Spring 2020

KHF Hemosphere

Vegasville Gala

On Saturday, February, 22nd, we commemorated the twenty-third anniversary of our Mardi Gras/Vegasville event at the historic Olmsted on Frankfort Avenue in Louisville. This event has been our primary special event fundraiser since its start. We were delighted to count Clark and Sally Rhea, the founders of the original event, among our guests. Cocktail hour and dinner entertainment was provided by Vikki & Mike who thrilled our guests with their upbeat retro tunes.

Sam Johnson, a junior counselor at KHF's Camp Discovery, and her mother, April Bryant Zimmerman, presented a riveting testimonial telling their story of living with a bleeding disorder and excelling at school, working, and volunteering while navigating and managing the daily challenges of having a chronic condition.

After dinner entertainment was provided by the local powerhouse band, Indigo, which lured many guests onto the dancefloor, while others tried their hand at blackjack, poker, roulette, and other casino style games.

Lady luck shone on Laura Webb of Louisville, who won the 50/50 raffle and Jill Oca of Jeffersonville, who won the gigantic grand prize bourbon basket. Dr. Joseph H. Cieslak of Louisville won an attractive wine basket in a complimentary drawing for Special Ask donors. An ample selection of must-have silent auction items went home with their highest bidders. Congratulations to all our winners!

We thank all donors and supporters for their generous contributions. Table sponsorships were provided by Bayer HealthCare, BioMarin, CSL Behring, Mr. & Mrs. Henry W. Boyd, III, Forcht Bank, Louisville Oral Surgery & Dental Implants, and Republic Bank & Trust Company. A special thank you as well to our day-of-event volunteers, especially John Silletto and friends, for our casino style gaming and Cory Meadows, board president, for emceeing the event. The event raised $40,000 for KHF's programs and services.

Special News

How Adolescents Understand Hemophilia

Laurie Kelley

What follows is a continuation of the article as seen in the Winter 2019/2020 edition of the KHF Hemosphere newsletter.

How Adolescents Understand Genetics

Compared to younger children, teens are more aware of, and ready to learn about, the concept of genetics—which can be very logical. Going through puberty shows your teen genetics in action: his sudden tall stature like his grandfather, nose like his father, or hair color like his mother. He's also learning about genetics in school, so he's now ready to understand hemophilia transmission—and, most important, how he got his hemophilia.

Your teen's first explanations of hemophilia transmission may not include abstract concepts like proteins, genes, or cells. When you start asking him about transmission, let him explain in his own words. You can coax him through it. Asking questions like "Why? And then what?" may help him think it through logically. As he grows from a young adolescent (ages 11–14) into an older one (ages 15–18), you can introduce more abstract concepts and terms, like chromosomes and DNA.

Then again, your teen may surprise you with a detailed description of the pattern of transmission from parent to child, including carrier status transmission. Or he may describe general patterns. He may be confused about details—whether his mother gives an X or a Y; on which chromosome the hemophilia gene is located; perhaps even what genes are. But he can try to solve the transmission puzzle by working it out step-by-step, beginning with the first step: "Genes have pieces of DNA in them. They tell you what you have, like your intelligence. They're strands of something. They give you your characteristics."

Try This

The birth of new nieces, cousins, or grandchildren is always a good time to raise questions about hemophilia and heredity. While holding the new family addition, ask your teen casually, ***"Do you think any of your children will inherit hemophilia? Why or why not?"*** Even if he doesn't answer, at least you can start him thinking.

Your teen may work it out this way: "Hemophilia comes from the family through your genes. Your genes live in the sperm. If your mom's brother had hemophilia, it might pass through the sperm when it hits the egg. The boy could get it by a 50-50 chance." One teen explained, "It runs in the family. The father with hemophilia has a daughter, so she has a 50% chance of having a boy with hemophilia. But if a guy with hemophilia has a boy, it'll stop right there. I'm not sure how that works."

Teens will eventually be able to explain genetic transmission and apply its patterns consistently. These won't be just genetic rules: "If I marry a carrier female, I may have a daughter with hemophilia." He'll be able to generalize,

How Adolescents Understand Hemophilia

Laurie Kelley *continued*

or explain why each rule is true. And he can apply the rules to different scenarios: “Girls get two X chromosomes, but boys only get an X and a Y chromosome. So if something goes wrong with the X chromosome, the Y chromosome can’t cover it as well. In a girl, if the X chromosome has something wrong with it, the other X can cover it. But girls can get hemophilia, too.”

