Vital Link

HEMOPHILIA OF INDIANA

…For Hoosiers Living with a Bleeding Disorder

March 2023

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

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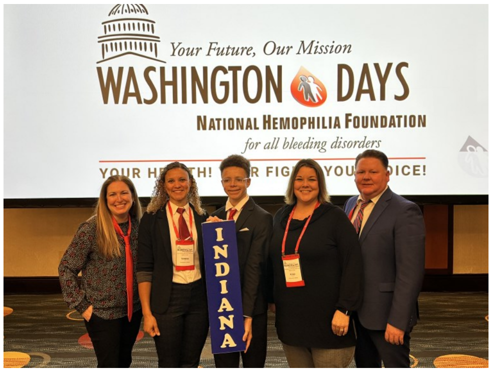
Washington Days 2023

The 2023 Washington Days was held March 8-10 in Washington DC. After 3 years of virtual, the Indiana team was excited for the opportunity to meet with Indiana's federal legislative members in person and advocate on behalf of the bleeding disorders community. The team included staff from the Indiana Hemophilia & Thrombosis Center, Hemophilia of Indiana staff, and community members. This year's "asks" include maintaining federal funding for programs that support the bleeding disorders community through the Center for Disease Control, the Health Resources and Services Administration, and the National Institutes of Health. These organizations maintain programs that support Hemophilia Treatment Centers, research, and education programs. The second "ask" is support to eliminate accumulator adjustor programs. Insurance plan's accumulator tallies up a person's co-pays and costs sharing up to their deductible and out-of-pocket (OOP) maximum. Accumulator adjustor programs disallow co-pay assistance from counting towards OOP. (See page 2). There is currently a bill in the House of Representatives to help achieve this goal and our team asked for support of this bipartison bill. On the Senate side, our team asked our Senator to introduce or support a companion bill. It was day full of great engagements and advocacy on behalf of the bleeding disorders community! Advocacy doesn't stop at Washington Days. How can you help? Reach out to your legislative representatives and ask them to support this year's asks!!



The HELP Copays Act Eliminates Harmful Health Plan Pricing Schemes and Protects Vulnerable Patients from Soaring Out-of-Pocket Costs

The sickest and most vulnerable patients—those who live with serious, complex chronic illness—are being targeted by health plan programs that undermine the benefits of copay assistance for medicines. The bipartisan Help Ensure Lower Patient (HELP) Copays Act eliminates barriers to treatment for patients ensuring that they can afford the necessary and life-saving medications prescribed by their doctors. The legislation requires health plans to count the value of copay assistance toward patient cost-sharing requirements. This would bring much-needed relief to vulnerable patients by ensuring that all payments—whether they come directly out of a patient's pocket or with the help of copay assistance—counts towards their out-of-pocket costs.

BACKGROUND

Patients are being asked to pay more. People living with serious, chronic health conditions often face multiple barriers to the therapies they need to treat their conditions, such as administrative hurdles like prior authorization and step therapy that limit access to specialty medications. And once approved, patients face skyrocketing deductibles and steep cost-sharing. With no other options to afford the medicine they need, many patients turn to charitable or manufacturer copay assistance to afford their drugs.

Copay accumulator adjustment programs (CAAPs) cut a critical lifeline for patients and leave them exposed. Under CAAPs, insurers have disallowed copay assistance from counting towards a patient's annual deductible or out-of-pocket maximum. As a result, many are faced with unexpected costs of thousands of dollars to get the medicines they need.

- The overwhelming share of medicines that are subject to programs like these (95%, according to the National Hemophilia Foundation analysis of the SaveOn SP Formulary) have no generic or biosimilar equivalents, leaving patients without a less expensive alternative.
- These programs disproportionately impact the most vulnerable patients who rely on certain medicines. A recent survey found that 69% of those who depend on such assistance make less than $40,000 a year, leaving them at risk of losing access to necessary health care.

The EHB loophole allows big companies to avoid paying for critical care for patients who most need help. A loophole under the Affordable Care Act (ACA) allows many employer health plans to deem certain categories of prescription drugs as "non-essential," even when they are life-saving or necessary for people with serious pre-existing and chronic conditions. When a covered drug is deemed "non-essential," the insurer will not count any cost-sharing toward the patient's deductible and out-of-pocket maximum. This loophole also allows employers to simply not cover drugs that treat expensive health conditions. By falling into the EHB loophole, patients in these plans often must pay hundreds or thousands of dollars in out-of-pocket costs for life-saving medicines and never hit their out-of-pocket maximum.

