Winter/Spring 2019

KHF Hemosphere

Vegasville Event 2019

The 22nd Annual Vegasville Gala is remembered as a fabulous event and KHF's primary fundraiser. Nearly two hundred guests enjoyed this year's festivities at the Olmsted in Louisville.

The event featured a delightful dinner during which we honored Elijah Eke and his mother, Aisha Irvin. Elijah was one of twenty-five talented young people from across the US who were invited to participate in the production of "Hemophilia: The Musical" on Broadway in New York City.*

Elijah spoke about the empowering experience of being a cast member and the inspiring message that the musical exudes to its audience. He also talked about growing up with hemophilia, his can-do attitude and positive outlook on life, and the encouragement and confidence he has derived from participating in KHF's summer camp every year. Elijah's mother spoke of the trials and trepidations of parenting a young child with a chronic condition and the joy and pride she has felt watching her son grow up to the accomplished and talented young man he is now. Elijah is about about to graduate from high school and moving on to college. Our guests were riveted by Aisha's and Elijah's testimonials and the subsequent snippet from "Hemophilia: The Musical."

We thank the many donors for their contributions during the subsequent special-ask period. A special thank you to Mike Francis from Octapharma, who was the lead donor with a generous $1,000 donation. A very large gift basket filled with spirits, poker chips, and more fun items was donated by our Vegasville Committee for a drawing to acknowledge all donors and as a thank you to one lucky donor, who turned out to be Robert Rhea.

After dinner, some our guests proceeded to the casino games that were offered by John Silletto and friends in the West wing and dance music provided by Indigo, a wonderful local band, while others perused the large selection of alluring silent auction items in the lobby. Sean Cuzzart of Louisville won the 50/50 drawing, and Carolyn Creech of Louisville won the lovely mystic topaz necklace set in 14 kt. gold, which was donated by Mr. & Mrs. Glen Hitt, Sr. and JStaples Jewelry.

All proceeds from this event benefit the programs and services provided by the Kentucky Hemophilia Foundation to make a positive difference in the lives of more than 1,000 men, women, and children affected by lifelong bleeding disorders in our state. We thank all donors and volunteers who helped make Vegasville a success, and especially this year's table sponsors: High Roller Sponsor - Forcht Bank; Blackjack Sponsors - Bayer HealthCare, CSL Behring, Novo Nordisk, Pfizer, Republic Bank, and Takeda.

*Another teen who participated from this area was Lilly Omerso from New Albany who was not able to attend our event.

Special News

Consumer Bill of Rights and Responsibilities for Healthcare Services

Approved by NHF Board of Directors July 6, 1994

Good healthcare involves teamwork between the health-care provider and the consumer: This two-part bill should serve as a set of goals for both the provider and consumer in seeking, providing and receiving high quality health care within a setting of honesty and respect. This bill takes into account the importance of both consumer rights and responsibilities.

PART I: CONSUMER BILL OF RIGHTS

I. **THE RIGHT TO BE TREATED AT ALL TIMES WITH RESPECT AND COURTESY…**within a setting which provides the highest degree of privacy possible.

II. **THE RIGHT TO FREEDOM FROM DISCRIMINATION…**because of age, ethnicity, gender, disability, religion, sexual orientation, values and beliefs, marital status, medical condition or any other arbitrary criteria.

III. **THE RIGHT TO FULL ACCESS TO INFORMATION…**from the health-care provider about current FDA-approved or other proven treatments. Also, any biases or conflicts of interest that the health-care provider may have should be disclosed. Consumers must be advised of the risks and benefits of any proposed treatment considered to be of an experimental nature. If needed, the health-care provider should discuss alternative or complementary treatments and should be allowed to make recommendations.

IV. **THE RIGHT TO KNOW…**the identities, titles, specialties and affiliations of the care coordinator and all healthcare providers. Also, consumers have the right to know about the health care center's and health-care provider's rules and regulations.

V. **THE RIGHT TO HAVE INFORMATION SHARED IN A WAY WHICH IS EASY TO UNDERSTAND…**taking into account differences in each consumer's background, culture and preferences.

VI. **THE RIGHT TO BE INVOLVED IN AND MAKE DECISIONS ABOUT THE PLAN OF CARE…**prior to the start of and during the course of treatment. Consumers must have the right to rethink, question and change the treatment care plan at any time. Also, when possible, request for transfer to another facility or health-care provider or for a second opinion should be promptly honored and carried out.

