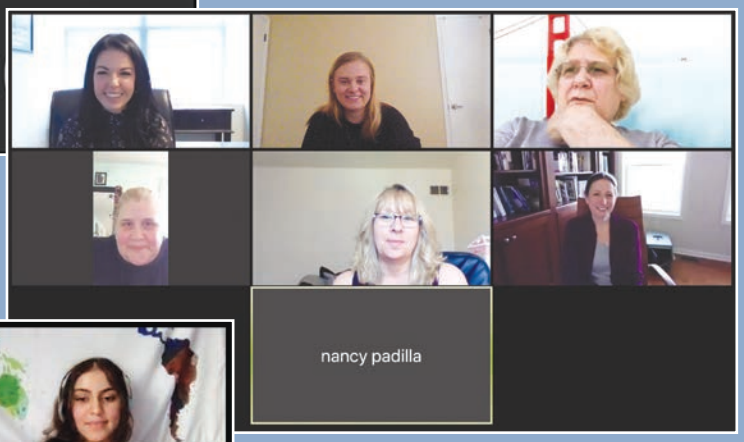
Golfer: $195
Hole Sponsorship: $250
Corporate Foursome: $1,000

Register online:
https://www.hemophiliasupport.org

Please direct questions to: Kelly McManus at kellym@hemophiliasupport.org or 484-445-4282

VIRTUAL PROGRAMS

Throughout the month of May, the Eastern PA Hemophilia Foundation connected with community members through Zoom gatherings. This included Men's Group Happy Hour, Women's Group Luncheon, Pre-Teens/Teens Trivia Night and Family Bingo Night. The programs allowed us to have some fun while also catching up with each other. Not seeing you at events is what we miss the most so thanks to everyone who was able to join us. More virtual programs will occur throughout the summer so be sure to check your emails from the Foundation, as well as follow us on Facebook and Twitter.



When it comes to your hemophilia A treatment

Move beyond the threshold[a]

A simple switch to Esperoct® can give you high factor levels for longer.[b]

Extend half-life beyond the standard

22-hour average half-life in adults[c]

High factor levels in adults and adolescents

At or above 3% for 100% of the time[a,d]

At or above 5% for 90% of the time[a,e]

Flexible on the go[c]

The only extended half-life product with stability up to 104°F[f]

[a]Trough level goal is 1% for prophylaxis.
[b]Compared with standard half-life products.
[c]Data shown are from 42 adults who received a pharmacokinetic (PK) assessment around the first Esperoct® 50 IU/kg dose.
[d]Data shown are from a study where 175 previously treated adolescents and adults received routine prophylaxis with Esperoct® 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.
[e]Steady-state FVIII activity levels were estimated in 143 adults and adolescents using PK modeling.
[f]For up to 3 months.

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® is not used to treat von Willebrand Disease

IMPORTANT SAFETY INFORMATION

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® 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® 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 pages.

Discover more at **Esperoct.com.**

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

esperoct®
antihemophilic factor (recombinant), glycopegylated-exei

esperoct®

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 from the date of manufacture until the expiration date stated on the label.

ESPEROCT® may be stored at room temperature (not to exceed 86°F/30°C), for up to 12 months within the 30-month time period. Record the date when the product was removed from the refrigerator. The total time of storage at room temperature should not exceed 12 months. Do not return the product to the refrigerator.

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: 02/2019

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

Manufactured by:
Novo Nordisk A/S
Novo Allé
DK-2880 Bagsværd, Denmark

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

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

US19ESP00010 August 2019

novo nordisk®

HOW TO HELP YOUR CHILD WITH A BLEEDING DISORDER COPE WITH ANXIETY AND STRESS IN THE PANDEMIC

ADVICE FOR FAMILIES IN THE BLEEDING DISORDERS COMMUNITY DURING THE COVID-19 PANDEMIC AND BEYOND

Author: Donna Behen

The COVID-19 pandemic has many families on edge right now. Jobs are being cut, routines are disrupted, and with social distancing requirements in place in most parts of the country, parents are juggling the demands of working at home with keeping their children healthy, happy and occupied with constructive activities, including online learning.

Families in the bleeding disorders community are dealing with all of these new stressors, of course, but that's on top of the unique everyday challenges that come with managing a bleeding disorder.

"Living with a bleeding disorder or parenting a child with a bleeding disorder can be very stressful anyway, but adding a worldwide pandemic just magnifies this stress," says Robert Louden, MSW, LCSW, a social worker at Indiana Hemophilia & Thrombosis Center in Indianapolis.

What can you do to help nurture and protect your child's emotional well-being during times of crisis? Here's what Louden and his fellow Indiana Hemophilia & Thrombosis Center social workers Gail Jordan, MSW, LCSW; DeAuntae Lawson, MSW, LSW; and Ashley Parmerlee, MSW, LCSW, recommend:

Keep your normal routines

Kids thrive on structure, so as much as possible stick to your normal household routines, including regular bedtimes, meals, chores, etc. That consistency helps kids, especially younger ones, feel calm and secure.

Be honest but reassuring

Talk to your children about what's going on, but in a way that doesn't induce or raise their anxiety. You want to create an environment where children feel comfortable expressing their concerns and asking questions, and where you can address any misconceptions they may have.

Check in with your children frequently to assess their current understanding and stress surrounding the crisis. Be on the lookout for signs of anxiety and depression, including changes in appetite, sleep disruptions, aggression, irritability, and fears of being alone or withdrawn.

Take care of your own physical and mental health

As parents, you should be modeling how to cope with stressful situations in positive ways by maintaining healthy habits, including exercise, adequate sleep and establishing some alone time, when possible.

Stay positive

Remind your children that being homebound is temporary, and that even in trying times, you can always find reasons to be grateful.

"While this is a time of uncertainty, it is also a time to be thankful for those around us," Louden says. "It gives us the ability to appreciate how precious time is, and how we can use these extra moments in a productive way."

On a practical level, the slower pace at home can make the home infusion process calmer and easier to schedule. "It may also enable kids to be more hands-on in the process, and possibly allow adolescents to take on a more independent role," Louden says.

Keep in touch with your HTC

If you have any questions or concerns, contact your local hemophilia treatment center (HTC). The social workers are there to help.

Says Louden: "Everyone is feeling very uncertain about everything going on, so we are trying to be as available as possible and well versed in all resources that could benefit our patients so that we can point them in the right direction when they need it."

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Eastern PA Women's Retreat

Friday-Sunday, November 13-15, 2020

Chubb Hotel & Conference Center, Lafayette Hill, PA

Get registration information on our website: https://www.hemophiliasupport.org
Contact Lindsay Frei at lindsayf@hemophiliasupprt.org or (484) 445-4282 by October 30, 2020

MedicAlert Memberships & IDs

The Eastern PA Hemophilia Foundation provides MedicAlert Memberships and IDs for patients with hemophilia, vWD and other factor deficiencies. To qualify, you must either live in Pennsylvania (Eastern PA's coverage area) or if you live outside the state, then you must be treated at one of the following six Hemophilia Treatment Centers:

- Thomas Jefferson University Hospital
- Hospital of the University of Pennsylvania
- Children's Hospital of Philadelphia
- St. Christopher's Hospital for Children
- Penn State Hershey Medical Center
- Lehigh Valley Hospital – Muhlenberg

Contact Lindsay Frei for more information at 484-445-4282 or lindsayf@hemophiliasupport.org.

MedicAlert FOUNDATION

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