Together, these practices undermine coverage for pre-existing conditions, hurt patient access to medicines, decrease drug adherence, and likely cost our health care system even more money.

ABOUT The HELP Copays Act

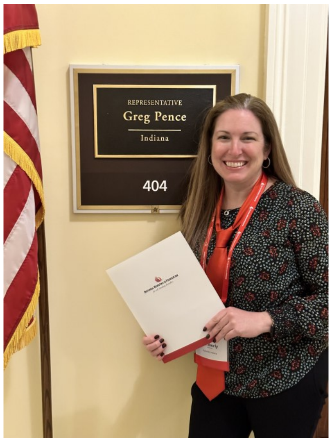
The HELP Copays Act is a two-part solution that

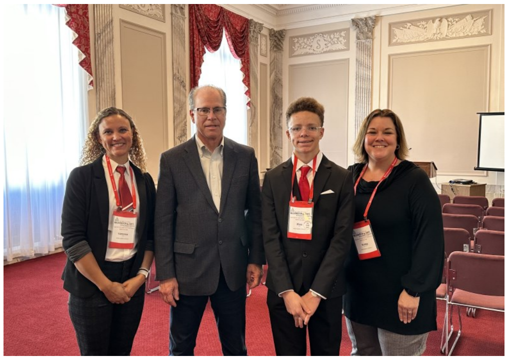
- Clarifies the ACA definition of cost sharing to ensure payments made "by or on behalf of" patients count towards their deductible and/or out-of-pocket maximum.
- Closes the EHB loophole to ensure that any item or service covered by a health plan is considered part of their EHB package and thus cost sharing for these must be counted towards patients' annual cost sharing limits.

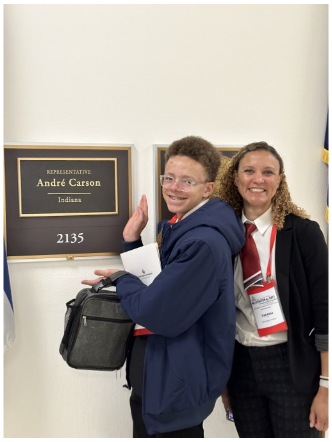
Congressional action is needed to protect patients. The bipartisan **HELP Copays Act** can help end these harmful pricing schemes and bring much-needed cost savings to vulnerable patients.

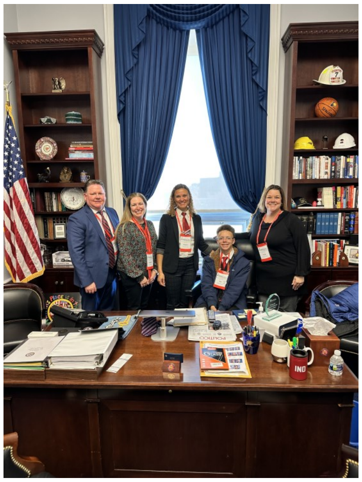
ALL COPAYS COUNT COALITION

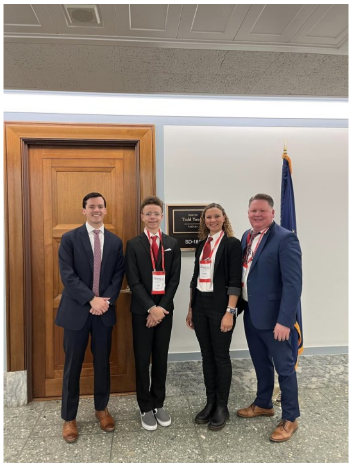
2023 Washington Days!

