

Vital Link

HEMOPHILIA
OF INDIANA

...For Hoosiers Living with a Bleeding Disorder

April 2020

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

Designed by: Kristy McConnell

Board of Directors

President

Joseph McKamey

Vice President

Jason Flora

Treasurer

Jeffrey Warner

Secretary

Melissa Breedlove

Directors

Greg Kil

Matt Shade

Corey McSweeney

Legal Counsel

Bryce H. Bennett, Jr.

Staff

Scott Ehnes

Executive Director

Kristy McConnell

Development and Event
Director

Angel Couch

Community Outreach
Coordinator

Hemophilia of Indiana

6910 N. Shadeland Ave.

Suite 140

Indianapolis, IN 46220

(317) 570-0039

(800) 241-2873

www.hoii.org

Washington Days 2020

Hemophilia of Indiana, Indiana Hemophilia & Thrombosis Center and several members of Indiana's bleeding disorders community were proud to participate in this year's Washington Days in Washington D.C. Washing Days, hosted by the National Hemophilia Foundation, had over 450 representatives and 48 states advocating on behalf of the bleeding disorders community. The Indiana team was excited to meet with the staff of various U.S. Representatives and Senators to advocate and tell "our stories". The bleeding disorders community asks all Members of Congress to support policies that ensure access to comprehensive insurance and health care services that are needed for healthy and productive lives. There were two major "asks" for the this year's Washington Day's meetings. These "asks" were to support federal hemophilia programs at CDC, HRSA, and NIH that support the bleeding disorders community. HRSA Maternal and Child Health Bureau Hemophilia Program provides funding to hemophilia treatment centers and allows participation in the 340B Program and support of comprehensive care services. The second ask was for support of the Hemophilia SNF Access Act (S.3233 and HR5952). People with bleeding disorders may need access to skilled nursing facilities (SNFs) after a hospitalization related to surgery for joint disease or a co-morbidity like HIV or hepatitis. Post hospital a SNF may be the best setting for the patient to fully recover before returning home. Skilled Nursing Facilities typically won't accept Medicare beneficiaries with bleeding disorders because the daily payment rate isn't high enough to cover the specific treatment costs associated with a bleeding disorder patient. If a bleeding disorder patient does not have access to a SNF it results in a longer hospital stay costing Medicare and taxpayers more money. This Act allows SNFs to bill Medicare the treatment costs associated with a bleeding disorder separately (similar to chemotherapy treatment). This change to the Medicare law will allow people with bleeding disorders to receive the care in SNFs, often the most medically-appropriate rehabilitative setting. The Act has been sponsored in both the House of Representatives and the Senate. The bleeding disorder community needs everyone help in getting the Hemophilia SNF Access Act passed! Contact your member of Congress and our Indiana Senators today!





Your Voice. Your Life.



DOWNLOAD OR VIEW BOOKS
filled with patient stories that can inspire, empower, and educate



LISTEN TO PODCASTS
that capture the voices of the hemophilia B community



VIEW VIDEOS
that feature members of the community sharing their personal experiences

Interested in stories and personal experiences from the hemophilia B community for the hemophilia B community? *Turn to B2B.*

Topics include:



EDUCATING YOUR CHILD'S SCHOOL
about hemophilia B



HEMO 101 for caregivers



MANAGING RELATIONSHIPS
with hemophilia B



LIFE FOR GIRLS AND WOMEN
with hemophilia B

Visit hemophiliavillage.com to check out all that B2B has to offer

HICKORY HALL
POLO CLUB

PRESENTED BY:



FIT LIVIN'

BENEFITING:

**HEMOPHILIA
OF INDIANA**

**FRIDAY,
JULY 10, 2020**

FOR TICKETS AND MORE INFO:

WWW.HOII.ORG/EVENTS/POLO

OR CONTACT KRISTY MCCONNELL AT (317) 570-0039 OR KMCCONNELL@HOII.ORG

ONLY \$20 PER CAR : SPONSORSHIPS AVAILABLE : FAMILY FRIENDLY : TAILGATING



**HEMOPHILIA
OF INDIANA**

2020 Annual Meeting

August 29th & 30th, 2020



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



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

2020 Hearts for Hemophilia “Golden” Gala: A Time of Remembrance

The 2020 Hearts for Hemophilia “Golden” Gala: A Time of Remembrance was held on Friday, February 7th at the Historic Grand Hall of the Crowne Plaza Hotel in downtown Indianapolis. This was a very special year for the Gala. This year’s theme was A Time of Remembrance in that we were honored to have Jeanne White-Ginder as our keynote speaker and celebrated the life and legacy of Ryan White. This year also marked the 30th Anniversary of the initial passing of the historic Ryan White CARE Act. Jeanne White-Ginder’s keynote speech was not just inspirational, but helped remind us how far treatment and care has come for those affected with a bleeding disorder as well as HIV. Hemophilia of Indiana would like to thank all those who attended and donated at the event helping support the many programs and services provided to the bleeding disorders community throughout the State of Indiana. A huge thank you to all of the event and table sponsors which allowed the opportunity to hold such a successful event! Check out more pictures on our Facebook page (@hemoindy)!