Teens age 15 and older are ready to attempt, sometimes correctly, more intricate explanations involving genes, chromosomes, and probabilities: “One in 10,000 boys get it. But most women are just carriers.” Sometimes, incorrectly: “A carrier means there’s a 99.9% chance you’ll end up with a kid with hemophilia.”

Teens may have trouble explaining why some children inherit hemophilia while their siblings do not. “Not all the mother’s genes contain hemophilia.” “The genes didn’t go through all the way. The sperm doesn’t have it.” Or, “Some kids get it on their X and some on their Y. If you get it on your X, you get hemophilia. If you get it on your Y, you don’t. It comes from your heritage, or your sister or mother being a carrier.”

But the hardest question may be, “When you become a father, will any of your children have hemophilia?” If your teen can try to explain this using X and Y chromosome patterns, he’s brave! Most will use percentages or general rules of transmission: “If I marry a carrier, then some of my girls might get hemophilia. If I marry someone who isn’t a carrier, then some of my boys would have a chance of getting it.”

Some teens mix percentages with general rules: “If I marry a man who has hemophilia, then my girls will all have it definitely, and probably my boys will, assuming that I’m a carrier. There’s a 50-50 chance.”

Look at the way one teen with hemophilia tried to figure out hemophilia inheritance: “None of my children will have it, but my daughters might be carriers . . . Yes, they’d definitely be carriers. The father gives an X to his daughter, and the mother gives an X. If I gave an X and the mother was a carrier, then my daughter would have both Xs affected, and she’d still be a carrier. She wouldn’t have hemophilia.”

In truth, she would have hemophilia, but this teen’s answer demonstrates a wonderful ability to think logically.

This is the second installment of this article. Look for subsequent Hemosphere Newsletter episodes for the next part.

Event News

Walk Rally

The annual Walk Rally in December is a training conference for all Walk Chapters that participate in the National Hemophilia Foundation's Walk Program. It is an opportunity to learn best practices, share ideas and experiences, and get excited to begin preparations for the next Unite for Bleeding Disorders Walk season. The conference was in San Antonio, Texas, which offered a nice change of scenery from wintry Kentucky and a chance to visit the historic Alamo.

KHF's 7th Unite Walk will be Saturday, October 10, 2020, at E. P. "Tom" Sawyer State Park in Louisville. It will be an exciting Walk and Community Event! We urge you to register early, build your teams, and start fundraising. We will have great prizes again for all winners. Our Walk web page is up and running and more user friendly, according to NHF's Walk staff. Register at www.uniteforbleedingdisorders.org/event/KY20.

Scholarship Award

We congratulate Andrew Harmon for receiving the Betty Meadors Mattingly Memorial Scholarship Award of $500 for the 2020 spring semester. Andrew attends Midway University in Midway, Kentucky, where he majors in Elementary Education. He is planning on graduating in 2020 with a Baccalaureate degree. Andrew is the son of Keith and Sharen Harmon of Bedford, Kentucky. The next deadline for submitting a scholarship application is July 15, 2020 for the Fall 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.

KHF Advocacy Day

This year's KHF Advocacy Day in Frankfort on February 27 was our 7th consecutive in-state advocacy event for Kentucky's bleeding disorders community. Meetings with legislators focused on access to care, premium assistance, and HB72, which addressed the unfair practice of accumulator adjusters by insurers. HB72 was introduced by Rep. Danny Bentley who took time out of his busy day to talk to our group of advocates about the importance of this bill. Our talking points were well received by legislators thanks to the orientation and training facilitated by Jim Romano of Patient Services Inc. (PSI) and the efforts of the Kentucky Access to Care Coalition (KACC) who provided us with all the pertinent facts and figures along the way. Mid-day our advocates joined members and guests invited by the National Organization for Rare Disorders (NORD) in the Capitol Rotunda, where we were presented with a proclamation signed by Governor Beshear recognizing the month of March as Bleeding Disorders Awareness Month alongside Patrick and Jennifer Dunegan, who received their proclamation in recognition of Rare Disease Day on February 28. Jim Romano gave a very impactful presentation telling his family's story of how their lives have been affected by hemophilia. The speaker testimonials were definitely the highlight of the day and a testimony to the many individuals affected by rare diseases, such as hemophilia and von Willebrand disease, whose voices were heard that day.

We concluded our day with a wrap-up and evaluation lunch at Serafini Restaurant. We thank our sponsors who made the KHF Advocacy Day possible. They were Takeda, Pfizer, Genentech, CSL Behring, and Novo Nordisk.

