Fall 2020

KHF Hemosphere

Virtual KHF Summer Camp "Camp Discovery"

Camp Discovery went virtual for the first time this year due to the ongoing pandemic and our desire to keep our campers and volunteers safe and healthy. Three Saturday Zoom sessions covered program content that we felt would appeal to our campers. The camp committee brainstormed and worked hard to arrive at feasible and fun virtual activities intertwined with some educational topics.

Two of our Junior Counselors, Taylor Curry and Sam Johnson, developed an excellent presentation for girls with von Willebrand disease and factor deficiencies under the guidance of our Infirmary Director, Missy Frey, entitled: "Bleeding Disorders in Girls." Our Camp Director, Justin Lindhorst, recruited facilitators, Shelby Smoak and Terry Rice, who discussed with the boys "No Need to Bleed: Making Joints Last a Lifetime." Treasure hunts, animated discussions, and impromptu musical entertainment by our participants in between sessions livened up our campers and committee members with unadulterated fun and laughter. Arts and Craft activities were developed and presented by Jennifer Dunegan, Eileen Moseley, and Christina Haffler and garnered some amazing results. A special thank you to Patrick Dunegan for running the Zoom sessions.

We were excited that among our participants were six new campers from eastern Kentucky, southern Indiana, and north central Kentucky. Adults and campers alike were sad to see the virtual camp end, but we will hopefully be seeing each other next summer in person at our Camp Discovery at Cedar Ridge Camp & Retreat Facility here in Louisville. The culmination of this year's Virtual Summer Camp was the drawing for some great prizes and the receipt of activity and giveaway boxes. We thank our sponsors, our camp committee members, and volunteers for helping us make a successful and productive transition into the virtual sphere with our summer camp this year. Sponsors were Takeda, Kosair Charities, HEMA Biologics, Pfizer, CVS Caremark, CSL Behring, Bayer HealthCare, Novo Nordisk, WHAS Crusade for Children, and Grifols.

Special News

How Adolescents Understand Hemophilia

Laurie Kelley

What follows is a continuation of the article as seen in the Spring 2020 edition of the KHF Hemospheres newsletter.

How Adolescents Understand Factor

By the time your child becomes an adolescent, he has learned that factor is more than his bottle of medicine. He knows that it's related to what's missing from his blood, but he also knows that it is a certain type of factor, which functions in a cascade with all the other factors. "Factor VIII is something your body is supposed to make. It stops internal bleeding."

The exact details may be confusing. He may say, "I'm not sure how many factors there are. Is there a factor X?" Or, "There's different types of white cells. These are factors." Or, "There's probably 100 factors. I'm missing all, well, 1% or something."

Ask your teen to explain how factor works once it's infused. This is a perfect topic to produce a logical explanation, because it involves the circulatory system, which operates step-by-step, with specific cause and effect. Many teens won't be able to give the following step-by-step explanation: "Factor is injected into a vein, travels to the heart, and is pumped through arteries to all sites in the body; it forms the fibrin net that eventually covers the torn blood vessel and allows healing." Yet most teens are capable of understanding this process.

Some school age children describe factor as "fighting," "pushing," or "vacuuming" the blood. Only a few older ones describe a "door" or "plug" forming over the torn blood vessel—the fibrin clot. Surprisingly, when teens lack concrete medical or scientific information, many will offer similar answers. But a school age child will be satisfied with his incomplete answer, while a teen usually will not; he may realize that he lacks information, that there are gaps in his thinking. This frustrates him! Look at these incomplete answers from some teens:

"Factor eats the bacteria in your arm. It helps it to heal."

"It makes a ball of blood and freezes up so it can't swell. It makes the cells stick together."

"Factor is trying to help the white blood cells get all the blood or red blood cells out of the knee. It pushes its way in."

Some teens explain how factor works by mistakenly describing the function of one of the blood enzymes—that is, factor "removes" excess blood from a joint! It seems that, as parents, our emphasis on treating joint bleeds and swellings has prompted our children to confuse swelling with the role of factor.

Yet other teens recognize that "factor goes to the injured spot. It clots the blood and makes new cells. It clots the hole and keeps the blood from spilling out."

Whatever your teen's response, know this: He is ready to understand a simple, three-step process of blood clotting. He craves the information. His brain is trying to fill in any information gaps. Help him by exploring what he knows.