VII. **THE RIGHT OF CHOICE AND ACCESS TO ALL NEEDED SERVICES…**including, but not confined to, referral for proper care, second opinions, physical therapy, drug trials, brand choices, home care services, counseling and peer support. Also, the consumer should not be denied, pressure, punished or left unaware of services because they are not available or adequate from the consumer's usual health-care provider or center. Third party payers should not be allowed to make treatment decisions on behalf of their consumers. These decisions must rest with the consumer and health-care provider.

VIII. **THE RIGHT TO DECLINE TO FOLLOW…**treatment plans, trials, counseling or any other service, as allowed by law, based upon the consumer's judgment of risks and benefits and without pressure or unwanted influence from the health-care provider.

IX. **THE RIGHT TO NAME AN ADVOCATE…**such as a family member or other person to support the consumer.

X. **THE RIGHT TO HAVE AN ADVANCE DIRECTIVE…**such as a living will, health care proxy or durable power of attorney for health care, and to have that directive followed within the context of existing law. Also, the consumer has a right to know, in a timely manner, any care center or health- care provider rules or preferences which may stop consumer's directives.

XI. **THE RIGHT TO INSPECT AND RECEIVE AND EXPLANATION OF HEALTH CARE BILLS OR PROPOSED CHARGES…**regardless of payment source, and to receive needed referrals and/or help with reimbursement problems.

Consumer Bill of Rights and Responsibilities for Healthcare Services

cont…

XII. **THE RIGHT TO VOICE COMPLAINTS AND SUGGEST CHANGES…**and to be informed of the process to do that within the center's/ health-care provider's chain of command for problems resolution, without interference, pressure, or reprisal. Also, the consumer has a right to receive a response in a timely manner.

XIII. **THE RIGHT TO CONFIDENTIALITY AND ACCESS TO…**all treatment records and communications to the consumer's case. Information on getting copies of records should be readily available. Copies of requested records must be furnished and at a fair cost, as allowed by law.

XIV. **THE RIGHT TO BE FREE FROM ALL TYPES OF CONSTRAINTS…**in all dealings with health-care providers and treatment plans.

XV. **THE RIGHT TO ADEQUATE PAIN MANAGEMENT…**through the application of approved and alternative treatments.

PART II: CONSUMER BILL OF RESPONSIBILITIES

I. **HEALTH CARE PROVIDERS HAVE THE RIGHT TO BE TREATED AT ALL TIMES WITH RESPECT AND COURTESY.**

II. **THE CONSUMER IS RESPONSIBLE FOR GIVING CORRECT AND COMPLETE INFORMATION TO THE CURRENT HEALTH CARE PROVIDER…**about his or her health status, and the use of other treatments, medications and health-care providers. If on home care (infusion of concentrate, use of other products, etc.) patient should periodically submit a record of product use and bleeding episodes. Consumers should come prepared to appointments with a list of any questions and concerns, so that health-care providers can have the change to address them.

III. **THE CONSUMER IS RESPONSIBLE FOR SEEKING THE FACTS AND ASKING QUESTIONS ABOUT THE RISKS, BENEFITS, AND FINANCIAL ASPECTS…**of a recommended procedure or course of treatment if he or she does not fully understand.

IV. **THE CONSUMER IS RESPONSIBLE FOR FOLLOWING THE AGREED UPON TREATMENT PLAN…**If the consumer is not following the agreed upon treatment plan at any time, including when involved in a clinical trial, he or she need to inform the health-care provider of this.

V. **CONSUMER IS RESPONSIBLE FOR THE RESULTS IF HE OR SHE CHOOSES TO ACT AGAINST MEDICAL ADVICE…**or does not follow instructions of an agreed upon treatment plan. The consumer should feel free to discuss his or her reasons for this choice.

VI. **THE CONSUMER IS RESPONSIBLE FOR KEEPING SCHEDULED APPOINTMENTS…**or canceling them in a reasonable time frame.

VII. **THE CONSUMER IS RESPONSIBLE FOR MAKING SURE THAT THE FINANCIAL BURDENS OF HIS OR HER CARE ARE ADEQUATELY ADDRESSED…**by giving correct information about payer sources, promptly submitting reimbursement forms or asking for help prior to receiving health care services.