Event News

Washington Days

Washington Days is the National Hemophilia Foundation's yearly advocacy event in Washington, DC, at the end of February. Several hundred people gather from all over the country to advocate for the needs and concerns of the bleeding disorders community. We were proud to sponsor Myra Loeser, Bradley and Jackson Woods to participate in this important activity. After an orientation and training the night before, they spent all day the next day on the Hill meeting with legislators from Kentucky to educate them about life with a bleeding disorder and its implications for access to treatment, available and affordable insurance, and needed protections. By all accounts, Myra, Bradley, and Jackson had a great experience and a great time. Jackson, our teen advocate, clearly had done his homework and impressed the legislators they met with his knowledge, well-spoken delivery of his personal story, and maturity! Congrats, Jackson, we are very proud of you!

NHF Leadership Training

The National Hemophilia Foundation's Chapter Leadership Seminar took place in Dallas, Texas, in March this year. Training sessions and roundtable discussions covered many topics including fundraising, programming, volunteer and board development as well as chapter advancement. This was an excellent training opportunity to learn about cutting edge strategies and methodologies. In addition, peer discussions were very insightful and great learning experiences. A special treat was the opportunity to meet Dr. Len Valentino, NHF's new CEO. He is a very knowledgeable, dedicated, and amicable man who values the work done by NHF's chapters for the common good, namely our bleeding disorders community.

Easter Lily and Spring Flowers Sale

The Easter Lily and Spring Flowers Sale has been one of our primary fundraisers for many years. I look forward to it every year because we are usually surrounded by an abundance of Easter lilies, tulips, and hyacinths with their glorious spring colors and fragrances as we wait for the orders to be picked up. This year unfortunately, this important fundraiser did not proceed as expected because of the COVID-19 pandemic that has brought so many changes, uncertainties, and fears into all of our lives. We thank the individuals and churches that were able to participate in this fundraiser and greatly appreciate their support. We especially thank Sharon McMahan in Owensboro for her efforts and dedication during this difficult season.

More News

COVID-19 Relief Provided by HFA (Hemophilia Federation of America)

HFA is providing financial relief for bleeding disorder families facing urgent need and lost income due to COVID-19. HFA recently announced that the COVID-19 Relief Fund is now available for the bleeding disorders community. HFA has created the COVID-19 Relief Fund to provide financial relief for members of the bleeding disorders community who are grappling with a significant loss of income due to COVID-19 and need urgent assistance to pay an essential bill for housing (rent or mortgage), utilities (electric, water, phone), or transportation (vehicle payment). Learn more at http://www.hemophiliafed.org/COVID-Fund. Please let us know if we can refer you for assistance.

Patient Services Inc. (PSI) Emergency Assistance Program

PSI has created an emergency assistance fund in response to COVID-19 to help patients navigate uncharted territory. The COVID-19 pandemic has negatively impacted individuals, families, and businesses, affecting finances and health. PSI is dedicated to financially assisting patients with chronic illnesses; and they understand that this population is at greater risk for COVID-19. To support PSI patients and their families affected by the virus, they have introduced the PSI Emergency Assistance Program to assist active PSI patients in getting over the financial hurdle that may have been created due to the pandemic. To be eligible for program support, you must be a current active PSI patient who meets income criteria and have either been diagnosed or had a family member diagnosed with COVID-19 or have suffered a job loss or reduction in workforce hours due to COVID-19. Assistance is limited to one patient per household. If approved for support, eligible patients may receive a one-time grant of $500.00. Funds can be used to pay for rent/mortgage, phone bills, utilities, groceries and emergency childcare.

For more information about PSI's Emergency Assistance Program, visit the FAQ page of PSI's website or call (800)-366-7741 to speak with a PSI representative.

KHF CARES

Kentucky Hemophilia Foundation will 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 will be 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. Donations to this fund are also being accepted.

More News

2019 – 2020 Kentucky Hemophilia Foundation Membership

We thank all of the members of the Kentucky Hemophilia Foundation for their support of the current program year

Individual/Family Memberships, 20+
Sara Ceresa
Curtis & Winnie Jacobs
James M. Meade
David & Terry Moore

Supporting Memberships, $35+
Batty Lynn Hatfield
Judy Hayes
in memory of Jason Hayes
Donald L. Mattingly
Sadalia Sturgill

Patron Memberships, $50+
Danny & Maritza Adams
Charles Music
John & Carol Nord
Stacey & Troy Powell

Sustaining Memberships, $100+
Barbara W. Grayson
D. Spalding Grayson
Glen E., Sr. & Deborah Hitt
Dr. David & Leslie Houvenagle
Vivian Marcum
Keith Peterson