How Adolescents Understand Factor Deficiency Type and Severity

Most teens know their factor deficiency and often their severity level. "I have hemophilia A, the most common. I'm missing factor VIII." "Hemophilia B means I'm missing factor IX. I have severe hemophilia. I get bleeds, and they don't go away that easily. Mild bleeds go away faster." Pretty sophisticated! (…continues on page 6)

Irish Investigators Review Fetal Precautions and Delivery Mode in Congenital Bleeding Disorders

It is well established that the clinical management of pregnant women with congenital bleeding disorders (CBDs) is challenging, as healthcare providers, including obstetricians, hematologists and other specialists must consider potential varying complications, including levels of bleeding risk for both mother and child. There are therefore several intrapartum precautions and fetal restrictions, such as the use of mid-cavity forceps, that are designed and often advised to mitigate bleeding risks associated vaginal delivery in pregnant women with CBDs.

A team of researchers from Ireland sought to better understand the effect of CBD-related restrictions on maternal and neonatal outcomes, including the rate of emergency Cesarean sections. The study was led by Dr. Bridgette Byrne, Royal College of Surgeons in Ireland, Department of Obstetrics and Gynecology, Coombe Women and Infants University Hospital in Dublin. Byrne and her team performed a retrospective review of obstetric outcomes within a large group of women with CBDs who had received care at a specialized obstetric/hematologic antenatal clinic over a six-year period.

Included in the review were 76 patients, encompassing 94 pregnancies. Of these, 20 patients were carriers of hemophilia, 28 had low von Willebrand Factor levels or VWD, eight had other coagulation factor deficiencies, and 20 had an unspecified bleeding disorder. Of the 94 pregnancies, 83 (88.3%) had fetal precautions advised, while 11 (11.7%) did not. There was no significant difference between the groups in the numbers of non-labor elective Cesarean section, emergency Cesarean section not in labor, or emergency Cesarean section in labor. Of the 63 patients who went into labor with fetal precautions, six (10%) underwent Cesarean section because of the precautions. Primary postpartum hemorrhage was noted in nine patients (12.2%) overall.

While Byrne and her team acknowledge the study's limitations, they also note that these findings could be instructive as it relates to planning for labor and delivery.

"This study is not of sufficient size to comment on maternal and foetal safety with different modes of delivery in different CBDs. It does show, however, that 10% of women who labour with foetal precautions in place are delivered by Caesarean section because of these restrictions. This is important information when counselling this group of women about mode of delivery," concluded the authors.

The study, "The Impact of Foetal Restrictions on Mode of Delivery in Women with Inherited Bleeding Disorders," was published in the European of Journal of Haematology. Source: Hematology Advisor, July 21, 2020

Event News

2020 Golf Scramble

On the last Monday in August under sunny skies, KHF's annual golf scramble fundraiser commenced. We set up our registration tables outside the clubhouse at Glen Oaks Country Club in Prospect to greet our players and sponsors. Everyone was masked and happy to see each other, ready for a fun day on the golf course for a good cause. And fun they had according to post-event feedback. Box lunches and take home dinners sustained our golfers throughout the day accompanied by some welcome cold beverages. We congratulate all our winners! Team winners were in 3rd place, Octapharma; in 2nd place, HEMA Biologics; and in 1st place, William Black and Friends I. The Longest Drive was won by Mike Francis and the Longest/Straightest Drive by Ronnie Taylor. Closest to the Pin prizes were awarded to Vince Poma, Mike Francis, Tim Kelley, and Erik Winquist. Joey Constantine won the 50/50 Raffle, while Jeff Marks won the Ball Drop and generously donated his winnings back to KHF. We also had an attractive selection of silent auction items, which all found a good home to go to.

We are very grateful to our event, team, player, and tee sponsors who made our event a success. They were Silver Level Sponsor, Novo Nordisk; Bronze Level Sponsors BIOMARIN and Octapharma; Team and Tee Sponsors are HEMA Biologics; LTC (R) John and Mrs. Patricia Tharp in Memory of Gary Bandy; Player Sponsors William Black & Friends I and II, Glen Hitt Sr. and Friends I and II, and Marwood Live Edge Slabs & Lumber. Business Tee Sponsors are Marwood Live Edge Slabs & Lumber and Soleo Health Innovations in Specialty Infusions. We also extend our thanks to all our donors, our golf committee headed up by William Black, our day-of-event volunteers, and Glen Oaks personnel who helped us put on a seamless event while meeting compliance with COVID-19 restrictions. The event raised $18,117 for KHF programs and services benefitting Kentucky's bleeding disorders community.

