

Vital Link



...For Hoosiers Living with a Bleeding Disorder

September 2017

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

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Annual Meeting Recap

This year's Annual Meeting was a huge success! We had a record high 224 attendees! The meeting kicked off with an incredible opening session, "Care Throughout the Lifespan", by Jen Maahs, PNP, Dr. Amy Shaprio, and Dr. Anne Greist that included discussion and recommendation of care through the lifespan of a bleeding disorder patient. Some of the afternoon educational topics included "Self-Care for Bleeding Disorder Caregivers: Put Your Oxygen Mask on First", "Planning Ahead: Aging with Hemophilia", "Hemophilia: The Female Connection", "Spotlight On Unaffected Siblings", and "The Family Tune Up"! While the parents enjoyed the educational programs, the kids, ages 4-12, had a blast at the zoo. The teens participated in a program hosted by Chris Bombardier and Gut Monkey teaching teens how to deal with stress followed by an afternoon of adventure at a high ropes course! Chris Bombardier was also our key note speaker on Sunday and included an incredible, interactive, and inspirational presentation! Saturday nights dinner included the 2016 Award presentation and the 2017 Judy Moore Scholarship recipients.

Award Winners:

2016 Distinguished Individual Volunteer: Matt Shade

2016 Distinguished Business: The Art Press

2016 President's Award: Jeff Warner

2017 Judy Moore Scholarship Winners: Zachary Crabtree, Matthew Olovich, William Lehman, Cole Sullivan, Sarah Phillips, Ralph Alter, and Ethan Dunham

Congratulations to all of our winners!

Upcoming Educational Programs:

October:

Indianapolis-Southside

Topic: Lanes Not Divided sponsored by Octapharma

When: Thursday, October 12th, 2017

Time: 6:00PM

Where: Shallos Antique Restaurant- 8811 Hardegan St. Indianapolis, IN 46227

Indianapolis-Northside

Topic: Gateways to Education sponsored by Bioverativ

When: Tuesday, October 17th, 2017

Time: 6:00PM

Where: Aristocrat Pub & Restaurant- 5212 North College Ave., Indianapolis, IN 46220

November:

Indianapolis

Topic: Factor 8 and Von Willebrand Disease Product Information sponsored by Shire

When: Saturday, November 4th, 2017

Time: Adynovate(Hemophilia A product)11:00-1:00PM

Vonvendi(Von Willebrand Disease) 2:00-4:00PM

Where: Cooper's Hawk- 3815 E. 96th St., Indianapolis, IN 46240

**Please attend the educational program timeslot specific to your diagnosed bleeding disorder.*

Indianapolis

Topic: Insurance

When: Thursday, November 9th, 2017

Time: 6:00PM

Where: TBD

RSVP to Angel at 317-570-0039 or acouch@hoii.org

2017 Hemophilia Walk

The 2017 Hemophilia Walk was Saturday, September 9th at Fort Harrison State Park. The weather was absolutely beautiful and the turnout was even better! We had 278 registered participants for this year's walk and an event attendance of 225! This year NHF initiated a new donor program called "Factor Club", for those donor's who individually raised over \$500. Hemophilia of Indiana is proud to announce that we had 6 individuals that became "Factor Club" members. Congratulations to Dave Currey, Travis Rivers, Deja Sturdivant, Chase Tulledge, Maggie Glodowski, and Carla Glodowski! Our teams really stepped up their game this year as well!! We had multiple teams that raised over \$1500! Our top fundraising team presented by Shire went to Currey's Cane-anites, Team Captain Deb Currey. Bleeding Hearts for Blake, Jacker Backer's, Little Rascals, and Hiking for Hemos round out our top five teams. Our top individual winner presented by Novo Nordisk went to Dave Currey of Currey's Cane-anites! Thank you to everyone who attended and donated! A very special thank you to all of our sponsors and volunteers! Big changes are coming to the Walk for 2018! Stay tuned!!