Benefactor Memberships, $250+
Charles & Ruth Hall

Champion/Corporate Members, $500
Rosemary Johnson-Dean
for her father, Robert B. Johnson
LTC (R) John & Pat Tharp

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

Donors, $1,000 – $3,000
Patricia P. Thomas Estate
Zoeller Company via Louisville
Community Foundation
LTC (R) John & Pat Tharp, Forcht
Society Donors

Donors, $500 – $999
Chevron Matching Employee Funds
David Hasch
Kroger Community Rewards
Donald L. Mattingly, Forcht Society Donor

Donors, $200 – $499
Kenny's Department Store
John & Leah Graham
Bill Stopher
Chris Saul

Donors, $100 – $199
Jennifer Hitt
Kentuckiana Squares Square Dance Club
Greg Fiscus
Central Presbyterian Church-Owensboro
Michael A. Gatton
for Camp
Lynnhurst United Church of Christ
Lindsay Martin
Gail Yates
for Herb Schlaughenhoupt, Jr.
Memorial Scholarship Fund

Donors, $50 – $99
Dr. Donald L. Stokes
Louisville Web Group
Stan Hankins
Robert & Shirley Gardner
for Scholarship Fund
Holly Hadley
Andrew Hartmans
Ursela Kamala
Carol Nord

Donors, Up to $49
Frontstream
Deborah Hitt
Bob Crawford
Curtis & Winnie Jacobs
Charles & Cheri Music
Richard Sloan
Delores Davis
Sadalia Sturgill
Amazon Smiles
Fr. William L. Fichteman

To All To Whom These Presents Shall Come:

WHEREAS, President Ronald Reagan declared March 1986 as Bleeding Disorders Awareness Month, which was expanded thirty years later when the U.S. Department of Health and Human Services designated March 2016 as National Bleeding Disorders Month; and

WHEREAS, The Commonwealth of Kentucky joins this effort aiming to bring together people with all inherited bleeding disorders and to raise awareness of these rare conditions and their potential health problems; and

WHEREAS, Bleeding disorders are characterized by extended bleeding after injury, surgery, trauma or menstruation, and can lead to significant harm or death if not properly treated; and

WHEREAS, Bringing awareness of these disorders will generate greater understanding of not only hemophilia but all inheritable bleeding disorders;

NOW, THEREFORE, I, ANDY BESHEAR, Governor of the Commonwealth of Kentucky, do hereby proclaim March 2020, as

BLEEDING DISORDERS AWARENESS MONTH

in Kentucky.

DONE AT THE CAPITOL, in the City of Frankfort, the 20th day of February, in the year of Our Lord Two Thousand Twenty and in the 228th year of the Commonwealth.

ANDY BESHEAR
GOVERNOR

Michael G. Adams
Michael G. Adams

Do The Five

Follow these steps to prevent or reduce complications of bleeding disorders

1. **Get an annual comprehensive checkup at a hemophilia treatment center.**
2. **Get vaccinated – Hepatitis A and B are preventable.**
3. **Treat bleeds early and adequately.**
4. **Exercise to protect your joints.**
5. **Get tested regularly for blood-borne infections.**

To find out more about the National Prevention Program developed by the National Hemophilia Foundation in collaboration with the Centers for Disease Control and Prevention (CDC), click on www.hemophilia.org or call toll-free 800-42-HANDI.

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

WHAS CRUSADE FOR CHILDREN

We are proud of our 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.

KENTUCKY HEMOPHILIA FOUNDATION
1850 Taylor Avenue #2
Louisville, KY 40213-1594

Non Profit Org.
U.S. Postage
PAID
Louisville, KY
Permit No. 883

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

248-660-7384 chris.liddell@pfizer.com

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

PP-HEM-USA-1092-01

Printed in USA/September 2018

Pfizer

KHF Event Calendar

Celebrating 60 Years of Service in 2020

Camp Discovery Announcement: Due to the Covid-19 pandemic, we will not be holding Summer Camp in the traditional way this year. Instead, we will have Camp Activities at various other events this year.