2020 Teen Impact Awards

Every year, Patrick James Lynch of Believe Limited hosts the Teen Impact Awards at the National Hemophilia Foundation's annual Bleeding Disorders Conference. This youth awards program is sponsored by Takeda. Among the honorees this year were three amazing teens from the greater Louisville area, Isaac Webb and Jackson Woods from Louisville and Marissa Johns from Shepherdsville.

Eligible teens are affected by bleeding disorders, 13-18 years old, and active in their respective communities through volunteerism, civic involvement, mentorship, and excellence in scholastic achievement and sports. We congratulate Isaac, Jackson, and Marissa for their well-deserved awards, and we are proud to count them among our Youth Leaders at our Camp Discovery summer camp and as Youth Advocates on the state and national level!.

Event News

2020 Charles Stanley Hamilton Legacy Award

With much pride and gratitude, we congratulate Carl Weixler of Lexington for having been awarded the 2020 Charles Stanley Hamilton Legacy Award by the Hemophilia Federation of America (HFA). Carl is known all across the bleeding disorders community not only in his home state of Kentucky but also on the national level. Carl is a lifelong, ardent advocate for the bleeding disorders community. He currently serves as board president of The Committee of Ten Thousand and is a past board president of the Hemophilia Federation of America and the Kentucky Hemophilia Foundation.

KHF's Upcoming Scholarship Opportunity

The next deadline for submitting a scholarship application is January 15, 2021 for the spring semester. For an application form and guidelines, contact the KHF office at 502-456-3233 or 1-800-582-CURE (2873) or send an email to info@kyhemo.org.

2019 – 2020 Bi-Annual Fund Drive

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

Donors, $3,750 - $5,250
Snow Companies
Delta Dental of Kentucky Foundation

Donors, $1000 - $3,000
Sanofi Genzyme
Patricia P. Thomas Estate
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via Louisville Community Foundation
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for Easter Lilies
Amazon Smiles
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for Poinsettias

More News

How Adolescents Understand Hemophilia

continued from page 2

It's important for teens to know their factor deficiency type—for their medical care, and even for their self-esteem. Imagine a teen admitting he doesn't understand this basic information. It's like not knowing his phone number, address, or birthday. To feel more confident, he should understand that factor deficiency refers to the blood protein that is "missing," or not active, and that this results in prolonged bleeding.

Before you begin teaching your teen, understand that adolescents often confuse factor deficiency with severity level. For example, they may believe that being factor IX deficient means bleeding more often, as with severe hemophilia. You'll need to find out what your teen believes, to correct any misconceptions.

Try This

As parents, we're often in "functioning mode" when completing forms and applications for our children. Try letting your teen complete his own applications for school, hemophilia camp, or clinic. The forms will require him to list his factor type and severity level, and which medicine he uses. This good parenting action makes your teen more responsible.

Of the two concepts, the one best understood by adolescents seems to be severity level. This is probably because the idea is still somewhat concrete—you typically bleed more often when you have severe hemophilia. Teens understand severity correctly as how much factor works or is present in their blood. "Severe means you're missing a lot of factor." Or, "I'm mild to moderate. I don't have to be as careful because I don't bleed as much. Severe is worst."

Severity is simpler to understand than hemophilia type because of direct clinical symptoms. The hardest thing to explain about severity is how it relates to the percentage of factor active in the blood. Compared to school age children, adolescents should be more experienced with percentages, but using percentages to describe factor activity may still mystify them. Look at how three teens try to explain severity:

Teen 1: "I'm 3% moderate. It's 3% factor, something like that. It's better than having zero. With zero you bleed a lot easier."

Teen 2: "Severe is less than 1% clotting ability. Moderate is 1% to 15%, and mild is 25% to 50% . . . no, to 100%. Normal is 150% to 200% clotting ability. That means how fast and how well you clot."

