

# Vital Link



...For Hoosiers Living with a Bleeding Disorder

September 2024

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

Designed by: Kristy McConnell

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## 2024 Annual Meeting

The 2024 Annual Meeting was held on August 17th and 18th and the freshly renovated Crowne Plaza Hotel - Indianapolis Airport. It was another successful event hosting over 125 members of Indiana's bleeding disorders community. The Annual Meeting is a weekend of education and community support. The event began on Saturday with a two part general session hosted by staff from Innovative Hematology - Indiana Hemophilia & Thrombosis Center. Topic included Life Transitions and their impact on a bleeding disorder, Trauma informed care, and the IHTC's restructuring. The day continued with afternoon breakout sessions with incredible topics such as Pharmacy Engagement, Shared Decision Making, Tools for Success in College, Women's Health, Updates in Treatments, How to Tell your Story, and much more! This was also the 2nd year for a complete Hispanic Education Track! Hemophilia of Indiana is proud of its efforts to provide a variety of education topics that fit the needs of all attending regardless of their bleeding disorder diagnosis. The Annual Awards Dinner was held Saturday evening where we celebrated the 2024 Judy Scholarship Winners (see article on page 3), Camp Brave Eagle Award Winners, and 2024 Award Winners.

Sunday morning of the 2024 Annual Meeting began with a screening of "On the Shoulder's Of Giants" (courtesy of Believe Limited) and an incredible and interactive presentation by Dr. Anne Greist. "On the Shoulders of Giants" shows how for the first time in history, an entire generation of people with hemophilia are living into their 50's and beyond. It explores this remarkable milestone through the real-life stories of the aging hemophilia community. It was an incredible reminder to see how far the bleeding disorder community has come and the importance of continued advocacy. The event came to a conclusion with support group breakout sessions. It was another great year and planning has already begun for the 2025 Annual Meeting!!



# Thank you to our 2024 Annual Meeting Sponsors!!!!

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## 2024 Judy Moore Memorial Scholarship Recipients

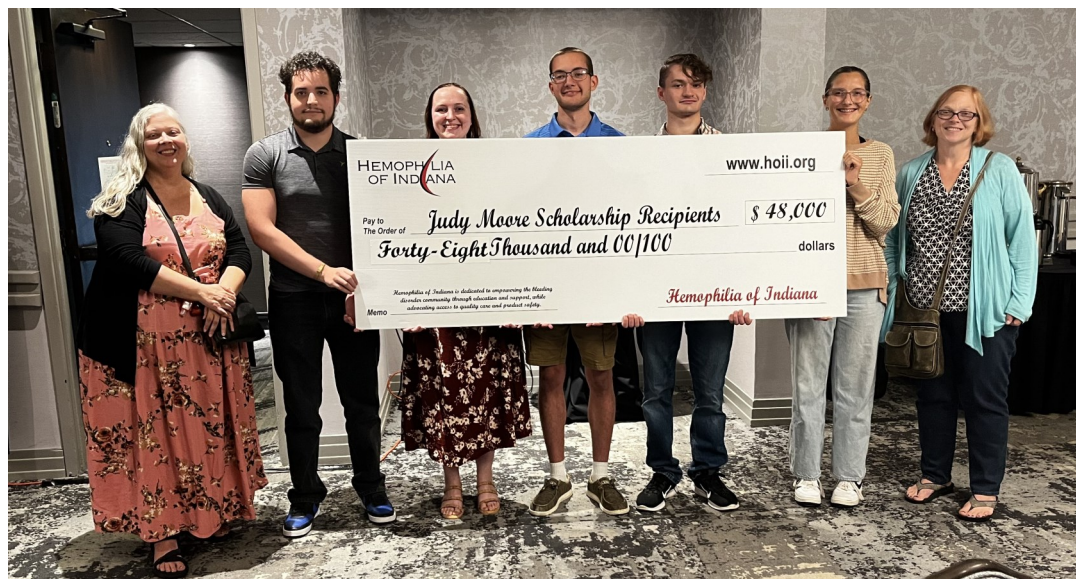
Judy Moore joined the Indiana Hemophilia & Thrombosis Center as a social worker in 1999. She first entered the hemophilia care arena in 1990 through employment at Hemophilia of Indiana. Judy's experience serving the bleeding disorders community spanned the HIV/AIDS epidemic, the transition to recombinant clotting factor concentrates, and most recently, healthcare reform. Judy was an inspiration to all – patients, families, friends, and coworkers. She leaves a proud legacy of care, having touched many lives during her thirteen years at the IHTC and her prior years serving the bleeding disorder community.