Post-Secondary Education Scholarship
Submission Deadline for Fall 2020 Semester
July 15th
Call or email KHF office for application and guidelines

Family Day at the Louisville Zoo with Camp Activities
Information, Picnic, Games for Kids & Walk Call to Action
Saturday, August 22nd
The Louisville Zoo
Louisville, KY

Play A Round for a Cure Golf Scramble Fundraiser
Monday, Monday, August 31st
Glen Oaks Country Club
Prospect, KY

Summer Family Event with Camp Activities
Annual Education Meeting, Post-Meeting Social Activity, & Walk Kick-Off Lunch
Saturday, September 12th
Hyatt Regency
Louisville, KY

Kentucky Unite for Bleeding Disorders Walk with Camp Activities
Saturday, October 10th
E. P. "Tom" Sawyer State Park
Louisville, KY

Year-End Family Event
Sunday, November 29th
Holy Trinity Clifton Campus
Louisville, KY

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]

[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.

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

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

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.

Revised: 02/2019

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

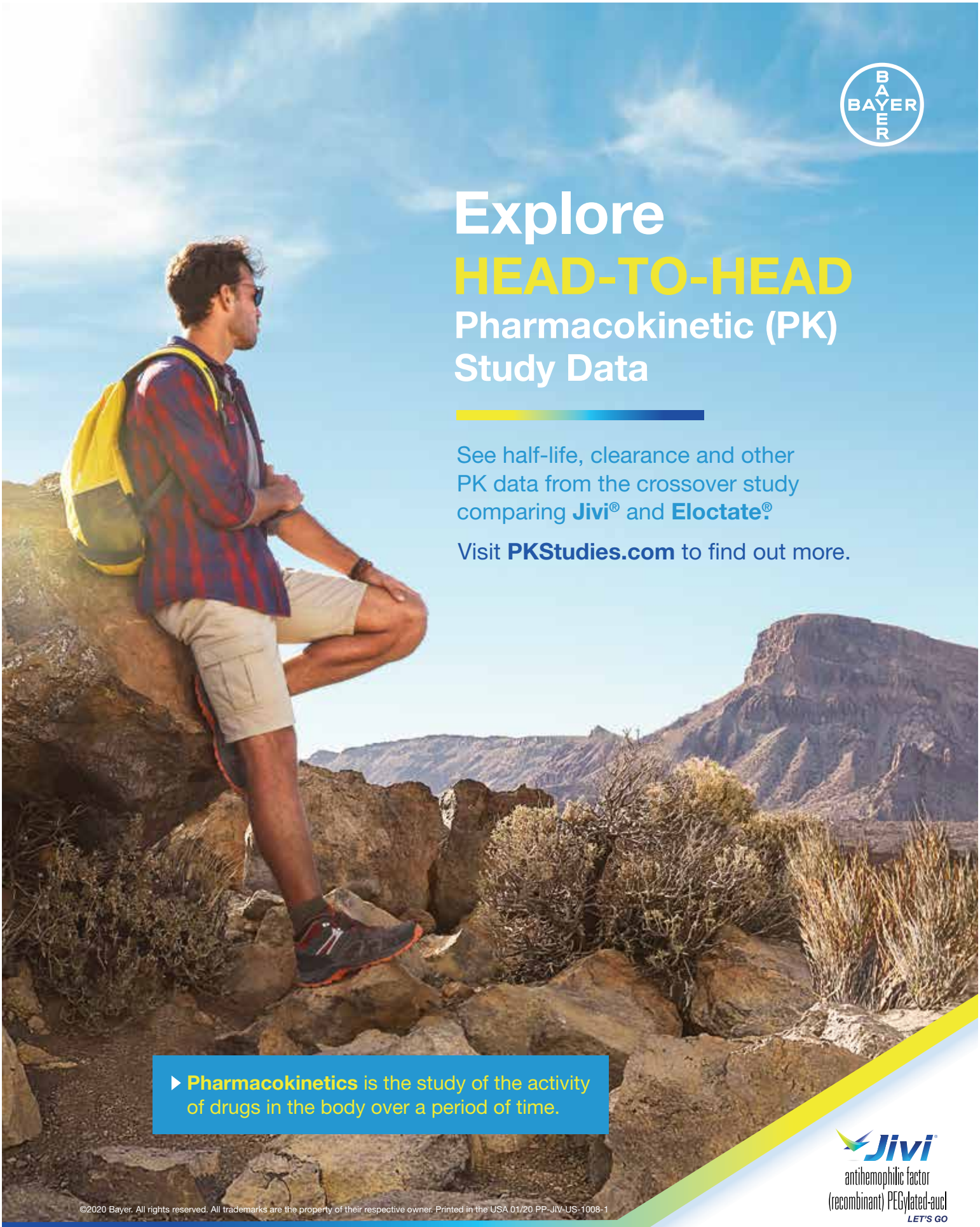
Manufactured by:
Novo Nordisk A/S
Novo Allé
DK-2880 Bagsværd, Denmark

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®



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

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
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