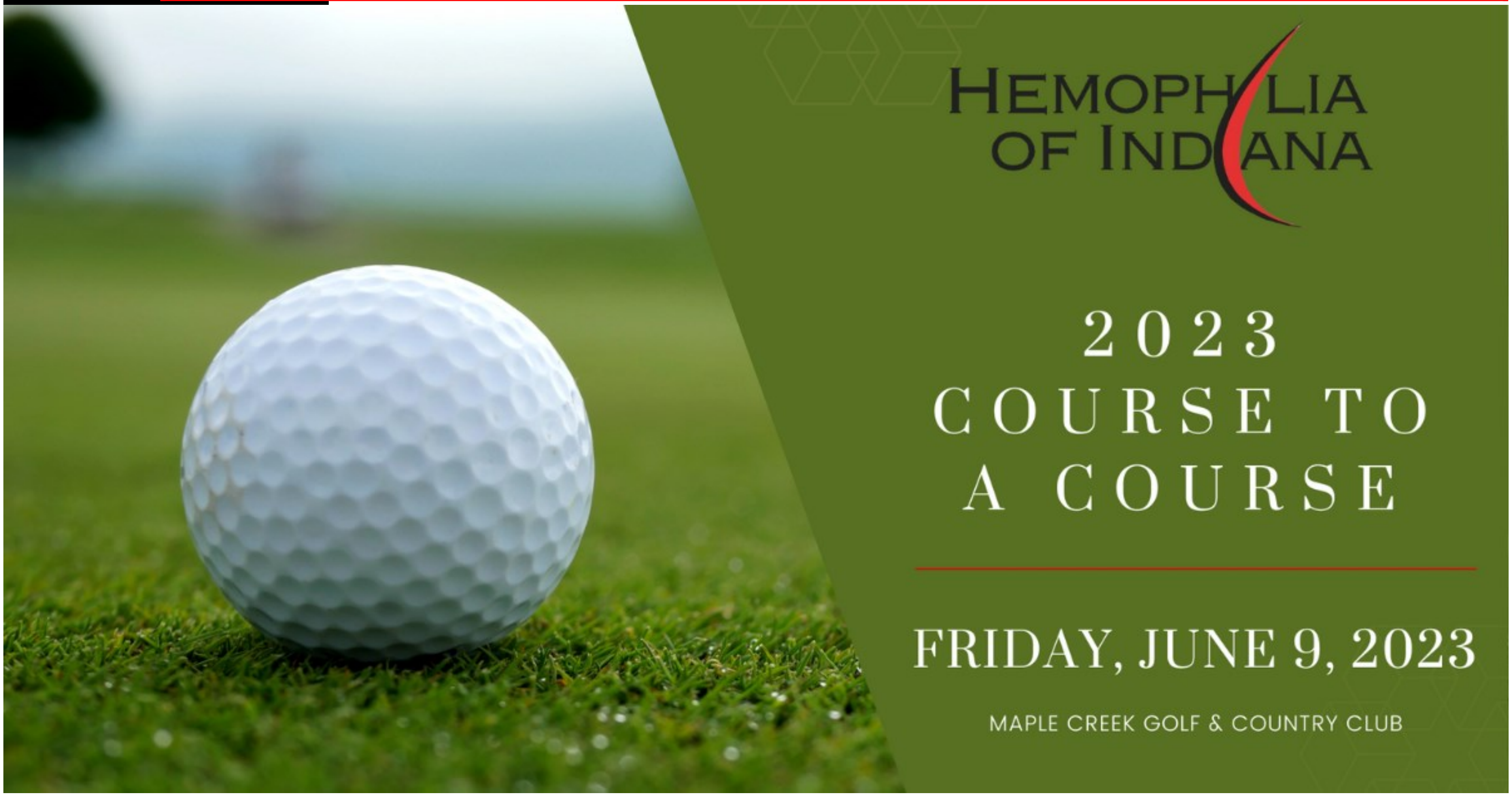










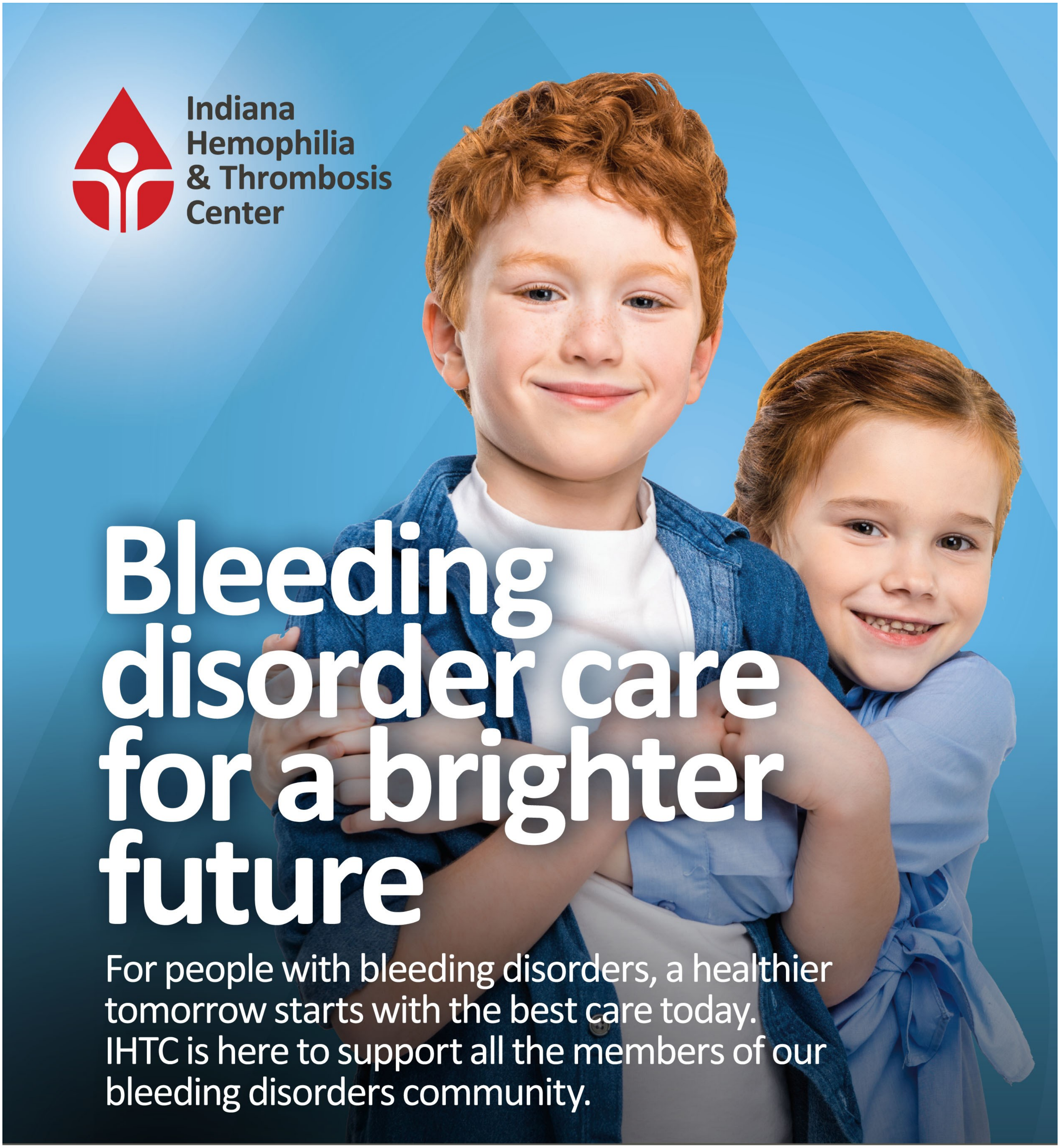


HEMOPHILIA
OF INDIANA

2023
COURSE TO
A COURSE

FRIDAY, JUNE 9, 2023

MAPLE CREEK GOLF & COUNTRY CLUB



For people with bleeding disorders, a healthier tomorrow starts with the best care today. IHTC is here to support all the members of our bleeding disorders community.

The IHTC is home to Indiana's experts in rare bleeding & blood disorders, including:

Hemophilia | HHT | HVLM | Thrombosis & Clotting | Sickle Cell Disease | von Willebrand Disease

The Indiana Hemophilia & Thrombosis Center (IHTC) provides advanced care for both adult and pediatric patients with rare bleeding and blood disorders. As Indiana's only federally recognized hemophilia treatment center, IHTC is one of the nation's largest HTCs, delivering innovative, multi-disciplinary care in Indianapolis and at outreach clinics across the state. Visit ihtc.org

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Indiana Hemophilia & Thrombosis Center, Inc. | 8326 Naab Road | Indianapolis, IN 46260 | 877.CLOTTER

Scholarship Opportunities

Applications are now being accepted for the 2023/2024 Judy Moore Memorial Scholarship Program and the 2023/2024 Ed Magoni Scholarship. Application forms and instructions can be found under the Member Resources tab on Hemophilia of Indiana's website: (www.hoii.org/member-resources/scholarships)

Scholarships will be awarded to those inflicted 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.