2017 Polo on The Prairie

The 2017 Polo on the Prairie presented by Fit Livin' was held Saturday, September 16th at the Hickory Hall Polo Club in Whitestown, IN. It was a beautiful day and we had a great turnout! Thank you to all who attended! We would like to thank our partner organization, Fit Livin', and Donna and Greg Chandler owners of the Hickory Hall Polo Club (www.indypolo.com). Hickory Hall Polo Club is the only Polo club in the state of Indiana and partners with various not-for profit and charity organizations throughout their season with the proceeds benefiting those partnering organizations. Hemophilia of Indiana benefitted in the proceeds from the gate entrance fee's as well as a 50/50 raffle drawing. Fit Livin' is an incredible organization that drives culture to healthy lifestyles by assisting individuals in reaching their maximum potential in three key areas: Health, Fitness, and Mental Attitude! Check out their website at www.fitlivin.com or download the Fit Livin' mobile App. A very special thanks to our Title Sponsors of the event The Indiana Hemophilia and Thrombosis Center and Shire. Thank you also to our Chukka Sponsor Pfizer. It was an afternoon of family fun of watching a great polo match as well as "stomping the divot's and a candy drop from an airplane at Half Time. The Kids had a blast! A very special thank you goes out to all of our volunteers, whom without the event would not have been such a success! The date for 2018 will be posted on our Facebook page and website in mid-January so stay tuned!!!





DEDICATION AND PERSONAL SUPPORT

The Patient Affairs Liaison role was created based on community feedback about the importance of helping to connect patients and caregivers with Pfizer Hemophilia tools and resources.



Working for you—From the home of Motown to the Bluegrass State

Name: Chris Liddell

Home state: Michigan

Fun fact: If I'm watching TV, it's most likely sports-related. Go Tigers!

Ideal vacation spot: Anywhere quiet, unplugged from all electronics

What past experiences can you bring to this job?

I've worked in hemophilia for over 10 years, so I've collaborated with and advocated for different members of this community.



To get in touch with Chris, call Pfizer Hemophilia Connect 1.844.989.HEMA(4366)

What we do:

- ✓ Provide helpful information about Pfizer Hemophilia programs and services
- ✓ Serve as a resource to hemophilia treatment centers to help patients obtain access to Pfizer medicines
- ✓ Serve as a primary point-of-contact for local advocacy groups
- ✓ Participate in local and national events and programs
- ✓ Upon request, meet with patients and caregivers to answer questions related to Pfizer Hemophilia resources

"IT'S IMPORTANT TO CONNECT ON ALL LEVELS: HTC's, PATIENTS, FAMILIES, THE WHOLE COMMUNITY."

—Chris Liddell

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THANKSGIVIN DAY RUN / WALK

Presented by:



INDIANA
HEMOPHILIA &
THROMBOSIS
CENTER, INC.



4 Mile Run/Walk

1.5 Mile Walk



www.hoii.org/events/fitlivin



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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 revolutionary products and programs, while always striving toward our ultimate goal: **a life free of bleeds but full of dreams.**



bleedingdisorders.com

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- 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

NHF Annual Meeting Recap

The National Hemophilia Foundation held their Annual Meeting in Chicago , IL on August 24th to 26th. Hemophilia of Indiana sponsored 68 patients and family members to the event in Chicago! The Opening Session began with Val Bias , NHF CEO, setting the tone for exploring the new frontier in the world of bleeding disorders as well as NHF's commitment of \$2 million dollars to support research for bleeding disorders to the National Institute of Research. The night was capped off with the opening of the Exhibit hall where our families could explore the different industry and organization's exhibit booths. NHF provided on-site child care as well as a fun trip for the kids to Shed Aquarium. The educational breakout sessions were broken down by categories such as vWD, Women with Bleeding Disorders, Adult Men, Teens and Young Adults, and Partners and Spouses. This gave our adult attendees, parent's and caregivers the opportunity to attend educational sessions that were geared to their specific interests and bleeding disorder. Friday evening our families attended a Hello Talk, hosted by our local sponsor Shire, at an incredible Italian restaurant. The talk was interactive for both the adults and children attending and the food was delicious! The NHF's Final Night Event was held at the Field Museum and our families were transported to the museum via buses where they got to explore the museum and enjoy music and appetizers! Overall it was a very successful and educational 3 days! Special thank you to our sponsors Shire and Novo Nordisk whose support made it possible for Hemophilia of Indiana to have one of the largest group at NHF Annual Meeting!

