

Vital Link

HEMOPHILIA
OF INDIANA

...For Hoosiers Living with a Bleeding Disorder

July 2024

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

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The 2024 Camp Brave Eagle was held June 11-16 at the beautiful YMCA Camp Crosley. Camp Brave Eagle is Indiana's only "traditional" summer camp for kids affected with a bleeding disorder and their siblings. Campers ages 7-16 participate in "traditional" camp activities such as archery, swimming, canoeing, kayaking, and much more! In addition, our campers are given the opportunity to earn their "Big Stick". Every camper goes through self-infusion training with staff from the Indiana Hemophilia & Thrombosis Center. If successful, the camper receives their "big stick". Each "big stick" is engraved with the campers name and year and bring back each year they attend camp. This training is vital to our affected campers to teach them independence with their care. Their siblings get the opportunity to "put themselves in their siblings shoes" and get a small idea of how bleeding disorders affect their sibling. The campers encourage each and support each other through the process cementing life long bonds and friendships. This year 89 campers earned their big stick! There were 33 campers that earned their big stick for the first time of which 15 were new campers! Two campers completed their big stick for the 5th time! Hemophilia of Indiana would like to thank all of our 2024 Camp Brave Eagle sponsors as well as all of our donors who help make camp possible. Through this generous support, Hemophilia of Indiana was able to provide full and partial scholarships to 95% of the campers. Check out our Facebook (Hemolndy) more pictures from the 2024 Camp Brave Eagle!

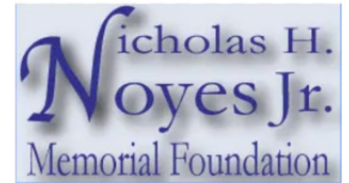


Thank you!



Thank you!

2024 Camp Brave Eagle Sponsors



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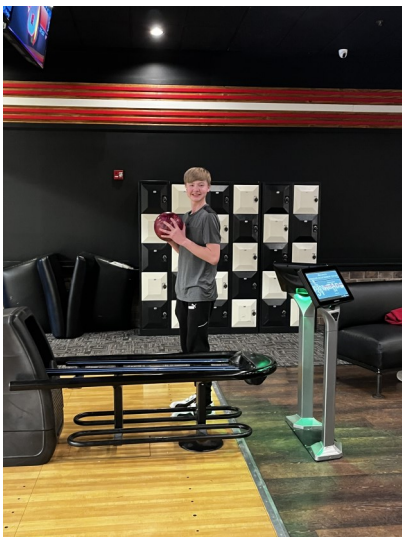


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2024 Bowling for Bleeding Disorders

The 2024 Bowling for Bleeding Disorders event was held April 21st at Pinheads in Fishers, IN. Bowling for Bleeding Disorders is a community event and fundraiser for the Judy Moore Memorial Scholarship Program. Started in 2013, the Judy Moore Memorial Scholarship Program provides scholarships for students affected with a bleeding disorder attending a junior college, undergraduate or postgrad university, or vocational school. Judy Moore's dedication and support of the bleeding disorders community spanned the HIV/AIDS epidemic, the transition to recombinant factor concentrates, and healthcare reform. She was an inspiration to all and left a proud legacy of care. It was a fun and successful afternoon that included education and bowling! It was another great turnout and everyone had a fun time bowling and supporting the bleeding disorders community!



2024 Course to Cure

The 2024 Course to a Cure originally scheduled to be May 17 was moved to Friday, June 28th and was at Maple Creek Golf & Country Club. This is the 35th Anniversary of the Course to a Cure event! It was a beautiful day for our 28 teams and was a very successful fundraising event for the bleeding disorders community of Indiana! Hemophilia of Indiana would like to thank the staff at Maple Creek for their efforts in help making the event so successful.



OUR VISION: A WORLD WHERE NO LIFE IS LIMITED BY GENETIC DISEASE



Learn about gene therapy research for hemophilia.



Interested in enrolling in a Spark-sponsored hemophilia gene therapy clinical trial?



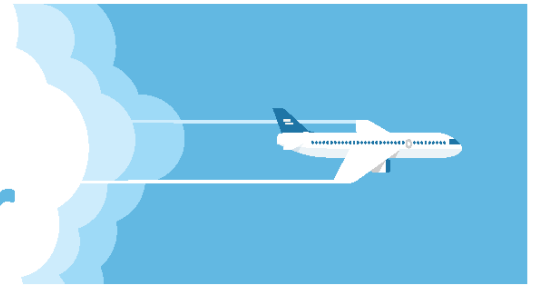
Want to know more about gene therapy clinical trials?

At Spark® Therapeutics, we are committed to discovering, developing and delivering gene therapies.

Discover more about gene therapy research



Traveling with a Bleeding Disorder



As you schedule summer plans and upcoming travel, it is important to consider your bleeding disorder.

Travel should be enjoyable and easy. Here are some tips to make it smooth for you and your family:

General Preparations

- Call the IHTC for a travel letter and always carry it with you on your trip.
- Plan ahead and make sure you have extra medications and supplies in case you have any travel delays.
- If you need extra supplies or a prescription from IHTC, please call at least 2 weeks before you leave for your trip.
- Avoid placing medications in a hot car; maintain at room temperature. Hemlibra should be kept in a cooler; it is only stable at room temperature for a combined 7 days.
- Find the contact info of the HTC closest to your travel destination in case of an emergency.

