# Vital Link

## ...For Hoosiers Living with a Bleeding Disorder

March 2018

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

Designed by: Kristy McConnell



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## Washington Days

On March 7th-9th, Hemophilia of Indiana, Indiana Hemophilia and Thrombosis Center and several Indiana Community members attended Washington Days in Washington D.C.. Washington Days is hosted by the National Hemophilia Foundation and over 48 states were represented accounting for more than 500 individual bleeding disorder advocates. The Indiana Team was excited for the opportunity to meet with 7 of Indiana's U.S. Representatives and Senators. The meetings focused on issues relating to the Affordable Care Act, including support for Essential Health Benefits, continued support for pre-existing conditions, and continued ban on lifetime policy caps. Additionally, we were able to discuss the importance of 340B funding for Treatment Centers and encouraged continued support for the CDC and HRSA grant. Most importantly, Washington Days allows our Community members to share their story with our Policy makers on "The Hill".


## A Legend Leaves Us

The hemophilia community has struggled to comprehend that Barry Haarde, arguably the most popular and recognizable person with hemophilia in America, passed away unexpectedly on Saturday, February 17. His passing has devastated our community, which watched his lanky figure on his Cervélo cycle across America six times over the years. He was a steady fixture at regular hemophilia events, giving motivation to groups from Alaska to Florida, often with his bike by his side.

Barry was only 52, and spent much of his life actually avoiding the hemophilia community. Diagnosed at age 19 with HIV, he withdrew socially, instead throwing his talent, time and energy into music. Barry was a professional trombone player in the Tommy Dorsey band, and others, and traveled the world. Jazz was his specialty, though he enjoyed a broad spectrum of music. He loved Jimmy Buffet and was a "parrothead"!

His brother John had hemophilia, as did his brother-in-law Pat. In time, Pat was diagnosed with HIV and passed away. Then 17 years later, John passed away. As these losses mounted, Barry came out of his emotional wilderness, and connected with the hemophilia community—in a huge way. Barry was special; nothing about him was trite, insincere or superficial. Everything he did had purpose. He reconnected with the community—and proceeded in a short time to become the most famous person with hemophilia in America.

He loved the work we did overseas in developing countries and decided to do something to help others who suffered, as he knew what suffering truly was. He proposed to ride across America in 2012, to raise funds for **Save One Life**, the child sponsor program I founded. We called it "Wheels for the World." Three thousand plus miles later, he dipped his wheel in the Atlantic Ocean at Rye Beach, New Hampshire, and a legend was born. The community took notice of this gentle giant of a man, with a contracted knee, who seemed to come out of nowhere to take center stage and show what was possible.

The next year, he proposed another ride; then another, then another! In total, six rides throughout the US (including Alaska, his final one), with over 20,000 miles logged. He knew I loved the band the Doors, and named his bike "The Coffin Dodger," after a song by Robby Kreiger (guitarist for the Doors) from his new album and band.

Barry had overcome so much in his life: so much pain, so much loss. Two years ago his beloved mother, Emily, died at age 86. They shared a love of music. Then Barry lost his job with Hewlett Packard, after the hurricane flooded Houston last year. His health took a downturn. A person's body can only take so much.

Barry, in just six years, touched so many lives through his humble, quiet persona in person, and his raging athleticism on the road. People were in awe of him. He became a symbol of the possible, of hope, or resilience. And that's what we want to remember. This incredible man who put aside his personal pain to serve others. His rides raised over $250,000 to help those in poverty overseas. That's a life well lived.


Barry will be remembered at a memorial service on March 3, in The Woodlands, Texas, where he lived. In lieu of flowers, the family asks that you make a contribution to **Save One Life** in Barry's name, a name which goes down in history.