Submission deadline for both scholarships is May 22, 2023. Late submissions WILL NOT be accepted. All submissions must be typed and submitted via email as attached document or sent via mail. Contact Angel DiRuzza at 317-570-0039 or adiruzza@hoii.org with any questions.

Upcoming Educational Dinners

Contact Angel DiRuzza at adiruzza@hoii.org to register.

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

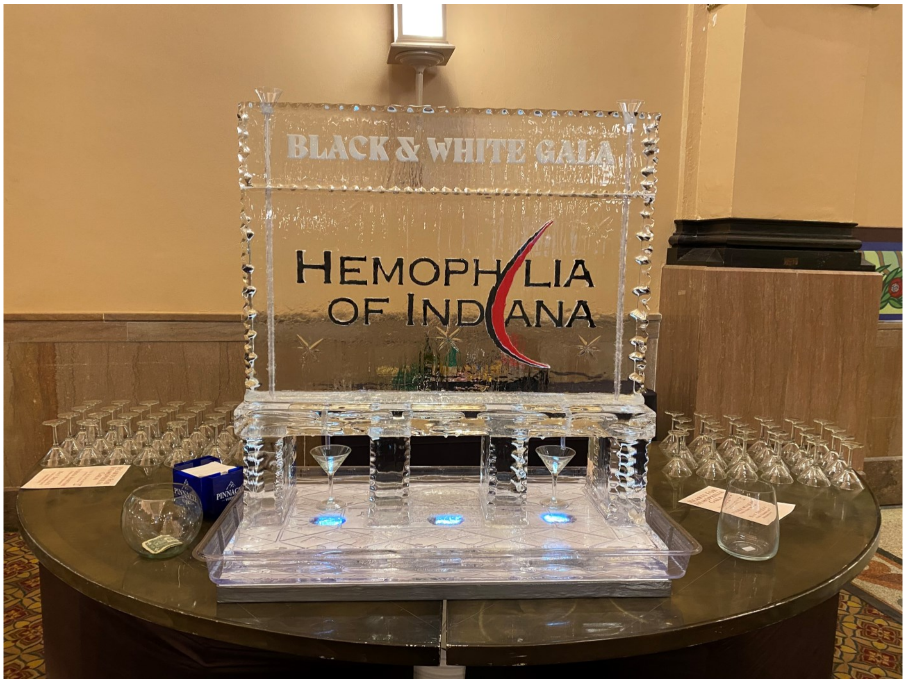
Topic: World Hemophilia Day Celebration
Sponsored by Octapharma
When: Monday, April 17th
Where: Paramount Theater Centre & Ballroom
Anderson, IN 46051

Topic: TBD
Sponsored by Sanofi
When: Tuesday, May 2nd
Where: Fort Wayne - Venue TBD

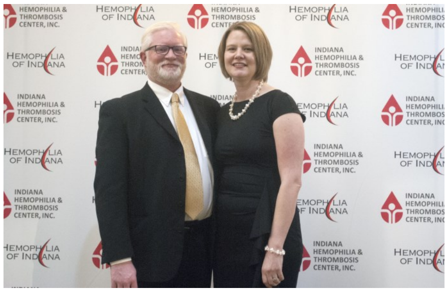
Topic: TBD
Sponsored by Medexus
When: Thursday, May 25th
Where: Das Dutchman Essenhaus
Middlebury, IN 46540

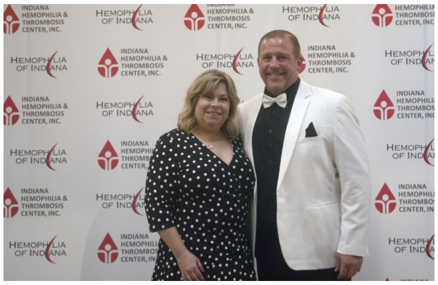
2023 Hearts for Hemophilia "Black & White" Gala

