

Vital Link



...For Hoosiers Living with a Bleeding Disorder

March 2022

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

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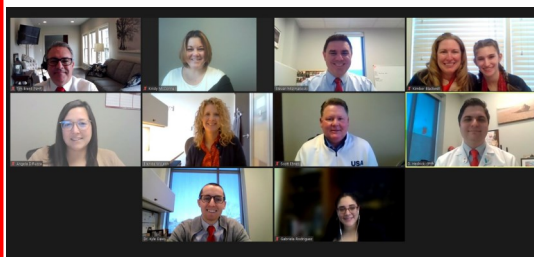
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Washington Days 2022

2022 Washington Days were held virtually on March 2nd. Washington Days is an opportunity to meet with Indiana's federal legislative members and advocate on behalf of the bleeding disorders community. The Indiana team was made up of staff from Hemophilia of Indiana, the Indiana Hemophilia & Thrombosis Center, and community members. This year's issues included Bleeding Disorders Awareness Month (March!), Federal Funding for Bleeding Disorders Programs, and The HELP Copays Act. Maintaining support for federal bleeding disorder programs is crucial to further research, enhance prevention, and access to care. Our ask to our representatives was maintain all current funding levels for the National Institute of Health, Health Resources and Services Administration (HRSA), and the Center for Disease Control and Prevention (CDC). In addition to maintaining federal funding levels, the other big "ask" this year was to support policies that increase affordability and access to care. The HELP Copays Act was introduced in the House of Representatives (HR-5801) and would require all insurance plans to count all copays (regardless of who pays) towards a person's OOP maximum (please see next page for more detailed information). The bill is a bipartisan and we were asking Representatives to co-sponsor and support the bill. In the Senate, we asked our Senators to either introduce a companion bill or support one when introduced. Overall, the meetings were very engaging and it was a great opportunity to support and advocate on behalf of Indiana's bleeding disorders community!



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.





Indiana
Hemophilia
& Thrombosis
Center

Bleeding disorder care for a brighter future

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 HTC's, delivering innovative, multi-disciplinary care in Indianapolis and at outreach clinics across the state. Visit ihtc.org

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

Upcoming Educational Dinners:

Contact Angel DiRuzza at adiruzza@hoii.org to register.
Check out our Facebook (@HEMOINDY) page and website calendar for
more details on upcoming in person
educational dinners!

Topic: World Hemophilia Day 2022 Program
Sponsored by Sanofi Genzyme

When: Tuesday, April 5th

Where: Giordano's
4110 E 82nd St
Indianapolis, IN 46250

JIVI[®]
ADYNOVATE[®]

Jivi
antihemophilic factor
(recombinant) PEGylated-augl
LET'S GO

PK (Pharmacokinetics) Study Data



Talk to your doctor
about the study.



Scan the QR code to learn more
about PK at UnderstandingPK.com

PK; Pharmacokinetics

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Mindful March: Healthy brain exercises

IHTC Mental Health experts recommend these easy mindfulness techniques

March marks the second anniversary of many of the changes resulting from the pandemic; and COVID-19—like an unwelcome houseguest—has vastly overstayed its welcome. Although there are some reasons for cautious optimism (vaccine availability, increased immunity, *hopefully* declining positivity rates), the last 24 months have really done a number on our mental and physical health. The place where mental health and physical health most clearly overlap is in the brain. So what has living through this unprecedented stressor done to our brains?

More anxiety. The perfect biological recipe for anxiety is a threat or stressor plus uncertainty. Since COVID-19 was a novel coronavirus, we initially knew very little about it or what to do. *What was safe and what was being paranoid?* As time moved on, this transitioned to: *When will schools and workplaces reopen and when will this be over?*

Less growth. Social isolation has been bad for our mood and relationships, but it has also meant less interaction and stimulation for our brains. Brains do not like to be bored. With less interaction, there is less to encourage brain cells to grow. When we are lonely and disconnected from others, our brains literally work less well—with greater cognitive decline associated with this type of isolation.

More fuzzy. There has been a lot of hype about pandemic brain fog. Brain fog is real. Long-term stress—like the stress of what feels like a never-ending pandemic—makes it more difficult for our brains to work, so it takes more effort to think clearly. In the same way it is harder for our body to run at top speed when we have not slept well, brains can't work as well when they're tired.

So, our brains are jittery, shrinking, and fuzzy ... but there is good news! We do not have to wait for the pandemic to officially end for our brains to get back to their pre-pandemic level of function (see techniques above)!

Mindful eating

Taking the time to focus on eating in the moment can help reduce overeating as well as stomach upset.

Take the time to focus all of your energy on the process of eating. After banishing phones, tablets, computers, and TVs, take a few slow deep breaths. Try to listen to your body. *How hungry are you?* As you take a bite, slow down and really experience the flavor, texture, and experience of eating this specific bite. As you continue with your meal, take note of how you are feeling. *How do you notice you are getting full other than the plate being empty?*



Mindful walking

Mindful walking does not require a long walk or even a specific location.

Make a point of focusing on what your body does as you are walking. The way your foot comes in contact with the pavement and how your knee and leg work together to pick up your foot. *What do you see, hear, and smell around you?* A short walk can help reduce stress, improve attention and focus and help your body too. If you are having a moment that is especially anxious, fuzzy, or overwhelmed, try the 5 senses technique (just search "54321 Grounding Technique" online!).



Above are some easy mindfulness techniques you can try. Mindfulness techniques can be helpful to address issues with anxiety, cognitive decline and brain fog. Mindfulness simply refers to an increased focus on what we are experiencing in the moment, without interpretation or judgment.