*I would rather that my spark should burn out in a brilliant blaze than it should be stifled by dry-rot.*
*I would rather be a superb meteor, every atom of me in magnificent glow, than a sleepy and permanent planet.*
*The function of man is to live, not to exist.*
*I shall not waste my days trying to prolong them.*
*I shall use my time.*

Attributed to Jack London


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For over 60 years we have been inspired by people like you. Shire is the relentless champion that supports you with pioneering products and programs, while always striving toward our ultimate goal: a life full of dreams and free of bleeds.
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# Hearts for Hemophilia Gala "Mad Hatter's Ball"

The 28th Annual Hearts for Hemophilia "Mad Hatter's Ball" was held Friday, February 9th at the Historic Union Station Grand Ballroom at the Crowne Plaza Hotel Downtown Indianapolis. The theme for the Gala was "Mad Hatter's Ball" with guests wearing their favorite "Mad Hats"! The event included dinner, a live and silent auction, a casino, and dancing to the music of Stella Luna and the Satellites! The special guest speaker this year was Zachary Crabtree. Zach is a member of Indiana's bleeding disorders community and is currently a senior at Indiana University and will be starting medical school this fall at Marion University. Zach did an incredible job telling "his story" and giving the guests a glimpse into the life of a person living with a bleeding disorders. All proceeds from the Gala benefit the many programs and services offered by Hemophilia of Indiana to the bleeding disorders community. These programs include emergency financial assistance, educational programs, MedicAlert ID program, Camp Brave Eagle, and the Doug Thompson Teen Leadership Camp. Hemophilia of Indiana would like to thank our title sponsors the Indiana Hemophilia & Thrombosis Center and Shire. Other sponsors include Bayer Healthcare, Cook Medical, Katz Sapper & Miller, Jason Flora Law Office, General Hotels Corporation, Novo Nordisk, Tharp Investments, Pfizer, CSL Behring, Genentech, Waypoint Global, and Republic National Distributing Company. Mark your calendar for next year's Hearts for Hemophilia Gala to be held February 8th, 2019!

HEMOPHILIA OF INDIANA

# Bowling for Bleeding Disorders

**When: April 15, 2018 from 11am-2pm**
**Where: Pinheads (13825 Britton Park Rd, Fishers, IN 46038)**
**What: Educational program and bowling event raising $$ for Hemophilia of Indiana's Judy Moore Scholarship Program**

## HOW TO GET INVOLVED:

#1) Register to attend the Bowling for Bleeding Disorders Educational Program online at www.hoii.org/events/bowling
(Program includes education program and pizza lunch)

#2) Form your team (up to 5) and ask friends/family/coworkers to support you and your team! Donations can be made by credit card at www.hoii.org/donate or cash or check to be collected day of event! No amount is too little!

*All donations are tax deductible!
*All participant must be registered!
***Registration deadline Thursday, April 7th!**
*Contact Kristy McConnell @ kmcconnell@hoii.org or (317) 570-0039 with any questions!

**Presenting Sponsor:**

INDIANA HEMOPHILIA & THROMBOSIS CENTER, INC.

# Upcoming Educational Dinners:

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

**Southern Indiana:**
**Topic:** **Constructive Conversations by Pfizer**
**When:** March 20th, 2018
**Time:** 6:00pm
**Where:** **Zaharakos**
**329 Washington St**
**Columbus, IN 47201**

**Central Indiana:**
**Topic:** **Talk About Hemophilia-How It Can Help**
**When:** April 5th, 2018
**Time:** 6:00pm
**Where:** **The North End BBQ**
**1250 E 86th St**
**Indianapolis, IN 46240**

**Northern Indiana:**
**Topic:** **The Journey of Factor**
**When:** April 17th, 2018
**Time:** 6:00pm
**Where:** **Essenhaus Inn & Conference Center**
**240 US-20**
**Middlebury, IN 46540**

INDIANA HEMOPHILIA & THROMBOSIS CENTER, INC.