Scholarships are awarded to those diagnosed with a bleeding disorder, including but not limited to von Willebrand's disease, Hemophilia A, or Hemophilia B. The scholarship will be presented to the applicant that provides the best combination of a creative and persuasive essay, excellent recommendations, and superior academic standing.

This year The Judy Moore Memorial Scholarship committee awarded \$48,000 to 12 very deserving individuals:

Hery Acosta Acosta  
Raygan Ballew  
Tyler Bumbalough  
Raebecca Gerald  
Clay Kistler  
Jackson Kroeger

Cortland Jackson  
Zoe Moser  
Jennifer Oldfather  
Nicholas Oldfather  
Jack Shade  
David Stephens



\*Not all recipients were able to be present for the Award Ceremony

## **Upcoming Educational Dinners:**

Contact Angel DiRuzza at [adiruzza@hoii.org](mailto:adiruzza@hoii.org) to register.

Check out our Facebook (@HEMOINDY) page and website calendar for more details on upcoming in person educational dinners!

**Topic:** **My Life With Hemophilia: Vaughn Ripley Shares his Story**

Sponsored by Novo Nordisk

**When:** Thursday, October 10th

**Where:** Ripple & Company  
1007 Main Street  
**Lafayette, IN 47901**

**Topic:** **Hemgenix: Steps to Treatment Educational Program**

Sponsored by CSL Behring

**When:** Thursday, November 7th

**Where:** Four Day Ray - The Private Room  
11671 Lantern Road  
**Fishers, IN 46038**

**Topic:** **Program TBD**

**When:** Tuesday, November 12th

**Where:** Restaurant TBD  
**Fort Wayne, IN**







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# Teens, Bleeding, & Menstruation

The right care plan for a teen with a bleeding disorder begins with the right care team.

Hemophilia carriers can have heavy menstrual bleeding (HMB). Although this is more common in carriers with low factor levels, it has been observed in all carriers irrespective of their levels. They can also have any of the symptoms listed below.

## Symptoms and signs:

- Iron deficiency, anemia, or need for blood transfusion
- Missing days of school or work due to bleeding
- Excessive bleeding after surgery, dental work, or childbirth
- Frequent and prolonged nosebleeds
- Prolonged bleeding from cuts or wounds
- Easy bruising
- Family history of a bleeding disorder

The American College of Obstetricians and Gynecologists recommends teenage girls make their first reproductive health visit between the ages of 13 and 15.<sup>1</sup>

For adolescents who have a bleeding disorder and menstruate, it is especially important to begin reproductive health visits in their early teens to discuss what to expect during the periods and how best to be prepared for them.

Innovative Hematology/IHTC's GO+ Clinic provides comprehensive care for adolescents and adults with bleeding or clotting disorders who have heavy menstrual bleeding or need specialized gynecological care.

Visit the  
GO+ Clinic  
online to  
learn more:



**Innovative  
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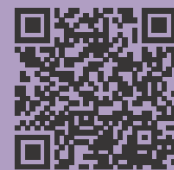
**PODCAST**

## 7-2-1: All you need to know about periods

Dr. Sweta Gupta, Innovative Hematology/IHTC Pediatric Hematologist, hosts *7-2-1: All you need to know about periods*, a podcast answering the most pressing questions about periods and heavy menstrual bleeding.

7-2-1 refers to the signs of a heavy period:

- 7 – cycles lasting longer than 7 days
- 2 – changing a pad/tampon every 2 hours or less
- 1 – passing blood clots more than 1 inch or a quarter in size



## Reference:

1. The initial reproductive health visit. ACOG Committee Opinion No. 811. American College of Obstetricians and Gynecologists. *Obstet Gynecol* 2020;136:e70-80.