Scan the QR code to view the HTC directory.



Prepare for Flying

- Pack clotting factor products and supplies in your carry-on luggage to avoid damage or loss.
- Medicines should have their original label attached.
- Call the airline two days before your travel to see if they have specific rules about flying with medicine.
- Call TSA Cares, a hotline for those with disabilities or medical conditions (1-855-787-2227).

Contact the IHTC with any questions as you prepare for summer travels (317) 871.0000.

Introducing Innovative Hematology

We are proud to share the news of the creation of IHTC's new parent organization, Innovative Hematology. Patients will continue to receive the same comprehensive care they have always received. Scan the QR code and learn what Drs. Amy Shapiro and Anne Greist have to say about this exciting change.



Unite
for Bleeding Disorders



HEMOPHILIA OF INDIANA

**HEMOPHILIA
OF INDIANA**

14th Annual Walk



10:15 to 11:30am

(CHECK-IN: 9:00 - 10:15 AM)



Sept. 7

SATURDAY



**FORT HARRISON
STATE PARK**
Indianapolis, IN

CONTACT US:

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www.uniteforbleedingdisorders.org



4 Sneaky Money Traps for Young People with Bleeding Disorders

Try to avoid costly culprits such as payment plans and auto-renewing subscriptions.

Author: Celeste Sepessy

Posted

January 5, 2024

Gen Z's spending power is growing, thanks to a historic job market and strong starting salaries. But young adults can face financial problems, and quickly, if they don't realize how much they're spending.

Natalie Stanger, a member of the [American Association of Daily Money Managers](#), recommends carefully monitoring your monthly income and expenses. Start with a budgeting app such as Mint, Honeydue, or You Need a Budget, or an online resource from your bank. But remember: "These apps are a tool," she says. "You have to do the work to review and modify your cash flow."

As you look through your finances, watch out for these four money traps.

Buy Now, Pay Later Plans

BNPL plans are alluring because they break up larger purchases into smaller payments, and some do so with no interest for, say, the first year. Nearly two-thirds of Gen Z buyers — more than any other generation — have used a BNPL plan, according to a [March 2023 survey by LendingTree](#).

The risk is that these installment plans may cause you to lose sight of the total purchase cost and take on unnecessary debt.

Stanger recommends using BNPL strictly for items you need but may not have the cash on hand to buy in one transaction, such as appliances, and only if you can pay off the plan within the interest-free period.

"That way you have stretched out your money, and it hasn't cost you anything in interest," she says. If you extend payments beyond the introductory period, transfer the balance to a lower-interest credit card.

Monthly Subscriptions

Americans spend \$219 per month on subscriptions, [according to C+R Research](#). From music streaming to curated clothes delivery, auto-renewing services quickly accumulate.

“Prioritize which subscriptions are best for you. You don’t need every service,” says Brian DuVal, a 22-year-old with severe hemophilia A. After considering his options for streaming services, for example, DuVal decided on YouTube Premium and opted out of others.

Stanger suggests periodically reviewing your financial statements to know what you’re paying for and canceling the subscriptions you no longer use.

Food Delivery Charges

The pandemic normalized food delivery services, but the convenience comes at a cost — more than 40% of the average meal price includes fees that go to the service provider and delivery person.

“These conveniences add up to a lot of money in a month’s time,” Stanger explains.

Next time you’re craving a carne asada burrito, walk or drive to your favorite spot to skip the delivery fees. Better yet, buy the ingredients from a store and make the meal at home. If you want food delivery, save it for a rare occasion.

Health Insurance

Managing health insurance costs starts with selecting the best plan for you, which might not be the least expensive one, DuVal says. Plans with lower premiums might end up costing you more for the treatments you need.

DuVal recommends meeting with someone at your hemophilia treatment center or an insurance navigator to ensure your plan will provide adequate coverage for your care.

“People with bleeding disorders can face an additional financial burden,” he says. “We rely on expensive medication, and receiving access to medication should always be the first priority.”

Originally posted in the National Bleeding Disorders HEMAWARE Magazine

2024 Hemophilia of Indiana Annual Meeting August 17 & 18, 2024

Crown Plaza Hotel - Indianapolis Airport

Annual Meeting Agenda

Topics:

Life Transitions
Pharmacy Engagement
Women's Health - Chance to talk to
the Experts
Shared Decision Making
Recipe for Healthy Lifestyle
Celebrating Connection
Spanish Track!

And Much More!!!




Registration deadline - August 1st

<https://hoii.org/educationalprograms/annual-meeting/>



Innovative Hematology

Indiana Hemophilia
& Thrombosis Center



A future where you can flourish with a blood disorder

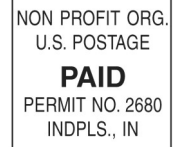
A future where you flourish starts with the best care today. The IHTC is here to support all the members of our bleeding disorders community.

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



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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!

- 2024 Annual Meeting - August 17th & 18th
- Unite for Bleeding Disorders Walk - September 7th
- NBDF Bleeding Disorders Conference - Sept. 12th-14th

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!

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