VIII. **THE CONSUMER IS RESPONSIBLE FOR FOLLOWING RULES AND REGULATIONS…**of the health-care providers and centers involved in their care.

IX. **THE CONSUMER IS RESPONSIBLE FOR BEING THOUGHTFUL OF THE RIGHTS, PROPERTY AND CONFIDENTIALITY OF OTHERS.**

X. **THE CONSUMER IS RESPONSIBLE FOR VOICING COMPLAINTS AND ASKING FOR CHANGE…**in an appropriate and timely way, though the health-care provider's/facility's chain of command.

Event News

2019 Spring Semester Scholarship Award

The $500 Betty Meadors Mattingly Memorial Scholarship was awarded to John Rhea who is pursuing a graduate degree in Health Administration at the University of Kentucky with an impending graduation date of May 2019. John plans to work in the healthcare field and has a strong desire to focus on bleeding disorders in particular. We congratulate John on receiving a Master of Health Administration degree in the very near future and on his recent engagement to Miss Hannah Maddox. John is the son of Clark and Sally Rhea of Louisville. Scholarship applications and guidelines may be obtained from the KHF office by calling 800-582-CURE (2873) or sending an email to info@kyhemo.org. Applications for a 2019 fall scholarship award are due by July 15, 2019.

6th Annual Kentucky Advocacy Day

Bleeding Disorders Advocacy Day in Frankfort was a very impactful experience as thirty-five advocates gathered to meet with legislators on February 27, 2019. Early morning training and orientation was facilitated by James Romano from Patient Services, Inc. (PSI) and Roy Pura from CSL Behring. A surprise visit by Kollet Koulianos from the National Hemophilia Foundation (NHF) helped shed more light on the Co-Pay Accumulator issue, which was included in this year's talking points. The focus of this year's state advocacy day was the enhancement of patient access to care and treatment and the continuation of state funding for the Kentucky bleeding disorders premium assistance program. Specifically, advocates sought legislators' support for 1) Senate Bill 54 - a prior authorization reform bill, which would ease and expedite obtaining prior authorization and since then has been signed into law by Governor Bevin; 2) House Bill 374 - which would keep insurers from prohibiting third-party financial assistance for prescription drugs from being applied toward any cost sharing unless the prohibition is required to comply with federal law; and 3) Senate Bill 16 - which asked for the establishment of a rare disease advisory council and was passed as well. Individual legislative meetings were followed by the presentation of proclamations in recognition of the month of March as Bleeding Disorders Awareness Month and February 28th as Rare Disease Day. The proclamations were presented respectively to KHF and NORD by Senator Julie Raque Adams.

Among the speakers invited by NORD to address their guests in the rotunda were Laura and Isaac Webb, who aptly represented KHF. A wrap-up lunch at Serafini Restaurant concluded a productive advocacy day. The KHF Bleeding Disorders Advocacy Day is a joint program with the National Organization for Rare Diseases (NORD) and Tri-State Bleeding Disorder Foundation (TSBDF). We thank all who attended as well as our sponsors who were CSL Behring, Pfizer, Takeda, Genentech, and Novo Nordisk.

What follows is a Kentucky Bleeding Disorders Advocacy Day Press Release Submitted to Manchester Kentucky Enterprise Newspaper by KHF's Brand New Advocates, April Smith and Billie Baker

The 2019 Kentucky Bleeding Disorders Advocacy Day at our Capitol in Frankfort was attended by two local Clay County advocates, April Smith and Billie Baker. These ladies joined others from the Kentucky Hemophilia

Event News

Foundation (KHF) and the Tri-State Bleeding Disorder Foundation to meet with legislators seeking support for two bills, SB-54 and HB-374. SB-54 sets forth prior authorization reform, and HB-374 addresses the accumulator expense issue. After meeting with the legislators, the team then attended a presentation by NORD (National Organization for Rare Disorders) in the Capitol Rotunda, where Senator Julie Raque Adams presented Ursela Kamala from KHF with a proclamation signed by Governor Bevin in recognition of the month of March as Bleeding Disorders Awareness month.

Ms. Smith and Mrs. Baker were both thankful for the opportunity to join the team in advocating for the bleeding disorders community. Ms. Smith's two sons both have severe Hemophilia A, a rare inheritable blood disorder. They are missing an essential clotting protein, which can cause them to have spontaneous bleeding in their joints, muscles, and organs.

