Vital Link

...For Hoosiers Living with a Bleeding Disorder

September 2019

The Vital Link is published quarterly by Hemophilia of Indiana, Inc.

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2019 Hemophilia of Indiana Annual Meeting

The 2019 Hemophilia of Indiana Annual Meeting was held August 10th and 11th at the Crowne Plaza Hotel - Indianapolis Airport. It was another record year with over 250 patients and families attending. The opening session was another incredible presentation by Dr. Amy Shapiro and Jennifer Maahs from the Indiana Hemophilia & Thrombosis Center an engaging and informative presentation and a great way to start the weekend. There was a slightly different format to the afternoon breakout sessions this year in which here were 3 - one hour sessions instead of 2 - two hour sessions. This allowed for our consumers to attend more sessions and absorb as much information as possible. Our industry partners did an incredible job and there was wide variety of topics available. Saturday ended with the Annual Awards & Recognition Dinner. During this dinner, all of our Camp Brave Eagle and 2018 Unite for Bleeding Disorders award winners are recognized as well as our 2019 Award Recipients and the 2019 Judy Moore Scholarship recipients. Hemophilia of Indiana is extremely proud to announce that The Judy Moore Scholarship awarded $30,000.00 to eleven recipients. In addition, the Ed Magoni Scholarship was added as a new scholarship and awarded $5,000.00 to 3 recipients.

2019 Volunteer of The Year Award - Lisa Swaney

2019 Distinguished Business Award - Miller Transportation

2019 Distinguished Group Award - The IHTC Social Work Team

2019 President's Award - Brittany Savage

2019 Judy Moore Scholarship Winners:

John Bontrager, Irvin Castillo, Mary Lang, Ralph Alter, Matthew Olovich, Rachel Conyer,

Easton Meyer, Kyleigh Lay, Gabriel Buening, and Jessica McCorkle

2019 Ed Magoni Scholarship Winners: Oliva Hoff, Easton Meyer, and Gabriel Buening

Sunday morning kicked off the end of the 2019 Annual Meeting with an informative general session "The Importance of Staying Insured led by Director of Finance and Business Operations for the IHTC Eric Gray, and included and a Q & A panel by the IHTC insurance coordinators. Support group breakout sessions followed the general session and ended another successful Hemophilia of Indiana Annual Meeting. Information on various support groups are available on Hemophilia of Indiana's website www.hoii.org. Planning has already begun for the 2020 Hemophilia of Indiana Annual meeting that will be held on August 7th & 8th, 2020!!

Hemophilia of Indiana would like to thank all of the sponsors for the 2019 Annual Meeting:

Title Sponsors:

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Indiana Hemophilia & Thrombosis Center

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Indiana Hemophilia & Thrombosis Center

COMPREHENSIVE BLEEDING DISORDER CARE ALL AT ONE CENTER

All members of IHTC's clinical care team have extensive experience and deep expertise in bleeding disorders. This offers our patients the comfort and convenience of having every aspect of their bleeding disorder care all in one location.

Pediatric Hematologists
Adult Hematologists
Nurse Practitioners
Physician Assistants
Nurses
Physical Therapists
Dental Hygienists
Pharmacy Team
Psychologist
Genetic Counselor
Research
Social Workers
Registered Dietician
Career & School Counselors
Patient Insurance Coordinators
Child Life Specialist






Indiana's only Center of Excellence for bleeding & clotting disorders

The state's only federally-designated Hemophilia Treatment Center and the first HTC in the U.S. to receive national medical home certification

Certified as a Medical Home by AAAHC Accreditation Association for Ambulatory Health Care, Inc.

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Anticoagulation Center of Excellence

8326 Naab Road · Indianapolis, IN 46260 · 317.871.0000 · www.ihtc.org

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. HEMLIBRA may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

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

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

Medication Guide
HEMLIBRA® (hem-lee-bruh)
(emicizumab-kxwh)
injection, for subcutaneous use

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
  - confusion
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - stomach (abdomen) or back pain
  - nausea or vomiting
  - feeling sick
  - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - swelling in arms or legs
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - trouble seeing

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

See "**What are the possible side effects of HEMLIBRA?**" for more information about side effects.