Teen 3: "Serious factor VIII means less than 1%. That's the amount I have. Normal is 33%. Moderate means you have more factor VIII in your body."

Even though two of these responses are not technically accurate, these teens have attempted to apply abstract math to abstract blood proteins.

How can you teach your adolescent about severity and deficiency? As always, first find out how he understands each concept. Have him draw pictures if that helps. Explain that factor VIII and factor IX refer to blood proteins vital in clotting blood. Try using a clotting cascade diagram.1 (Please don't use the domino analogy with teens; it's far too simple.) Show what happens when one of the blood proteins is missing. To explain severity, use percentages, but first review what percentages mean. Use pie charts and analogies—batting averages are great! Use the idea of a dollar bill (100 cents as 100% factor working). What would a penny mean?

A nickel? Now translate that into how much of his factor works, and what this means clinically—that is, how often does he bleed?

How Adolescents Understand Hemophilia

	PreSchool (ages 3 – 7)	School Age (ages 7 – 11)	Adolescent (ages 11 and older)
Hemophilia	It's when I get hurt. I get a shot. I go to the hospital.	Something's missing in my blood.	It's a blood disorder. I'm missing a clotting factor, which makes my blood not clot.
Heredity	You're just born with it. God gave it to me.	It came from my family, my mother. It gets passed along to the baby. The baby catches the X thing.	It comes from the X, Y chromosomes. The X carries hemophilia and when a boy is made, he gets the mother's X.
Bleeding	You bleed, and then it stops. Bandages make it better. My knee get puffy, then it goes down.	You bleed, then you get a scab and skin grows back. The knee fills up with blood, then it stops. It takes time to heal.	You bleed, you clot, skin regenerates. Veins are repaired. Platelets make a wall to stop the blood.
Factor	It's my medicine. It makes me better. It's a bottle.	It's what I'm missing in my blood. It pushes the blood away. It scares, fights, vacuums the blood. It blocks the vein.	A blood protein that I'm missing. It makes cells stick together. It pushes blood away, eats bacteria, plugs a leak.
Severity	It's when someone gets factor more than another because he got hurt more.	There's severe, moderate, and mild. Severe means missing a lot of factor. Severe means bleeding more.	*Often confuses type with severity.* Severe means you're missing a lot of factor in your body I only have 2% of mine.
Factor Deficiency	*May recite factor, or his deficiency but no knowledge of meaning*. I have factor VIII deficiency. I don't know what that means. It's what I have.	It's one of the factors I'm missing. I'm factor VIII deficient.	It's the factor type I'm missing. There's several types of factor needed to stop bleeding.
Having Hemophilia When Grown	I don't know what that means. It's what I have.	You'll still have hemophilia when you're old, unless there's a cure. It's in you.	I'll always have it. It's made in the liver (or cells or genes).
Cure	Putting new blood in me makes hemophilia go away. Taking new medicine will cure it.	Hemophilia will go away if you get new blood. If you get someone else's blood, you'll still have hemophilia, because you'll still have your heart, liver.	There's gene replacement, implants, DNA research. I'd still have hemophilia even if I got new blood because I'd still have the same cell, genes, liver, heart.
Overall Stage Characteristics	*Hemophilia is external, perceptual, and what I see or experience personally. No time involved, no varying degrees, no subsets of a whole. Magical thinking.*	*Hemophilia is a condition. Step-by-step external sequence with time involved. Still perceptual, becoming internal. Analogies are useful for teaching. Concrete thinking.*	*Considers whole and parts, hypothetical situations, internal processes, future. Often feels invincible, in denial. Abstract thinking.*

(This article concludes in the next *Hemosphere* issue)

KHF CARES

Kentucky Hemophilia Foundation continues to provide financial assistance to bleeding disorder families whose household income has decreased because of loss of job, lay off, furlough, or reduced hours during the current COVID-19 health crisis and who are unable to pay a specific household bill. Requesting families must reside in Kentucky, and the person seeking assistance must either have a bleeding disorder or be the parent of a minor child with a bleeding disorder. Assistance is contingent on the availability of funds.

Call 502-456-3233 or 800-582-CURE (2873) or send an email to info@kyhemo.org to make a request.

60 Years of Service!

Please remember KHF when doing your estate planning! This will help us continue our service to Kentuckiana's Bleeding Disorders Community.