Ms. Smith and Mrs. Baker met with Senate President Robert Stivers and Senator Julian Carroll to share the issues that Ms. Smith's children, Bradley and Samuel, face daily living with Hemophilia. They also discussed how important it is that the bleeding disorders community has their support regarding the bills in question.

Washington Days

Washington Days represent the National Hemophilia Foundation's annual advocacy activity on the Hill in Washington, DC. Several hundred members of the entire US bleeding disorders community convened to advocate for their needs and concerns and those of their peers. Their collective advocacy was a very impressive and impactful event. Teams from many states, including Kentucky, met with their respective legislators to educate them about living with a bleeding disorder and related challenges. Teams focused on seeking legislative support for ensuring that the healthcare protections that are in place right now for individuals with chronic conditions would continue under any future forthcoming legislative changes regarding healthcare. Our group of five advocates from Kentucky worked hard to make a compelling and lasting impression during each meeting, telling their stories and conveying specific talking points. Our two younger advocates, Mason Stout and Isaac Webb, put forth a formidable effort and deserve special recognition. Laura Webb of Louisville recalls: *"It was such a great experience to take part in a national effort to make a positive impact on the lives of those living with bleeding disorders. Sitting side by side with legislators and their staff, discussing the insurance and healthcare concerns of the bleeding disorders community and sharing Isaac's story, gave us both a greater appreciation for how fortunate we are to live in a country where our voices are allowed to be heard."* I want to thank our entire group for advocating for Kentucky's bleeding disorders community so admirably.

Easter Lily and Spring Flowers Sale

Celebrating the onset of spring, KHF continued with its long-standing Easter Lily and Spring Flowers Fundraiser this year. We received orders from Lexington, Frankfort, Cynthiana, Lebanon Junction, Campbellsville, Columbia, Owensboro, the Louisville Metro area, and southern Indiana. Most orders are delivered to various churches and businesses in these communities. Our dedicated volunteers are the ones who facilitate and place many of the orders.

We want to thank Sharon McMahan, Sadalia Sturgill, Tina Pelly, Jenifer Schultz, Nita Wayne-Zehnder for helping us sell 700 plants with this important fundraising effort.

More News

From Food to Factor: The Road to New Therapies in Hemophilia

Wendy Owens

This is part 1 of a multi-part article. The article will continue in subsequent newsletters

Hemophilia treatment has come a long way in the past 100 years. A century ago, if you lived in Chicago, for example, you may have seen hematologist Dr. Gordon G. Burdick. At that time, Dr. Burdick approved the use of lime salts in treating hemophilia. He and other hematologists of his era also used gelatin "to increase coagulability of the blood."[1] Today, gelatin is used in all manner of jiggly desserts and to strengthen nails; lime salt (aka calcium chloride) is used in sports drinks to balance electrolytes. With the rise of the pharmaceutical industry and its scientific advancements, doctors now have many non-food-related options to treat hemophilia, and so do you.

Today, there are 31 different FDA-approved therapies on the US market for hemophilia. In addition to the FDA-approved therapies, as of this writing, there are 14 new factor therapies and three "novel" therapies, other than gene therapy, in some stage of drug development for treating hemophilia. The novel therapies use mechanisms other than factor replacement to

treat and prevent bleeds, and some can be administered subcutaneously.[2] Once approved, one of the new therapies may be right for you; but there are steps you, and others, must take for you to have ready access to them through your health insurance plan.

START WITH WHAT AND WHO YOU KNOW

If you want to use a new factor replacement product or novel therapy, talk to your hematologist to see if it's right for you. Do some research beforehand, so you're prepared for the discussion. Biopharmaceutical companies with new therapies in clinical trials, or with ones newly approved by the FDA, will have data and information on these therapies available on their websites. A heads-up: what you find on such sites will be data and information these companies legally can provide, like data from their clinical trials. These websites will not provide medical advice, but will give you a basic idea of how a treatment may work and how it performed in clinical trials.