# The Best Outcomes for You and Your Family

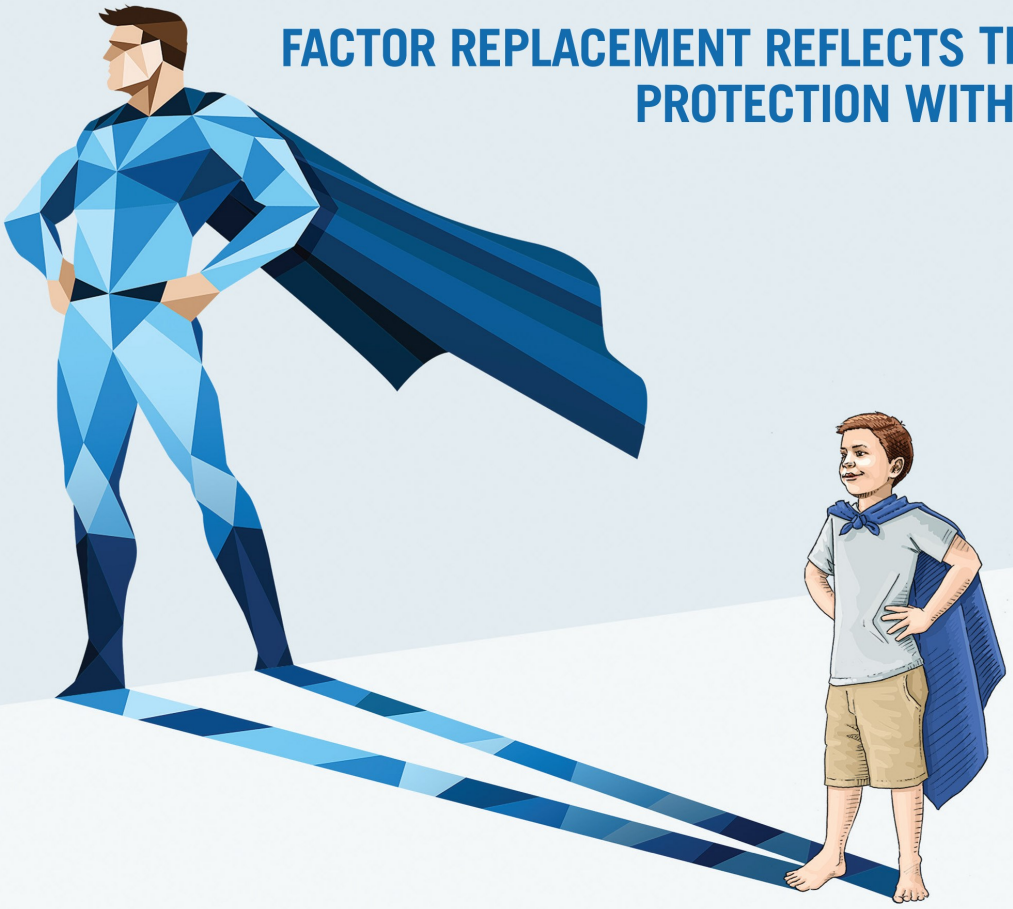
## *Indiana's only Center of Excellence in bleeding disorders*

- Comprehensive clinics with our expert multidisciplinary team
- Integrated pharmacy program accessible 24/7
- Nationally renowned for the treatment of bleeding and clotting disorders
- First HTC to receive Medical Home certification (AAAHC)
- Free CME education and 24 hours, 7 days a week consultative services for providers throughout the state
- Outreach clinics across Indiana, education and training for families
- Research to advance care and provide savings to patients and families

***For more information, please contact us at 317.871.0000***

To contact our Pharmacy, please call 317.829.7778

*Visit us online at www.ihtc.org and www.facebook.com/IndianaHemophilia*



# FACTOR REPLACEMENT REFLECTS THE PROTECTION WITHIN

*For people with hemophilia, Factor treatment temporarily replaces what's missing.[1] With a long track record of proven results, Factor treatment works with your body's natural blood clotting process to form a proper clot.[2,3]*

*Brought to you by Shire, dedicated to pursuing advancements in hemophilia for more than 60 years.*

## 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.** Wolberg AS. Plasma and cellular contributions to fibrin network formation, structure and stability. *Haemophilia.* 2010;16(suppl 3):7-12. **3.** King MW. Introduction to blood coagulation. http://themedicalbiochemistrypage.org/blood-coagulation.php. Last modified January 2, 2017. Accessed January 2, 2017.