The Shire logo features the word "Shire" in a bold, blue, sans-serif font. A stylized blue swoosh or arc is positioned above the letter "S".

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Indications for RIXUBIS [Coagulation Factor IX (Recombinant)]

RIXUBIS is an injectable medicine used to replace clotting factor IX that is missing in adults and children with hemophilia B (also called congenital factor IX deficiency or Christmas disease).

RIXUBIS is used to control and prevent bleeding in people with hemophilia B. Your healthcare provider may give you RIXUBIS when you have surgery. RIXUBIS can reduce the number of bleeding episodes when used regularly (prophylaxis).

Detailed Important Risk Information

You should not use RIXUBIS if you are allergic to hamsters or any ingredients in RIXUBIS.

You should tell your healthcare provider if you have or have had any medical problems, take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies, have any allergies, including allergies to hamsters, are nursing, are pregnant or planning to become pregnant, or have been told that you have inhibitors to factor IX.

Allergic reactions have been reported with RIXUBIS. Call your healthcare provider or get emergency treatment right away if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea, or fainting.

Your body may form inhibitors to factor IX. An inhibitor is part of the body's defense system. If you form inhibitors, it may stop RIXUBIS from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for development of inhibitors to factor IX.

If you have risk factors for developing blood clots, the use of factor IX products may increase the risk of abnormal blood clots.

Common side effects that have been reported with RIXUBIS include: unusual taste in the mouth, limb pain, and atypical blood test results.

Call your healthcare provider right away about any side effects that bother you or if your bleeding does not stop after taking RIXUBIS.

Please see following page for RIXUBIS Important Facts.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.



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RIXUBIS
[COAGULATION FACTOR IX
(RECOMBINANT)]

MOVING FORWARD

RIXUBIS **[COAGULATION FACTOR IX** **(RECOMBINANT)]**

Important facts about

RIXUBIS [Coagulation Factor IX (Recombinant)]

This leaflet summarizes important information about RIXUBIS. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about RIXUBIS. If you have any questions after reading this, ask your healthcare provider.

What is RIXUBIS?

RIXUBIS is a medicine used to replace clotting factor (Factor IX) that is missing in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Hemophilia B is an inherited bleeding disorder that prevents blood from clotting normally. RIXUBIS is used to prevent and control bleeding in people with hemophilia B. Your healthcare provider may give you RIXUBIS when you have surgery. RIXUBIS can reduce the number of bleeding episodes when used regularly (prophylaxis).

Who should not use RIXUBIS?

You should not use RIXUBIS if you

- are allergic to hamsters
- are allergic to any ingredients in RIXUBIS.

Tell your healthcare provider if you are pregnant or breastfeeding because RIXUBIS may not be right for you.

What should I tell my healthcare provider before using RIXUBIS?

You should tell your healthcare provider if you

- have or have had any medical problems
- take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies
- have any allergies, including allergies to hamsters
- are breastfeeding. It is not known if RIXUBIS passes into your milk and if it can harm your baby
- are pregnant or planning to become pregnant. It is not known if RIXUBIS may harm your unborn baby
- have been told that you have inhibitors to factor IX (because RIXUBIS may not work for you).

How should I infuse RIXUBIS?

RIXUBIS is given directly into the bloodstream. RIXUBIS should be administered as ordered by your healthcare provider. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia B learn to infuse their RIXUBIS by themselves or with the help of a family member.

Your healthcare provider will tell you how much RIXUBIS to use based on your weight, the severity of your hemophilia B, and where you are bleeding. You may have to have blood tests done after getting RIXUBIS to be sure that your blood level of factor IX is high enough to clot your blood. Call your healthcare provider right away if your bleeding does not stop after taking RIXUBIS.