Based on the advice of your hematologist, if you decide to switch to a new therapy, accessing it through your health insurance policy's prescription drug plan is your next step—or hurdle, in some cases. You'll need to find out if your health insurance will cover the new therapy. Remember, just because a new therapy receives FDA approval doesn't mean it's immediately available to you via your insurance plan. Your health insurer needs to be sure that any new FDA-approved therapy is safe, works as well or better than other therapies used to treat the same disease or condition, and is cost- effective. With some exceptions, health insurance companies cover a full range of—but not all currently available—FDA-approved clotting factor products for treating hemophilia. But there is no guarantee that new factor replacement products and novel therapies will enjoy the same coverage range as current clotting factor products.

According to Jennifer Luddy, director of corporate communications at Express Scripts, the largest pharmacy benefits manager (PBM) in the US, "There are a variety of agents to address the various needs of patients with hemophilia on our formulary, based on type of hemophilia, past therapy, and presence of inhibitors." But will Express Scripts and other PBMs and insurers cover new factor therapies and novel therapies once they are approved? That remains a question to be answered only by an evaluation process to which all new drugs are subjected. (to be continued…)

1. "The Medical Treatment of Hemorrhage," Medical Standard 37:1 (Jan. 1914).
2. As of this writing, the two novel therapies in clinical trials are Alnylam's fitusiran (ALN-AT3SC), an RNA interference (RNAi) therapy, in phase I/II of clinical trials; and Hemlibra® (emicizumab-kxwh), a bispecific monoclonal antibody, in phase III of clinical trials and granted priority review by the FDA for use by adults and adolescents 12 and older with hemophilia A without factor VIII inhibitors.

More News

KHF Membership

July 1, 2018 – June 30, 2019

We Give Thanks to Our Members!

Individual or Family Members, $20

Patricia Ashby
Arthur Hackman
Christi & Chad Hille
James P. Huff
Patricia Swearingen

Supporting Members, $35

Judy Hayes
in memory of Jason Hayes
Mary Marasa
Donald L. Mattingly
Charles H. Music

Patron Members, $50

Dr. David & Leslie Houvenagle
Cory W. Meadows
Travis Price
Ian & Elaine Thomas
Gail Yates

Sustaining Members, $100

Barbara W. Grayson
D. Spalding Grayson
Thomas & Alice Hendrix
Glen & Deborah Hitt
Venus & Eric Marcum
Vivian Marcum
Kathleen Nichols
Glenn & Laura Webb
Nita Wayne-Zehnder

Benefactor Members, $250

John & Lea Graham
LTC (R) John & Patricia Tharp

Champion/Corporate Members, $500

Ted & Jennifer Forcht
Terry & Marion Forcht
Rosemary Johnson-Dean
Keith & Kristin Forcht Urbahn, Benjamin and William Urbahn

In Memory

December 1, 2018 – March 31, 2019

Gone from our sight but never our memories; gone from our touch but never our hearts…

Jules Klein
Gail Yates, Janet Masterson, Myra Loeser for
Herb Schlaughenhoupt, Jr. Memorial Scholarship

Deborah "Becky" Walker
Dawson Springs Board of Education
Becky Pancake & David Kennedy

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.

Upcoming Events

Play-A-Round for a Cure Golf Scramble
Monday, June 24

Camp Discovery
Sunday, July 28 – Thursday, August 1

Summer Family Event
Saturday, August 24

Kentucky Unite for Bleeding Disorders Walk
Saturday, October 26

KOSAIR CHARITIES

COMMUNITY HEALTH CHARITIES™ KENTUCKY

WHAS CRUSADE FOR CHILDREN

KENTUCKY HEMOPHILIA FOUNDATION
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Louisville, KY 40213-1594