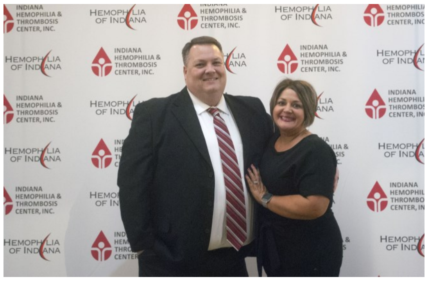
The 2023 Hearts for Hemophilia "Black & White" Gala was held Friday, January 29th at the beautiful Grand Hall at Union Station, Crowne Plaza Hotel in downtown Indianapolis. This year's theme was the "Black & White" Gala. The Hearts for Hemophilia Gala is one of Hemophilia of Indiana's largest fundraisers with the proceeds directly benefiting the many programs and services provided to the bleeding disorders community through out the State of Indiana. Hemophilia of Indiana (HoII) would like to thank this year's keynote speaker, Dr. Kyle Davis. Dr. Davis is a person with hemophilia and is one of the newest hematologists with the Indiana Hemophilia & Thrombosis pediatric team. Dr. Davis did an incredible job of telling his story of growing up with a bleeding disorder and his interests in bleeding disorder research , global health, and patient advocacy. The evening concluded with a casino and the music of Stella Luna and the Satellites! A good time as had by all and it was a successful night of fundraising and support for the bleeding disorders community. Hemophilia of Indian also like to thank all of our sponsors for their support. Make sure to mark your calendars for the 2024 Hearts for Hemophilia Gala that will be held on Friday, February 9, 2024! To see more pictures go to www.hoii.org or on our Facebook page (HemoIndy)!

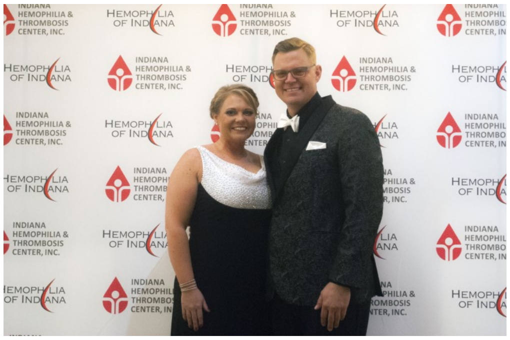


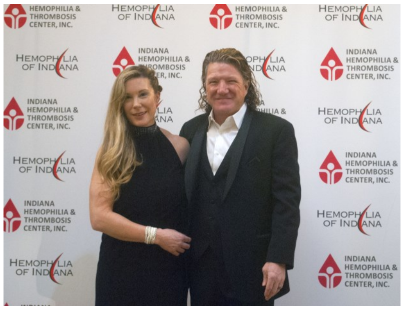
2023 Hearts for Hemophilia "Black & White" Gala











I have a bleeding disorder. What should I tell my family

If you are living with a bleeding disorder—or if you are a carrier—you should consider talking to family members.

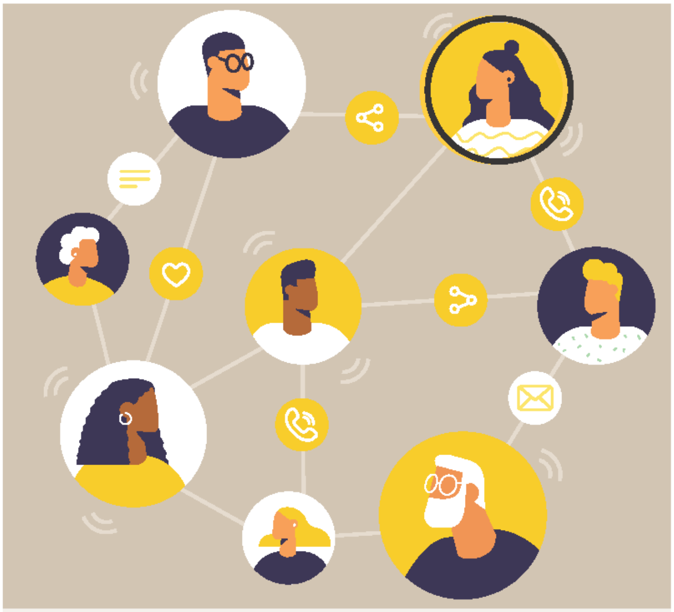
Bleeding disorders like hemophilia, von Willebrand disease (VWD) and others run in families. To help patients with inherited conditions understand the genetic aspects of their disorders, the Indiana Hemophilia and Thrombosis Center (IHTC) offers genetic counseling for patients and their families.

