

Vital Link



...For Hoosiers Living with a Bleeding Disorder

December 2024

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Designed by: Kristy McConnell

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Hemophilia of Indiana
6910 N. Shadeland Ave.
Suite 140
Indianapolis, IN 46220
(317) 570-0039
(800) 241-2873
www.hoii.org

Saying Good Bye to 2024!

How can it be the end of 2024?! It seems like the years go by faster and faster! 2024 was an exciting year for Hemophilia of Indiana! The year started with the hugely successful Hearts for Hemophilia Gala at the beautiful Grand Hall at Union Station. Over 200 attendees enjoyed a fun evening while supporting Indiana's bleeding disorders community. In March, our team headed to Washington DC to advocate on behalf of the bleeding disorders community across the country as part of the National Bleeding Disorders Foundation's (NBDF) Washington Days. Our fight for the HELP Copays Act is far from over and we will be returning next March to continue the fight. In April, the Hemophilia Federation of America (HFA) held their annual Symposium in Indianapolis. Hemophilia of Indiana and HFA partnered together to provide scholarships to Indiana community members and their families to attend the event! It was the first one of the national conferences were held in Indianapolis. Bowling for Bleeding Disorders followed and was held at Pinhead's in Fishers with 12 teams supporting the Judy Moore Memorial Scholarship Program. The Course to a Cure Golf Outing was held in early June and over 100 golfers enjoyed a beautiful day on the lynx and help support Holl. Camp Brave Eagle was also held in June and while the weather was on the hot side this year, the campers braved the heat and had a wonderful week at camp. 112 campers attended this year's camp and 89 campers earned their "Big Stick" though the self-infusion training. Of those 89 campers, 15 were first time campers and 2 campers completed the five-time big stick! The Doug Thompson Teen Leadership Camp was held in July and this year the campers traveled to West Virginia and spent the week at ACE Adventure Park. The campers enjoyed the week going zip lining, white water rafting, hiking, and exploring the area. The 2024 Annual Meeting was held in August at the Crowne Plaza Hotel - Indianapolis Airport with over 200 attendees. Right after the Annual Meeting we headed to Atlanta for the 2024 NBDF Bleeding Disorder Conference. Holl provided scholarships to multiple Indiana families to attend the conference and get the opportunity to connect with fellow members of the bleeding disorders community from throughout the country and attend some great education sessions. In October, Holl held our first Women's Retreat at the Renaissance Hotel in Carmel, IN. This inaugural event was hugely successful and we are excited to continue to grow this new annual event! The rain stopped and then held off for the 2024 THXRUN held at Dr. James A Dillon Park in Noblesville, IN. It was the 16th year for the THXRUN and we once again had close to 400 participants! The final event of the year was the Year End Education Event (more on page 3) and we got to kick off the holiday season with over 100 families and members of our bleeding disorders families! Make sure to check out our 2024 Events Calendar on page 10 and we wish everyone Happy Holidays!

Check out some pictures from 2024!!



2024 Year End Education Event

The 2024 Year End Education Event was held on 12/7 at the beautiful Wellington Banquet & Conference Center in Fishers, IN. The Year End Education Event gives our bleeding disorder community members and families a chance to reunite for the end of the year and start celebrating the holiday season. Over 100 community members attended this year's event and enjoyed a delicious holiday lunch, education component, and a visit from a special visitor from the North Pole! Thank you to all that attended and to our incredible sponsors!



Thank you to our 2024
Sponsors!!



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2024 Hemophilia of Indiana THXRUN

The 2024 Hemophilia of Indiana THXRUN was held the morning of Thanksgiving Day! Founded by bleeding disorder community members Matt and Kasey Shade 16 years ago, this year's event hosted over 350 Runners and Walkers! The THXRUN is 1.5 mile 4 mile Run/Walk with a Free Kids Run before the start. Proceeds from the THXRUN directly benefit the Judy Moore Memorial Scholarship Program. A special thank you to our Title Sponsor, Innovative Hematology, Mile Marker Sponsor, Integra Realty Resources, and our Kids Run Sponsor Skylar Paunwar! Thank you to everyone that participated and donated to this year's event!!