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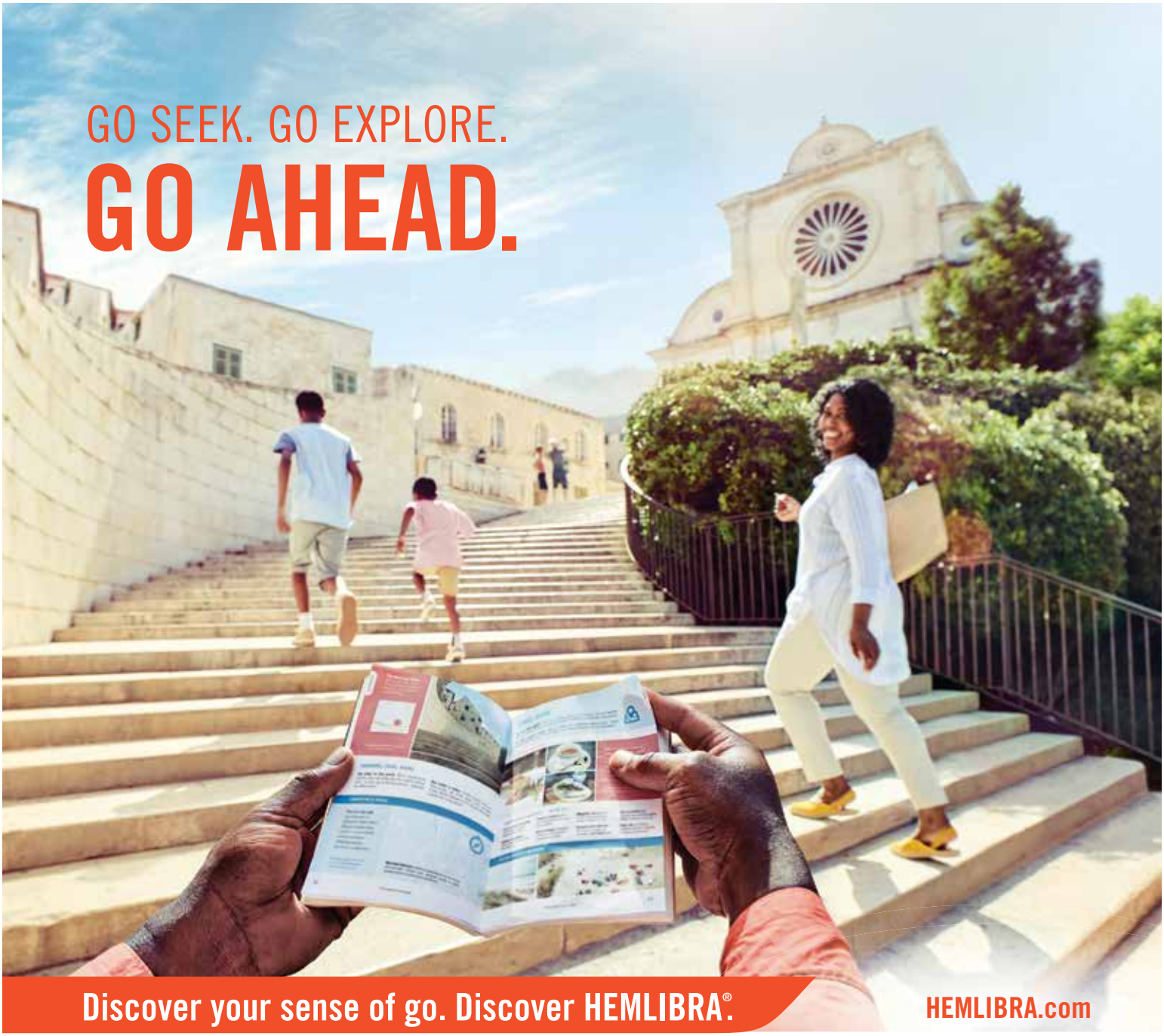

What is HEMLIBRA?

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

Genentech
A Member of the Roche Group

KHF Event Calendar

June 24

Play A Round for a Cure Golf Scramble Fundraiser
Monday, June 24, 2019
Glen Oaks Country Club
Prospect, KY
New Location!

Post-Secondary Education Scholarship
Submission Deadline for Fall 2019 Semester
July 15, 2019
Call or email KHF office for application and guidelines

July 15

July 28 – Aug. 1

Camp Discovery
(Summer Camp for Kentucky Children and Youths with Bleeding Disorders)
Sunday, July 28 - Thursday, August 1, 2019
Cedar Ridge Camp • Louisville, KY

Summer Family Event
(Annual Education Meeting, Post-Meeting Social Activity, & Walk Kick-Off Lunch)
Saturday, August 24, 2019
Hyatt Regency • Louisville, KY

Aug. 24

Oct. 26

Kentucky Unite for Bleeding Disorders Walk
Saturday, October 26, 2019
E.P. "Tom" Sawyer State Park
Louisville, KY
New Location!

Poinsettia Fundraiser
November/December 2019

Nov/ Dec

Dec. 1

Year-End Family Event
Sunday, December 1, 2019
Holy Trinity Clifton Campus • Louisville, KY