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I use HEMLIBRA?

See the detailed "Instructions for Use" that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.
- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. **Do not** give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

What are the possible side effects of HEMLIBRA?

- See "**What is the most important information I should know about HEMLIBRA?**"

The most common side effects of HEMLIBRA include:

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 86°F (30°C).
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

Keep HEMLIBRA and all medicines out of the reach of children.

General information about the safe and effective use of HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048

For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised : 10/2018

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

Genentech
A Member of the Roche Group

HEMOPHILIA OF INDIANA

Unite for Bleeding Disorders

SAVE THE DATE!

Participate. Volunteer. Donate.

Date: Saturday, October 19, 2019
Registration Check-In Time: 9:00am
Walk Start Time: 10:30am
Distance: 3 miles & 1 mile routes
Location: Fort Harrison State Park
Address: 6000 N. Post Rd., Indianapolis, IN 46216

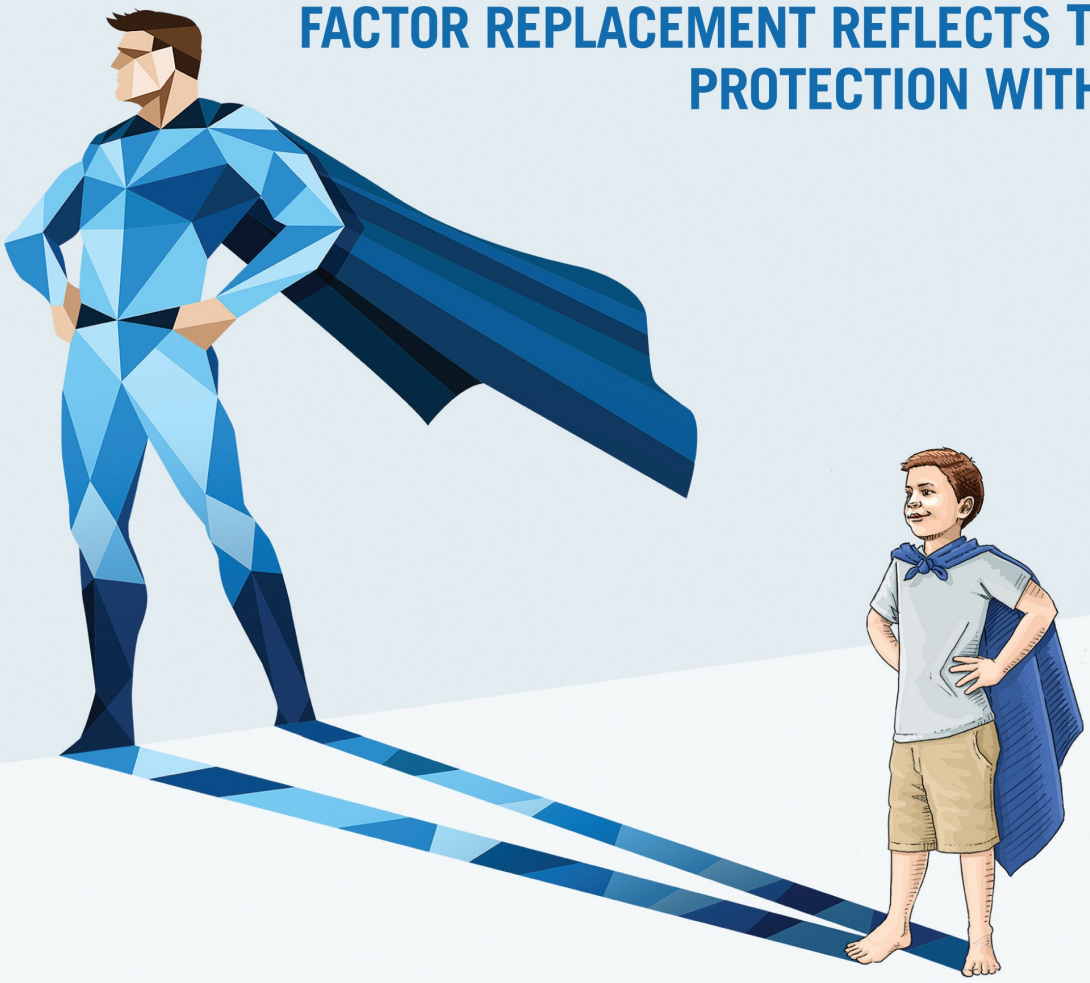
Join us to support the Unite for Bleeding Disorders Walk! We will walk to raise critical FUNDS and AWARENESS for the bleeding disorders community. Your support is greatly appreciated! There will be exhibit booths, a Kid's Zone, and fun for the whole family!