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Seasonal Affective Disorder

With darkness falling earlier and temperatures decreasing, it is important to be mindful of how the change of seasons can impact you.

Seasonal Affective Disorder (SAD) is a type of depression related to the changes in seasons. Symptoms usually begin when the days get shorter in the fall/winter. Symptoms usually decrease during spring.



Symptoms of SAD include¹:

- Persistent sad, anxious, or “empty” mood most of the day, nearly every day, for at least two weeks
- Feelings of hopelessness, pessimism, irritability, frustration, restlessness, guilt, worthlessness, helplessness
- Loss of interest in activities, social withdrawal
- Decreased energy or fatigue
- Changes in sleep or appetite, especially oversleeping or overeating

Treatment for SAD can consist of the following:

- Light therapy, also known as phototherapy, using a special light box
- Psychotherapy
- Antidepressants

Other considerations to keep in mind in the winter months:

- Difficulty traveling to and from appointments in the dark or in wintry weather
- Slips and falls on icy walkways, resulting in injury
- Chronic pain and blood flow can be worse when the temperature drops
- Dress in warm layers, including winter coats, gloves, hats, closed-toed shoes and socks, etc.

SAD is more common in those with existing diagnoses like depression and bipolar disorder. Depression is one of the most common complications of chronic illnesses. This can put patients with a bleeding disorder at a heightened risk of SAD.

Mental Health Resources

If you think you may be struggling with SAD or another mental health concern, contact the IHTC Mental Health Team:

Social Work Team
317-871-0000 Ext 1553

Clinical Psychologist
317-871-0000 Ext 1105

The IHTC psychologist provides mental health treatment services including assessment, individual therapy, as well as referrals to local

mental health care providers for patients with blood disorders.

The IHTC social workers help you find the best ways to handle issues that affect your health.

Scan the QR code below to learn more.



Reference:

1. National Institute of Mental Health. (2023). Seasonal Affective Disorder (NIH Publication No. 23-MH-8138). U.S. Department of Health and Human Services, National Institutes of Health. Retrieved December 03, 2024, from <https://www.nimh.nih.gov/health/publications/seasonal-affective-disorder> .











Join us for the 2025 Hearts for Hemophilia Masquerade Gala on Friday, February 7th at the beautiful Grand Hall at Union Station. Check in and cocktail hour begins at 6:30pm with dinner and our program starting at 7:30pm. This is your chance to be mysterious by wearing your favorite masquerade mask along with your finery! Want to make it a mini-get away? Contact the Crowne Plaza Hotel - Downtown Indianapolis to book a room under the Holl Hearts Gala room block! Room block will be available until January 7th! Additional information and ticket link is posted on our website at www.hoii.org/events/gala!

All proceeds from the Hearts for Hemophilia Gala directly benefit the programs and services Hemophilia of Indiana provides to the bleeding disorders community throughout the State of Indiana! See you in February!

Test Your Bleeding Disorder Smarts!

MYTH OR FACT?

- 1  Only girls have VWD.
- 2  VWD is one of many different bleeding disorders.
- 3  Hemophilia is the most common bleeding disorder.
- 4  Name 4 common symptoms of VWD.
- 5  People with bleeding disorders can die from a paper cut.
- 6  You can “catch” a bleeding disorder from a friend.
- 7  Many people in one family can have VWD.
- 8  A bleeding disorder is a type of cancer.