GO SEEK. GO EXPLORE.
GO AHEAD.

PEOPLE LIKE YOU. STORIES LIKE YOURS.
Explore more at HEMLIBRAjourney.com



Discover your sense of go. Discover HEMLIBRA®.

What is HEMLIBRA?

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

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

HEMLIBRA increases the potential for your blood to clot. 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**.



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

HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan
©2018 Genentech, Inc. All rights reserved.

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



© 2019 Genentech USA, Inc. All rights reserved. EMI/061818/0106a(2)
HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan.
The HEMLIBRA logo is a trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan.
The Genentech logo is a registered trademark of Genentech, Inc.
All other trademarks are the property of their respective owners.

Genentech
A Member of the Roche Group

©LA Kelley Communications, Inc. www.kelleycom.com
Reprinted with permission.

Publication: PEN 2.20

Column: YOU, *sponsored by Takeda*

Leadership Redefined

Laurie Kelley

The bleeding disorder community is filled with admirable leaders. Though I often say that no one is a born leader, leadership can be birthed. In our community, leadership arose from the cataclysmic devastation when HIV was discovered in the blood supply in the 1980s and infected about half of our community. This horrific event birthed many leaders, whose legacies stand today.

When we think of those leaders—like Corey Dubin, Dana Kuhn, Val Bias, Jeanne White-Ginder, and Louise Ray—we think of certain leadership qualities: vision, authority, courage, commitment. These are leaders who made history and secured a safer future for us all.

Yet today, when you ask regular moms and dads and hemophilia patients about leadership, a slightly different picture emerges, highlighting different qualities. It helps to know more about what our community members seek today in leadership—who they admire, and what they expect from the leadership of tomorrow.

Types of Leadership

There are many types of leadership, but I usually peg leaders as one of three types: positional, situational, and transformational. In a nutshell, positional leaders are usually elected, appointed, or inherited: think president, CEO, executive director, chief, even king or queen. Situational leaders may or may not be positional leaders, but they rise to the forefront when a problem, event, or situation calls for a leader. Think first responder, rescuer, or anyone who steps forward to take action, like Lech Walesa of Poland in 1980, or US Army Major Hugh Thompson, Jr., during the Vietnam War. Or even Ripley in *Alien*!

Transformational leaders influence a community, industry, group, or era to make massive and lasting changes: think Jesus, Gandhi, Walt Disney, or Steve Jobs. When asked about leaders, people often name leaders who fall into those three categories. Characteristics of these types of leaders? Powerful, authoritative, visionary, action-oriented, decisive, committed, communicative, innovative, influential, even charismatic. Do bleeding disorder families see leadership the same way?

The Softer Side of Leadership

Rather than describe leaders in our community as figureheads with power and influence, parents and patients associate softer qualities with leaders these days. These softer qualities include traits that make the “followers,” or beneficiaries of leadership, feel more secure and feel their needs are being met. We polled parents and patients on Facebook to see what leadership qualities they look for most in the bleeding disorder community. And top among these qualities is *listening*.

Eva Bagay replied, “For me, a good quality of leadership is to have an ear to listen, to communicate. To protect their member.” Krissy Pirehpour-Miller agreed. “Leadership is the ability to not just listen but truly hear you and your concerns. A leader inspires others and is someone who advocates passionately.”

Dr. Anupama Pattiyeri of India added that a leader must be “a patient listener and motivator—someone who focuses on solutions and not on problems alone.” Katelyn Popowich-Evans and Alicia Morado both put listening as their first sign of good leadership.

Wayne Cook remarked that leadership means “the ability to listen before deciding. Having ties to the community and leading with integrity, honesty and compassion.” Karla Brown of Texas agreed; for her, leadership means “commitment to our community combined with a personal connection.”

Tina Battillo noted that listening, combined with empathy, insight, and integrity, gives a leader the ability to understand life from a patient’s or caregiver’s point of view; the ability to understand important values of the community; and “the strength to stand up for those values.” In other words, parents and patients view the traditional forms of leadership as less important than “servant” leadership.

Servant Leadership

The style of leadership parents and patients most often mentioned is known as servant leadership. Servant leadership puts people’s needs first. A leader must understand the needs of the followers or constituents, be there with them, even suffer with them. Indeed, a trait of servant leadership is compassion, which means to suffer or feel alongside someone. It follows that traits of servant leaders include listening, empathy, stewardship, awareness, healing, commitment, and community-building. Historically, servant leaders have been either positional, situational, or transformational leaders too, but have always put their people’s needs first.

Raymond W. Stanhope agreed. “To be in service to the people you are leading—servant leadership” explains the style of leadership that works best today in our community.