To register, go to **www.hemophilia.org/walk**, select IN-Indianapolis, click "Create a Team" or "Join a Team."

CONTACT US

For more information, please visit **www.hemophilia.org/walk** or contact: Kristy McConnell, Local Walk Manager, at 317-570-0039 or **kmcconnell@hoii.org**

FACTOR REPLACEMENT REFLECTS THE PROTECTION WITHIN



For people with hemophilia, Factor treatment temporarily replaces what's missing.[1,2] *With a long track record of proven results, Factor treatment works with your body's natural blood clotting process to form a proper clot.*[2-6]

Brought to you by Takeda, dedicated to pursuing advancements in hemophilia for more than 70 years.[7]

Stay empowered by the possibilities.

References: 1. Peyvandi F, Garagiola I, Young G. The past and future of haemophilia: diagnosis, treatments, and its complications. *Lancet.* 2016;388:187-197. **2.** Canadian Hemophilia Society. Factor replacement therapy. http://www.hemophilia.ca/en/bleeding-disorders/hemophilia-a-and-b/the-treatment-of-hemophilia/factor-replacement-therapy/. Accessed May 18, 2018. **3.** Franchini M, Mannucci PM. The history of hemophilia. *Semin Thromb Hemost.* 2014;40:571-576. **4.** Hvas AM, Sørensen HT, Norengaard L, Christiansen K, Ingerslev J, Sørensen B. Tranexamic acid combined with recombinant factor VIII increases clot resistance to accelerated fibrinolysis in severe hemophilia A. *J Thromb Haemost.* 2007;5:2408-2414. **5.** Antovic A, Mikovic D, Elezovic I, Zabczyk M, Hutenby K, Antovic JP. Improvement of fibrin clot structure after factor VIII injection in haemophilia A patients treated on demand. *Thromb Haemost.* 2014;111(4):656-661. **6.** Berg JM, Tymoczko JL, Stryer L. Many enzymes are activated by specific proteolytic cleavage. In: *Biochemistry.* 5th ed. New York, NY: WH Freeman; 2002. https://www.ncbi.nlm.nih.gov/books/NBK22589/. Accessed May 18, 2018. **7.** Shire. Shire's 70+ year commitment to the hemophilia community. https://www.shire.com/en/newsroom/2018/january/7sossj. Accessed June 6, 2018.

Takeda

Publication: PEN 8.19
Column: As I See It

On Time Can Be Too Late

Michael Joshua

I have hemophilia, but it doesn't have me. And it won't hold me back as I prepare to head off to college in August.

On time can be too late when preparing to transition from high school to college. Because I have a diagnosis of severe hemophilia B, my mother always started preparing for the next school year before the end of the current school year. During that time she would meet with the school nurse or administrative staff for a medical packet and to schedule an in-service if necessary. My mom always told me that my medical history is my personal business, and it's up to me to decide to share with others. However, it's very important that I inform those who need to know about my hemophilia and educate them on what's necessary in case I require medical attention and assistance.

Waiting until you graduate from high school is too late to prepare for college. When you grow up with a bleeding disorder, you learn that your normal is different from the normal of people without a bleeding disorder. I researched and determined which schools were the best options for me to attend. After campus visits, I began the application process and was able to discuss my medical needs with an admissions counselor. By October, I had submitted an application for early action admission and completed the FAFSA (Free Application for Federal Student Aid). Immediately after receiving acceptance in November, I reached out to an accessibility counselor at the Office of Accessible Education to discuss available resources and what I will need to manage my disorder. I got the necessary paperwork via email, and had it in hand to present to the hematologist during my six-month visit to the hemophilia treatment center. During this visit, I was able to get my hematologist involved and discuss what I will need to move out on my own and have access to care. In January I also met with a rehabilitation counselor at the Office of Workforce Development Rehabilitation Services regarding available resources for college.