Shire

Publication: PEN 2.18
Column: YOU **Sponsored by Shire**

# SMART Women

Jessica O'Donnell

From personal to professional, the women profiled here turned their connections to hemophilia into real, life-changing achievements. While many of us set out to complete a task, we may not label it as a goal or plot out a deliberate path to achieve it. But each of these women had a vision, implemented a plan, and plotted a path to reach her goal.

Each woman's strategy was unique, but all the goals had something in common: they were all SMART goals. SMART goals are specific, measurable, accountable, realistic, and time-bound. Learn how Mischante, Angelie, Darlene, and Christy
and Elise worked hard to get results.

## A Better Future for Her Family

After Mischante Cortez's son, Adam, was diagnosed with hemophilia in 2006, Mischante decided to set a goal: to become a registered nurse to better advocate for Adam's healthcare needs. It wasn't easy. Pregnant at age 16, Mischante had dropped out of high school. So before starting her nursing program, she needed to obtain a GED and enroll in community college. After receiving her GED and being accepted into a nursing program, Mischante divided her goal into smaller, specific steps.

But her path wasn't without obstacles. While enrolled in the nursing program, Mischante was often left with no choice but to bring her three young children to school with her because she lacked childcare. Despite the setbacks, Mischante persevered. "I continued to strive toward my goal to be a nurse while raising three kids alone and working full-time as a certified nurse's assistant [CNA]. In May 2010, I graduated from college with my nursing degree. It was the best decision I ever made for my family."

Today, Mischante supports her family as a working nurse and single mother. "I am Adam's number-one advocate, and I get to heal people for a living. I am so grateful that Adam's diagnosis of hemophilia was exactly what I needed to get into gear."

## A Son's Diagnosis Prompts a Family Goal

When Angelie Garcia's son Zayden was diagnosed with hemophilia, Angelie recognized that he was unhappy while being infused with factor. So she told her husband, "Once we're taught by home nurses, within two weeks we will start involving Zayden." Then Angelie set a goal to have Zayden take an active role in the infusion process within one year.

Angelie and her husband divided their goal into small, attainable steps: the first was to make sure Zayden wouldn't be afraid of infusions.

On their path to achieving their goal, the family's largest setback was their location. "Our hometown hospitals need education on hemophilia," explains Angelie. "I'm the only one here that can infuse my son, and it terrifies me because they don't know about his condition and we are three hours away from our HTC [hemophilia treatment center]." Angelie learned very quickly that she had to be Zayden's primary advocate for his hemophilia care. Teaching him to help in the infusion process empowered Zayden, now four years old, to be more aware

of his condition. His proud mom says, "He is learning ab-out his condition and will tell you what he can and can't do."

## Lobbying for Specialized Emergency Treatment

Darlene Shelton founded Danny's Dose Alliance after her ten-month-old grandson was diagnosed with hemophilia. Although Danny always had his factor with him wherever he went, Darlene's family learned that paramedics and ER workers were not allowed to administer the factor due to conflicting treatment protocols and liability fears. So Darlene sprang to action and formed Danny's Dose with these goals in mind: (1) Raise awareness about the current gap in emergency treatment for people with rare diseases, chronic illnesses, and special medical needs; and see current protocols amended. (2) Assist with specialized education for EMS and ER personnel. (3) Provide education for affected families on how to better advocate for their treatment needs.

The organization's first goal was to amend protocols in the Sheltons' home state of Missouri within two years. Darlene says, "Goals can be lofty, but I believe if you don't set goals high, it removes some of the urgency." After their proposed legislation was passed in Missouri, Darlene looked forward to their next goal. "We passed EMS legislation, assisted with the beginning of paramedic education, and are helping that grow in 2018 and beyond. Of course, we can't be sure we will meet our five-year goal, but it looks promising, and we are determined to push hard." Darlene hopes to have improved treatment protocols for ER and EMS in place across the entire US within five years of their first state, Missouri.