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

KOSAIR CHARITIES

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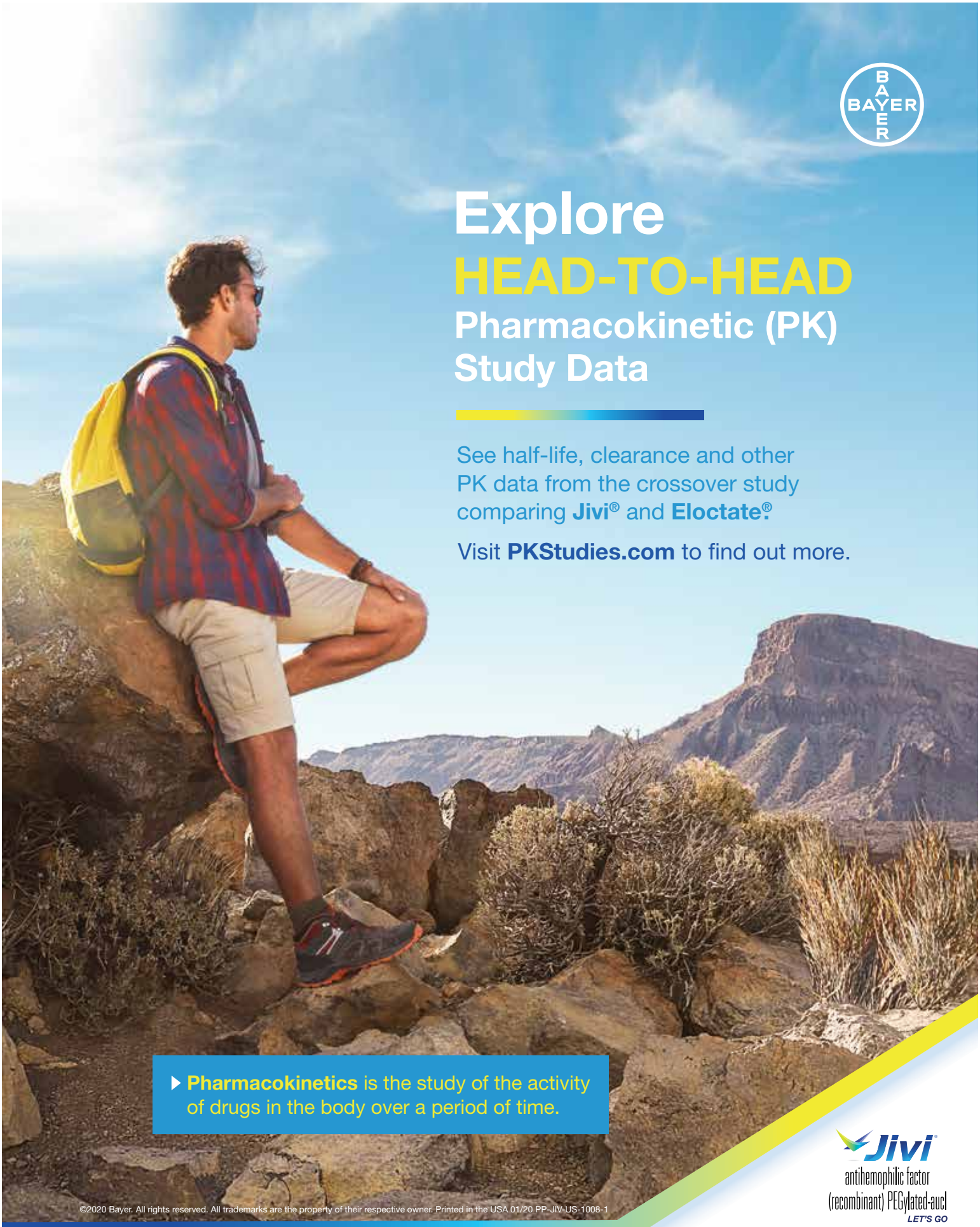