What are the possible side effects of RIXUBIS?

Allergic reactions may occur with RIXUBIS. Call your healthcare provider or get emergency treatment right away if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting. Some common side effects of RIXUBIS were unusual taste in the mouth and limb pain. Tell your healthcare provider about any side effects that bother you or do not go away. These are not all the side effects possible with RIXUBIS. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about RIXUBIS?

Your body may form inhibitors to factor IX. An inhibitor is part of the body's defense system. If you form inhibitors, it may stop RIXUBIS from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to factor IX.

Medicines are sometimes prescribed for purposes other than those listed here. Do not use RIXUBIS for a condition for which it is not prescribed. Do not share RIXUBIS with other people, even if they have the same symptoms that you have.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

The risk information provided here is not comprehensive. To learn more, talk about RIXUBIS with your healthcare provider or pharmacist. The FDA-approved product labeling can be found at http://www.shirecontent.com/P1/PDFs/RIXUBIS_USA_ENG.pdf or by calling 1-800-FDA-1088.

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Brought the leading extended half-life therapies to people with hemophilia—innovation that has changed the way hemophilia can be managed.

Sponsor free genetic testing for people with hemophilia and carriers through *My Life, Our Future*. Together with program co-founders the American Thrombosis and Hemostasis Network, Bloodworks Northwest, and the National Hemophilia Foundation, we are advancing disease understanding and research for the entire community.

Transformed humanitarian aid in hemophilia, with Sobi, by committing to donate up to one billion IUs of factor therapy over 10 years to help close the treatment gap in the developing world. More than 12,300 people have been treated through the WFH Humanitarian Aid Program, which is receiving 500 million IUs over five years.

We not only believe great science can conquer the toughest medical challenges, we live it every single day.

Study Yields Important Findings on the Functions of von Willebrand Factor

Researchers at the Boston Children's Program in Cellular and Molecular Medicine and the Harvard Medical School recently made important discoveries relevant to the functioning of von Willebrand factor (VWF). The study, "Flow-induced Elongation of von Willebrand Factor Precedes Tension-Dependent Activation," was published online, August 23, 2017, in the journal *Nature Communications*.

Using fluorescent imaging and microfluidic tools, Jiang and his colleagues recreated the blood flow that occurs in humans, particularly the function of VWF within the bloodstream. Through a series of valves, cylinders and tubes, investigators were able to mimic the increase in blood flow that occurs after an injury.

Experiments showed that as the blood flow grew more intense, changes in the shape of VWF would occur. VWF molecules, which are normally rounded and compact, quickly became rapidly elongated in response to the increased tension. Scientists also observed that as VWF elongates it binds with platelets to ensure that a viable blood clot forms. Notably, VWF activates locally at the site of an injury and not in other parts of the body.

"If you can imagine stretching out your arms, and then opening your hands to capture platelets, that's basically what we are seeing VWF do in response to bleeding," said researcher Wesley P. Wong, PhD. "It's so important that this process occurs only when and where it is needed—this two-step activation process makes that possible."

While these findings could have future implications for treatment, leading to more novel therapies, they are also scientifically noteworthy. Researchers are no doubt excited to uncover such valuable molecular-level insights on the intricacies of the bloodstream and the mechanisms of VWF.

"This experiment really represents a new platform for seeing and measuring what's happening in the blood on a molecular level," said Wong. "Through the use of novel microfluidic technologies that allow us to mimic the body's vasculature in combination with single-molecule imaging techniques, we are finally able to capture striking images that uncover the mystery of nature's forces at work in our bodies."

Source: **Genetic Engineering & Biotechnology News, August 23, 2017**



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.

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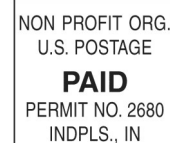
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Mark your Calendars!

Here are some of our upcoming events...

- **Thanksgiving Day Run**, Dillon Park, Noblesville - November 23rd
- **Year End Education Event**, Saturday December 2nd
- **Hearts for Hemophilia Gala**, February 9th, 2018

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!