FIND OUT MORE ABOUT YOUR BLEEDING DISORDER
AT STEPSFORLIVING.HEMOPHILIA.ORG

ANSWERS

1. **Myth:** Boys have VWD too, in equal numbers as girls do. 2. **Fact:** Other bleeding disorders include hemophilia and rare factor deficiencies. Each of these bleeding disorders has a different type of clotting factor in their blood that is missing, in low levels, or not working right. Clotting factors are proteins in the blood that control bleeding. If any of the clotting factors is missing or not working properly, bleeding continues for longer than it should. 3. **Myth:** VWD is the most common (about 1% of people in the US). Some people have more bleeding than others, regardless of having VWD or hemophilia. 4. Easy bruising, lots of nosebleeds that last a long time, lots of bleeding after surgery or dental work, heavy periods in girls 5. **Myth:** People with bleeding disorders can have life threatening complications but won't die from a paper cut or any other scrape. As they say “we bleed longer, not stronger.” With proper treatment, people with bleeding disorders live long, healthy, active lives. 6. **Myth:** Bleeding disorders are not contagious (which means you can't catch them by just being around someone who has one). Most are inherited, which means it was part of your family genes or make up, but some people are born with a bleeding disorder without anyone in their family having one. 7. **Fact:** Most bleeding disorders are inherited, which means it was part of your family genes or make up. Some kids have a lot of family members (parents, siblings, aunts, uncles, grandparents) who have a bleeding disorder. For other kids, they may be the only one in their family that they know that has a bleeding disorder. Even if many people in one family have a bleeding disorder, each individual may have different symptoms and treatment. 8. **Myth:** Bleeding disorders are not cancer. Some doctors who treat kids with a bleeding disorder also treat kids who have blood cancer, so you may end up meeting kids with different health issues when you go to the doctor.

WHAT DO THESE HAVE TO DO WITH YOUR BLEEDING DISORDER? ASK AN ADULT!

Find these words!

Bleed
Bruise
Coaches
Factor
Friends
Golf
Hematologist

Hiking
HTC
Infusion
Joint
Nose Bleed
Nurse
Physical Therapist

Social Worker
Support
Swim
Teachers
Von Willebrand
Disease
VWF

I B F R W J O T S I G O L O T A M E H R
H N S U P P O R T F B S B Y H T R Z J O
A I F O R H F F H E R L W F N T M D X T
A J K U I V B J Q S M I E I M X C N J G
P P M I S T Z B P R E Q E E M M K V P A
E Z I M N I N G V U N D M N D D T E H F
I O Z P N G O D C N X U S G D B Q O W X
G O Q M K X J N E N Y I P W L S I C B E
R A W I T A D U N O H D N W O B W W X F
V P A E G U P M R Q T F G Y X Q L K V F
D G R T G X V X D J K V Q D J F D F U I
V O N W I L L E B R A N D D I S E A S E
S E H C A O C Y P J Q B N F K V U V U K
G I W U S C C T C L E P M O W I B A H Y
R E K R O W L A I C O S Q A H I V Y I B
C U T F N P S U V Y Y J L A F M P W R G
P H Y S I C A L T H E R A P I S T U F O
J O I N T N D E E L B E S O N H I R C L
S R E H C A E T B M U W M L R S C I I F
T D C B A G Z W N C M G S Y E D X D N D



2025

CALENDAR OF EVENTS

Hearts for Hemophilia Gala: February 7

Bowling for Bleeding Disorders: March 22

World Hemophilia Day: April 17

NEW Women's Retreat: May 17-18

Camp Brave Eagle: June 8 - 13

Course to a Cure Golf Outing: June 13

NBDF Bleeding Disorder Conference, Aurora, CO: Aug. 21-23

Annual Meeting: September 27 - 28 (Date Change!)**

Thanksgiving Day Run: November 27

Year End Educational Program: December 6

Our mission:

Hemophilia of Indiana is dedicated to empowering the bleeding disorders community through education and support, while advocating access to quality care and product safety.

Hemophilia of Indiana, Inc.
6910 N. Shadeland, Ave., Suite 140
Indianapolis, IN 46220
Phone: (317) 570-0039 Fax: (317) 570-0058
Website: www.hoii.org



Innovative Hematology

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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



6910 N. Shadeland Ave., Suite 140
Indianapolis, IN 46220
www.hoii.org
(317) 570-0039

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Mark your Calendars!

- 2025 Hearts for Hemophilia Gala - February 7th
- 2025 Bowling for Bleeding Disorders - March 22nd
- 2025 Women's Retreat - May 17th & 18th

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!!!