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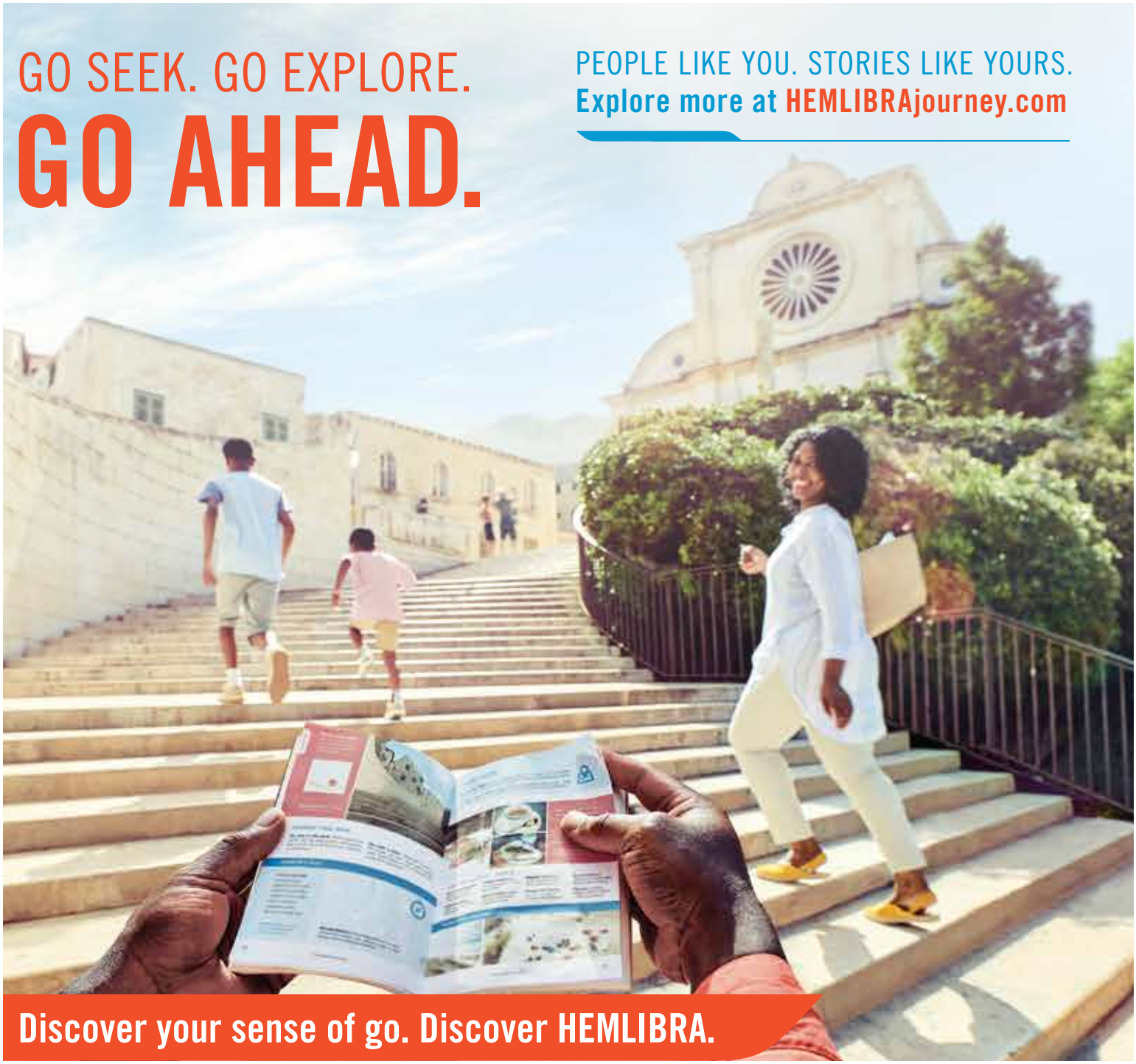

Discover your sense of go. Discover HEMLIBRA.