Who are the servant leaders in the bleeding disorder community? Kathe Gusler cited Dr. Lisa Boggio and Dr. Michael Tarantino, of Illinois: “Both physicians are excellent leaders...They always take time to explain to patients and integrate therapies into everyday life. I am a better nurse for knowing them.” Rayna Conetta mentioned Dr. Clifford Takemoto, currently at St. Jude’s, “for leading a whole generation of patients through recombinant therapies by studying the medicine and checking the facts. All the while he has a wonderful bedside manner to both parents and children.” Emma Miller-Clark added that Dr. Takemoto “would always make time to volunteer for the community. A true gem of a human being and a brilliant doctor.”

Kelly Lynn Gonzalez, who was nominated by respondents as a servant leader herself, listed integrity, compassion, and honesty as important qualities for our community leaders. These characteristics don’t require a leader to be in a position of authority.

But positional leaders—those in authority—can be servant leaders as well. Christal Reed nominated Jeff and Rose Watkins. “They started a chapter here in Illinois and do so much to help the underserved members of our community!”

Likewise, Tiffany Branham Maness recommended Sue Martin, executive director of Hemophilia of South Carolina, as a servant leader. “She gives our organization her heart and soul. She has turned our local chapter into a source of hope, progression and compassion for our bleeding disorders community. And most importantly she drives people to educate themselves on advocacy, so we can advocate strongly and effectively for our children, and teach them how to become strong advocates for themselves. I love her to bits!

She’s turned what I was afraid would be a curse into a blessing, and we feel like superheroes that can handle anything because of her work!”

Perhaps no one models servant leadership quite like Jonathan James, a person with hemophilia who founded and runs Hope for Hemophilia, a nonprofit in Louisiana. Renee Michelle wrote, “This

leader has the biggest heart in the world. He leads with so much compassion. Jonathan is not afraid to get in the trenches with anyone and hold their hand through a hardship. This guy gives all he has and then keeps giving...he leads from the heart. After spending time with Jonathan you walk away refreshed and feel like you can conquer the world because he is so positive and uplifting to his fellow bleeding disorder families.”

Ray Stanhope warned that as great as servant leaders are, they must ensure that they are not indispensable. In other words, leaders must develop other leaders.

Mentoring

The great British wartime leader Winston Churchill was called the “Old Lion.” I think of this when I think of the top leaders in our community who fought our war with HIV, and are now in their 60s. Mentoring a new generation of lions, then, is vital. Some mentoring happens at the top, with youth leadership programs from National Hemophilia Foundation (NHF), but mentoring can occur anywhere by any of our servant leaders. Renee Michelle nominated Benjamin Denman as a servant leader who mentors. “This guy has such a huge heart when it comes to our community. He wants to be so involved everywhere that he sometimes spreads himself too thin; but being there for his brothers and sisters is his passion. He has a list of guys he calls to check up on almost weekly. Benjamin has a heart to mentor the younger generation...to help people transition from teenagers to adults. He is loved and trusted by all because he is so real—and funny.”

Two mothers mentioned their own sons as servant leaders who mentor younger followers. Dawn Butler Spikes wrote, “My oldest son, Grant Spikes, age 25, is passionate about empowering younger kids. He never missed a year of Camp Ailihpomeh (Texas) since age seven, and even after moving out of state for a while, came back to work as a counselor in summers. He is now the Camp Ailihpomeh director! He graduated from Texas A&M and was in the Corps of Cadets all four years. He was not about to let severe hemophilia A slow him down, and wants to pass that message on to other kids and parents.” Servant leadership by example, combined with positional leadership, is powerful!

Kimberly Hennessy-Rosenfelt nominated her son Dakota J. Rosenfelt. She believes he has these leadership qualities, so important in servant leaders: integrity, honesty, loyalty, empathy, compassion, inspiration—and mentoring.

Unsung Heroes

Finally, Lisa-Marie Mathieu made a poignant suggestion: “I’d like to nominate all of the ‘silent leaders’...parents who take the time, often in private, to welcome new members, offer our help, guidance, experience as parents with a baby with a bleeding disorder...Often done behind the scenes, but very helpful and appreciated nonetheless.”

Sometimes the greatest leaders are the ones without the fanfare, tweets, photo ops, and popular achievements. They are the servant leaders who quietly and modestly, powerfully and permanently, change the world day by day, child by child. They are all of you—parents, patients, doctors, nurses—who dedicate their lives and careers to the bleeding disorder community.



Explore HEAD-TO-HEAD Pharmacokinetic (PK) Study Data

See half-life, clearance and other PK data from the crossover study comparing **Jivi**[®] and **Eloctate**[®].

Visit PKStudies.com to find out more.

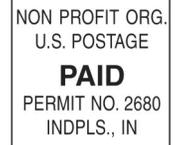
► **Pharmacokinetics** is the study of the activity of drugs in the body over a period of time.

©2020 Bayer. All rights reserved. All trademarks are the property of their respective owner. Printed in the USA 01/20 PP-JIV-US-1008-1


antihemophilic factor
(recombinant) PEGylated-augl
LET'S GO



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...

- Polo at Sunset - July 10, 2020
- HoII Annual Meeting - August 29 - 30, 2020
- Check out our social media pages for updates!!!

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