In February I attended the admitted student visit. Not only did I participate in the activities scheduled, I also took the time to personally meet the counselor at the Office of Accessible Education. Among other accommodations, it was confirmed that I would receive a private dormitory room with no additional cost. Next, I familiarized myself with the location of Student Health Services, and met the staff there. I informed the nurse about my treatment schedule and learned about their

hours, their services, and campus emergency numbers. Because factor is shipped by motorized delivery service and not by the US Postal Service, there is a specific process that has to be followed in order for the package to be received.

When preparing to transition from high school to college, it's very important to plan ahead, be assertive, know available resources, and establish a support network. Although it didn't take a long time to navigate this situation, if I had waited until orientation, after move-in, then the time of a shipment or an emergency would not have been the best moment to learn. A new chapter of my life begins this August, but I am ready and not afraid of the challenge. I have always challenged the limits rather than limiting the challenges. As Malcolm X once said, "The future belongs to those who prepare for it today."

Michael is set to graduate from Baton Rouge Magnet High School in 2019, with plans to study political science and English at Loyola University in New Orleans in the fall. He aspires to practice law or become a sports analyst. Michael has a strong passion for helping others and enjoys spending time with family and friends, volunteering in the community, watching sports, and participating in competitive swimming and weight lifting.

#THXRUN

Come and get a healthy head start on your Thanksgiving Day feast by joining us for the Fit Livin' ThanksGivin' Day Run!

Thursday, November 28, 2019!

This run not only benefits you and your appetite, but also supports **Hemophilia of Indiana (HoII)**. HoII is a 501c3 non-profit organization, that **serves over 1,400 Indiana patients and families affected by hemophilia and other bleeding disorders**. Proceeds from the event will support HoII's vital programs and services. Gather your family, friends, and come get some exercise and support a great cause! Each registered runner or walker will receive a finishing medal!

- **Race location:** Start/Finish at Dillon Park (146th and Hazel Dell behind Kroger) and scenic course through the beautiful **Lochaven** neighborhood.

· 4 Mile Run/Walk at 9:00am
$35.00 Registration (through 10/29)
$40.00 Onsite Registration November 11/27

· Kids 200 Yard Fun Run at 8:45am
» Free Registration (through 11/27)
***Kid's Race**: Every child will receive a medal for participating.

****NEW TO THIS YEAR LONG SLEEVE PERFORMANCE TEE'S W/A HOOD!!****

Awards: 1st, 2nd, & 3rd place male/female
Costume Prizes: 1st male/female - Turkey/ Pilgrim/Indian
Pumpkin Prizes: There will be 10 pumpkins throughout the course. Whoever carries a pumpkin over the finish line will receive a prize.

Upcoming Educational Dinners:

Contact Angel Couch at acouch@hoii.org to register.
Check out our Facebook (@HEMOINDY) page and website for details on educational dinners!

Indianapolis, IN
Topic: **"Spotlight on Unaffected Siblings"**
When: **Tuesday, October 15th**
Time: **6:00pm**
Where: **Restaurant to be determined**

Bloomington, IN
Topic: **Topic to be determined**
When: **Tuesday, November 5th**
Time: **6:00pm**
Where: **Restaurant to be determined**

Updates to the Educational Dinners will be posted to our Social Media Sites and Website Calendar!

HEMOPHILIA OF INDIANA

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www.hoii.org
(317) 570-0039

*The material provided in Vital Link is only for general information purposes. HoII does not give medical advice or engage in the practice of medicine. HoII recommends in all cases that you consult your physician or HTC before pursuing any course of treatment.

Mark your Calendars!

Here are some of our upcoming events…

- Unite for Bleeding Disorders Walk - October 19, 2019
- Fit Livin' Thanksgivin' Day Run - November 28, 2019
- Year End Educational Event - December 7, 2019

Call our office @ (317) 570-0039 or email Kristy McConnell @ kmcconnell@hoii.org if you would like to get involved in any of our events!