# #THXRUN



Come and get a healthy head start on your Thanksgiving Day feast by joining us for Hemophilia of Indiana's THXRUN Run!

## Thursday, November 28, 2024

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 benefit HoiI's Judy Moore Memorial Scholarship Program. This scholarship program has helped provide college and secondary education scholarships to over 125 students affected with a bleeding disorder!

- **Race location:** Start/Finish at [Dillon Park](#) (146th and Hazel Dell behind Kroger) and scenic course through the beautiful **Lochaven** neighborhood.
- Packet Pick Up Location TBD - updates to be posted on event website



### • 4 Mile & 1.5 Mile Run/Walk at 9:00am

\$35.00 Registration (through 10/31)

\$39.00 Registration (11/1 - 11/26)

\$40.00 Onsite Registration (11/27 & 28)

### • Kids 200 Yard Fun Run at 8:45am

» Free Registration (through 11/23)

\***Kid's Race:** Every child will receive a medal for participating.



**Awards:** 1st, 2nd, & 3rd place male/female

**Costume Prizes:** 1st male/female - Turkey/Pilgrim

**Pumpkin Prizes:** There will be 10 pumpkins throughout the course. Whoever carries a pumpkin over the finish line will receive a prize.

More info:

[www.hoii.org/events/#thxrun](http://www.hoii.org/events/#thxrun)





## WE'RE IN THIS TOGETHER.

**Friday 6:26 pm**

Sharing stories by the campfire with friends

Isaac, living with hemophilia B

Not an actual patient

### Let's make today brilliant.

Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world is stronger than ever.

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## 2024 Unite for Bleeding Disorders Walk

The 2024 Unite for Bleeding Disorders Walk was held Saturday, September 7th at Fort Harrison State Park! It was a beautiful day and Hemophilia of Indiana is proud to announce that we exceeded our goal of raising \$40,000 with the final total raised over \$43,000!

Congratulations to the 2024 Top Fundraising Team Captain - Carolyn Salazar with Emiliano's Advocates! Also a HUGE congratulations and THANK YOU to our top individual fundraiser, Bill Davis with Emiliano's Advocates! Thank you to all of our incredible Team Captains for all of their hard work!!

The Walk is about more than just fundraising or walking in a park. This is day to celebrate our bleeding disorders community and everyone who supports it! It is a day to come together and celebrate each other, support each other, and share a beautiful day together!



# National Youth Leadership Institute



NATIONAL BLEEDING DISORDERS FOUNDATION



Applications  
Nov 1, 2024 -  
Feb 28, 2025

## Highlights

- Enhancing Leadership Skills
- Develop Professional Skills
- Networking + Opportunities
- 3 Tracks: Research, Education, and Advocacy

## Requirements:

- Ages 19-24 years old
- Diagnosed with a bleeding disorder OR have a sibling with a bleeding disorder
- U.S Resident
- Able to travel to trainings and programs

## For More Information:



Heather Hicks

hhicks@bleeding.org





**Innovative  
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Indiana Hemophilia  
& Thrombosis Center

# A future where you can flourish with a blood disorder

A future where you flourish starts with the best care today. The IHTC is here to support all the members of our bleeding disorders community.

**Innovative Hematology, home to the IHTC, has leading experts in rare bleeding & blood disorders: Hemophilia | HHT | HVLM | Thrombosis & Clotting | Sickle Cell Disease | von Willebrand Disease**

The IHTC provides advanced care for both adult and pediatric patients with rare bleeding disorders. As Indiana's only federally recognized hemophilia treatment center, IHTC is one of the nation's largest HTC's, delivering innovative, multi-disciplinary care in Indianapolis and at outreach clinics across the state. Visit [www.innovativehematology.org](http://www.innovativehematology.org)

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## Mark your Calendars!

- 2024 Women's Retreat - October 19th - 20th
- 2024 Hemophilia of Indiana THXRUN - November 28th
- 2024 Year End Education Event - December 7th

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!

- Check out our social media pages for updates!!!