If you are diagnosed with a bleeding disorder—or if you are a carrier of a bleeding disorder—genetic counselors at the IHTC will help you understand how your condition is inherited and will review your family history to help you identify any family members who may benefit from testing.

Important facts to review with family

- The type of bleeding disorder identified in your family
- Availability of testing

Let your family know the IHTC is always available for any questions or concerns. You're always welcome to refer family members to us if they need assistance you cannot provide.



IHTC Genetic Counselors can help

Talking about your family history of a bleeding disorder can be hard. IHTC is available to help any way possible. IHTC genetic counselors can talk to you about:

- Who to talk to
- What to say
- How to approach family members

Contact IHTC Genetic Counseling

GC@ihtc.org
317-871-0011 Ext. 556

BetterYouKnow.org

This website by the National Hemophilia Foundation (NHF) is for women and men who may experience symptoms of a bleeding disorder but have not been diagnosed. The site's risk assessment, tools, and other information can help you learn whether you are at risk for a bleeding disorder and the next steps you can take to seek care.

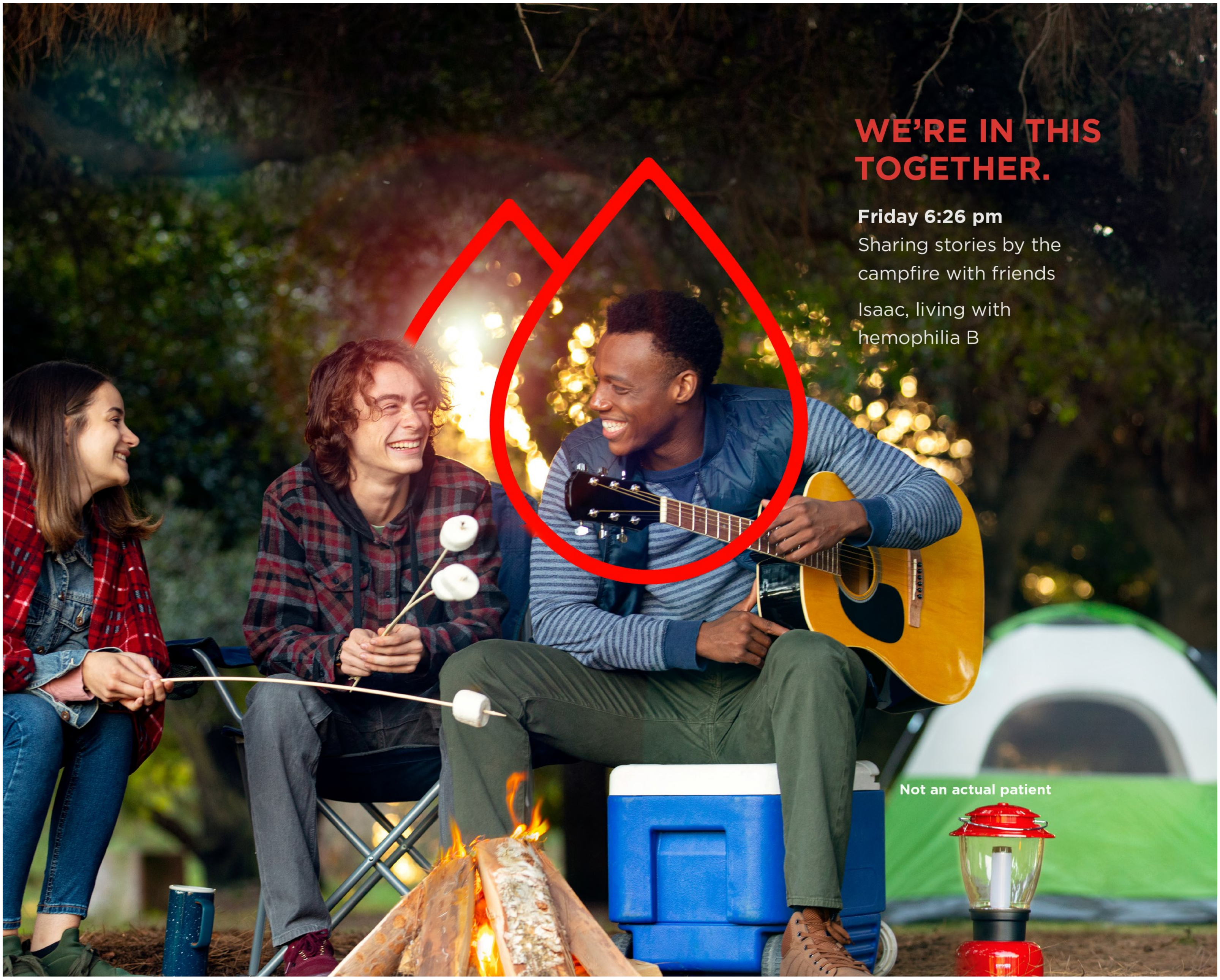
Indiana
Hemophilia
& Thrombosis
Center

8326 Naab Road, Indianapolis, IN 46260 • 317.871.0000 • ihtc.org

UNITE WITH US MAY 20TTH!!

Unite for Bleeding Disorders Walk

Fort Benjamin Harrison State Park
Indianapolis, IN



Let's make today brilliant.

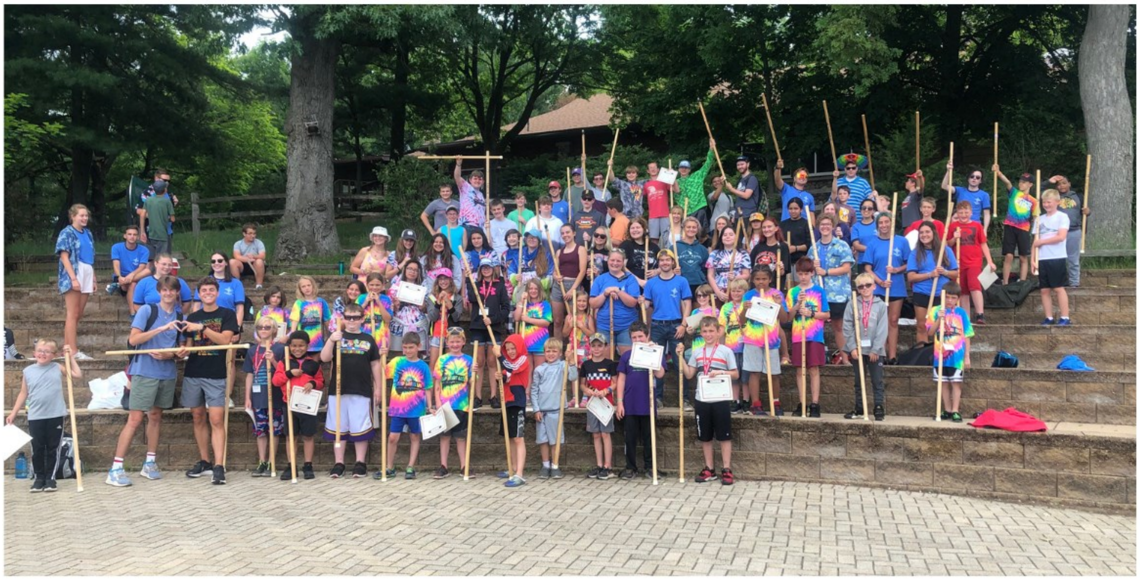
Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world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

bleedingdisorders.com | Takeda

CAMP BRAVE EAGLE

"Where the eagles soar!"

Indiana's summer camp for children with bleeding disorders and their sibings!



June 11 - 16, 2023
YMCA Camp Crosley
North Webster, IN

Hurry!! Register ASAP!!

https://www.ihtc.org/campbraveeagle

Deadline to register April 21st!!!

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*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!

- 2023 Unite for Bleeding Disorders Walk - May 20
- 2023 Course to a Cure - June 9
- 2023 Camp Brave Eagle - June 11-16

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!!!