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®) 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
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
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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

Genentech

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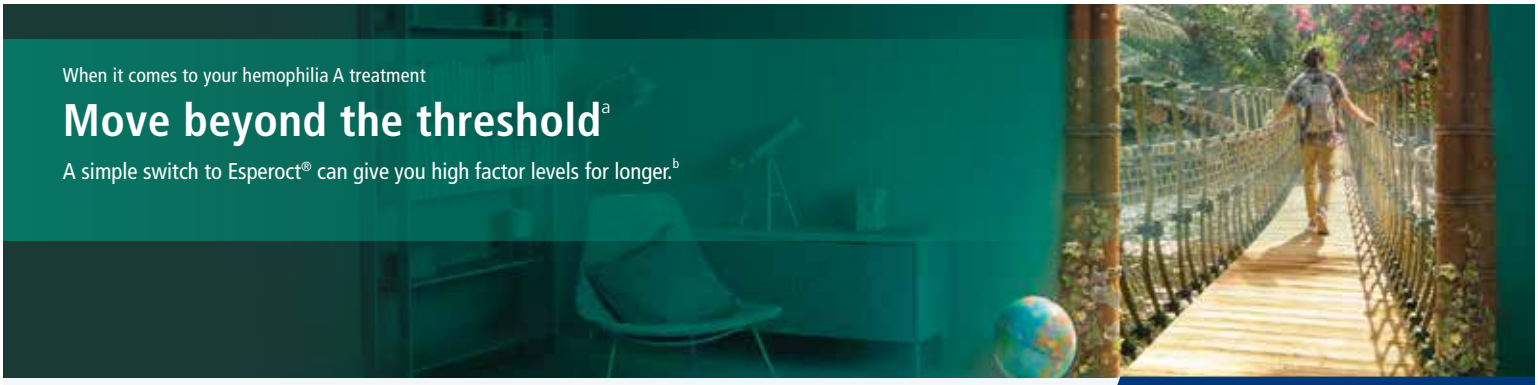
A simple switch to Esperoct® can give you high factor levels for longer.[b]



[a]Trough level goal is 1% for prophylaxis.
[b]Compared with standard half-life products.

Discover more at **Esperoct.com.**

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.

novo nordisk®

Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.
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esperoct®
antihemophilic factor (recombinant), glycopegylated-exei

Dana Clemmans

Patient supporter

About Dana

Dana is a Hemophilia Community Liaison who is driven by her passion to help patients. Her greatest contribution comes from letting those in the Greater Midwest area know she is there for them as a resource when they need it.

Connect with Dana

DLRC@novonordisk.com
(630) 291-3714

Hemophilia Community Liaison

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novo nordisk®

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.

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

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

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

For information about ESPEROCT® contact:
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800 Scudders Mill Road
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1-800-727-6500

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novo nordisk®

DEDICATION and PERSONAL SUPPORT

Your Pfizer Patient Affairs Liaison is a professional dedicated to serving you and the hemophilia community by connecting patients and caregivers with Pfizer Hemophilia tools and resources. We are committed to continuing Pfizer's more than 20 years of listening to the hemophilia community and working to meet its needs.

Chris Liddell

Southern OH, MI, KY, IN

"I've worked in rare disease for 15 years, and I have experience collaborating with and advocating for different members of this community."

PATIENT AFFAIRS LIAISONS

Pfizer Hemophilia

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MY WORK IS GUIDED BY:

Compassion

Listening to your needs and addressing questions and concerns that you may have

Commitment

Educating you about Pfizer's tools and resources, including the Pfizer Community Connections Program, the HemMobile® app for logging bleeds and infusions, B2B materials, and more

Connection

Connecting you with hemophilia advocacy groups and programs like Leading Edge, the National Hemophilia Foundation, the Coalition for Hemophilia B, and others

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Pfizer

60 Years of Service!

We are proud of our service to our bleeding disorders community. One of the most important things we do is to help the newly diagnosed and their families cope with all of the life changes that these disorders can cause. A few of the services we provide are:

- Bicycle helmets and other child safety items (soft shell helmets, knee pads, elbow pads)
- Emergency financial, transportation, and lodging assistance
- Medic alert emblems
- Scholarships for post-secondary education
- Cultural and recreational enrichment scholarships for children

For more information, call KHF at 502-456-3233 or 1-800-582-CURE (2873) or send an email to info@kyhemo.org

KHF

Hemdifferently

Exploring the science behind gene therapy research

Gene therapy research has the potential to bring an entirely new option to people with specific genetic conditions. Many gene therapies are in clinical trials to evaluate the possible risks and benefits for a range of conditions, including hemophilia. HemDifferently is here with gene therapy education, providing accurate information in a way you can understand.

Let's explore gene therapy together at **HemDifferently.com**

No gene therapies for hemophilia have been approved for use or determined to be safe or effective.

BIOMARIN®