The work of Danny's Dose doesn't just benefit people with hemophilia. "It benefits all individuals with special medical needs," says Darlene, "covering rare disease and chronic illness. This covers those with rare, lifesaving meds, those with particular treatments based on their illness, and those with complex medical devices like trachs and heart-pumps."

## Never Too Early to Start!

It's never too early to start teaching our children the importance of setting goals and achieving them.

Christy VanBibber's eight-year-old daughter Elise was disappointed by her neighborhood's lack of knowledge and awareness of hemophilia. When Elise began sharing the news about her baby brother Timothy, who has hemophilia, she realized that many people didn't know what hemophilia was. "She came home with a real concern," Christy notes, "and asked, 'Mom, why does nobody know what hemophilia is?'"

Elise made it her goal to generate awareness in her community about hemophilia—by making and selling beaded bracelets and then donating all proceeds to the Southwestern Ohio Hemophilia Foundation.

Christy recounts the initial success: "She made some bracelets and asked me to put them on Facebook. We decided to sell them for $3 each. Immediately she sold ten!" Elise went on to sell her bracelets at two local farmers' markets and local football games.

Christy was thrilled. "She raised $880! Also, people recognize Elise and Timothy at school and the grocery store, asking questions and praising her for such a great job. We are really proud of her!"

All these women—and one young girl—achieved their goals fueled by close-to-home, real-life concerns, and you can too! If you want to learn how you can reach your goals this year, check out our cover story and find out how to make your goals SMART.

# Now Approved

**A ONCE-WEEKLY SUBCUTANEOUS (GIVEN UNDER THE SKIN) INJECTION FOR PEOPLE WITH HEMOPHILIA A WITH FACTOR VIII INHIBITORS**

We extend our appreciation to the individuals, families, and healthcare providers who participated in the clinical trials that led to the approval of HEMLIBRA®. We thank you and celebrate with the community who made it a reality.

Discover **HEMLIBRA.com**

## 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 with hemophilia A with factor VIII inhibitors.

## WHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT HEMLIBRA?

**HEMLIBRA increases the potential for your blood to clot. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use. HEMLIBRA may cause the following serious side effects when used with 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 signs and symptoms of TMA during or after treatment with HEMLIBRA.
- **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 the signs or symptoms of blood clots during or after treatment with HEMLIBRA.

**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.**

HEMLIBRA™

emicizumab-kxwh

injection for subcutaneous use

150 mg/mL

## 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.**

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 OTHER POSSIBLE SIDE EFFECTS OF HEMLIBRA?

**The most common side effects of HEMLIBRA include:** redness, tenderness, warmth, or itching at the site of injection; headache; and joint pain. These are not all of the possible side effects of HEMLIBRA.

You may report side effects to the FDA at (800) FDA-1088 or www.fda.gov/medwatch. You may also report side effects to Genentech at (888) 835-2555.

Please see Brief Summary of Medication Guide on the following page for more important safety information, including **Serious Side Effects**.

## Medication Guide Brief Summary
## 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. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use. HEMLIBRA may cause the following serious side effects when used with 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 with hemophilia A with 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.
- 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.
- 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 before the next scheduled dosing day and then continue with your normal weekly dosing schedule. Do not double your dose 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 7 days at 86°F (30°C) or below.
- 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

**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
Issued: 11/2017

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



Genentech
*A Member of the Roche Group*

# SAVE THE DATE!

HEMOPHILIA OF INDIANA

**2018 Annual Meeting**

August 11th & August 12th

Crowne Plaza - Indianapolis Airport

2501 South High School Road
Indianapolis, IN 46241

HEMOPHILIA OF INDIANA

6910 N. Shadeland Ave., Suite 140
Indianapolis, IN 46220
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…

- Bowling for Bleeding Orders, April 15th, 2018
- World Hemophilia Day, April 17th, 2018
- Polo at Sunset, July 13th, 2018
- Camp Brave Eagle, June 10th-15th, 2018
- 2018 Annual Meeting, August 11th & 12th, 2018

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!

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