The IHTC team is here for you

IHTC's team of Mental Health experts specializes in how bleeding and blood disorders impact mental and emotional health. If you are an IHTC patient and you and your family need help to cope with your condition or to address other sources of stress that make your condition more difficult to handle, you can contact us any time.

Call 317-871-0000



The Judy Moore Memorial Scholarship

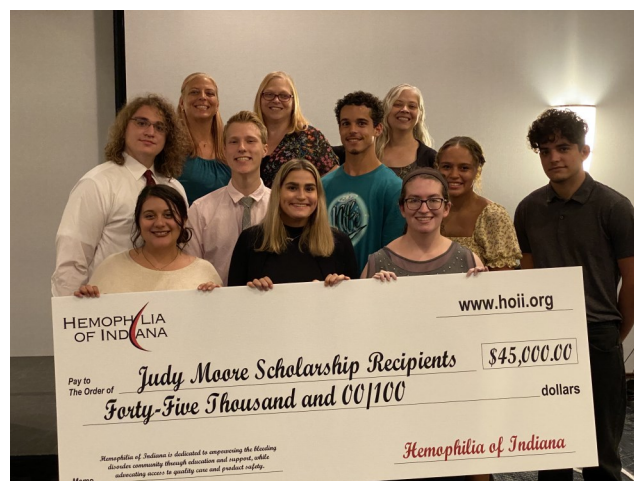
Judy Moore joined the Indiana Hemophilia & Thrombosis Center as a social worker in 1999. She first entered the hemophilia care arena in 1990 through employment at Hemophilia of Indiana. Judy's experience serving the hemophilia community spanned the HIV/AIDS epidemic, the transition to recombinant clotting factor concentrates, and most recently, healthcare reform. Judy was in 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 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.

To be eligible, you must:

- Have been diagnosed with a bleeding disorder, be an Indiana resident attending a school in the United States, and meet one of the following criteria:
- Be a high school senior or graduate, or
- Have completed high school or an equivalent (i.e. general equivalency diploma [GED]), or
- Be currently accepted to or enrolled in a junior college, college (undergraduate or graduate), or vocational school

Submission deadline for 2022 Judy Moore Memorial Scholarship is May 20, 2022. Late submissions will NOT be accepted. Please contact Angel Diruzza (adiruzza@hoii.org) with any questions.



Hemophilia of Indiana Ed Magoni Memorial Scholarship

Ed Magoni was a patient of the IHTC for 28 years. He was originally diagnosed with severe Hemophilia A in Dayton, Ohio, on his first birthday, despite having no family history. Ed was treated in Pennsylvania and New York before moving to Indiana where Dr. Shapiro and Dr. Greist and their staffs became integral parts of Ed's care and well-being.

Like many living with a bleeding disorder, Ed face many challenges and he met them head on. For example, his dream of becoming a professional football player was redirected to a career in sports journalism. Ed made many lasting friendships with fellow journalists as well as coaches and athletes. One of Ed's proudest accomplishments was his work with young, aspiring journalists and many of his interns have gone on to have successful carriers.

In the same spirit, Ed would be proud to encourage and support young people living with Hemophilia today. For this reason, his family has established the Ed Magoni Memorial Scholarship.

Scholarships will be awarded to those inflicted with a bleeding disorders, 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.

For the 2020-2021 academic year, Hemophilia of Indiana will award up to \$5,000 in college scholarships, including vocational schools.

To be eligible, you must:

- Have been diagnosed with a bleeding disorder, be an Indiana resident attending school in the United States. Deadline for the 2022 Ed Magoni Memorial Scholarship is May 20, 2022. Late submissions WILL NOT be accepted.

Applications for both scholarships and additional scholarship links can be found on the Hemophilia of Indiana Website!

2022 Hearts for Hemophilia “Fire & Ice” Gala

The 2022 Hearts for Hemophilia “Fire & Ice” Gala was held on Friday, January 28 at the historic Grand Hall at Union Station, Crowne Plaza Hotel - Downtown Indianapolis. There were over 150 attendees and it was an incredibly successful night with all proceeds directly benefitting the programs and services Hemophilia of Indiana provides to the bleeding disorders community of Indiana. The event included a silent and live auction, a casino, and the incredible music of Greta Speaks. Hemophilia of Indiana would like to thank all of our sponsors, supports, and donors! The 2023 Hearts for Hemophilia “Black & White” Gala will be held on Friday, January 27, 2023. More pictures from the evening can be found on the Hemophilia of Indiana website and Facebook page (@HemoIndy)!



A **ONCE-WEEKLY** TREATMENT OPTION FOR HEMOPHILIA B.



HOW DOES
THIS FACTOR IN?

To find out about a prescription
option, talk to your doctor or visit
[OnceWeeklyForHemophiliaB.com](https://www.OnceWeeklyForHemophiliaB.com)



Bowling for Bleeding Disorders

When: April **16th**, 2022 from 11am-2pm

Where: Pinheads (13825 Britton Park Rd, Fishers, IN 46038)

What: Help raise bleeding disorder awareness and raise \$\$ for Hemophilia of Indiana's Judy Moore Scholarship Program

HOW TO GET INVOLVED:

#1) Register to attend the Bringing Awareness through Bowling Program online at www.hoii.org/events/bowling
(Program includes education program and pizza lunch)

#2) Form your team (up to 4) and ask friends/family/coworkers to support you and your by donating at by credit card at www.hoii.org/donate or cash/check! No amount is too little or too much!!

*All donations are tax deductible!

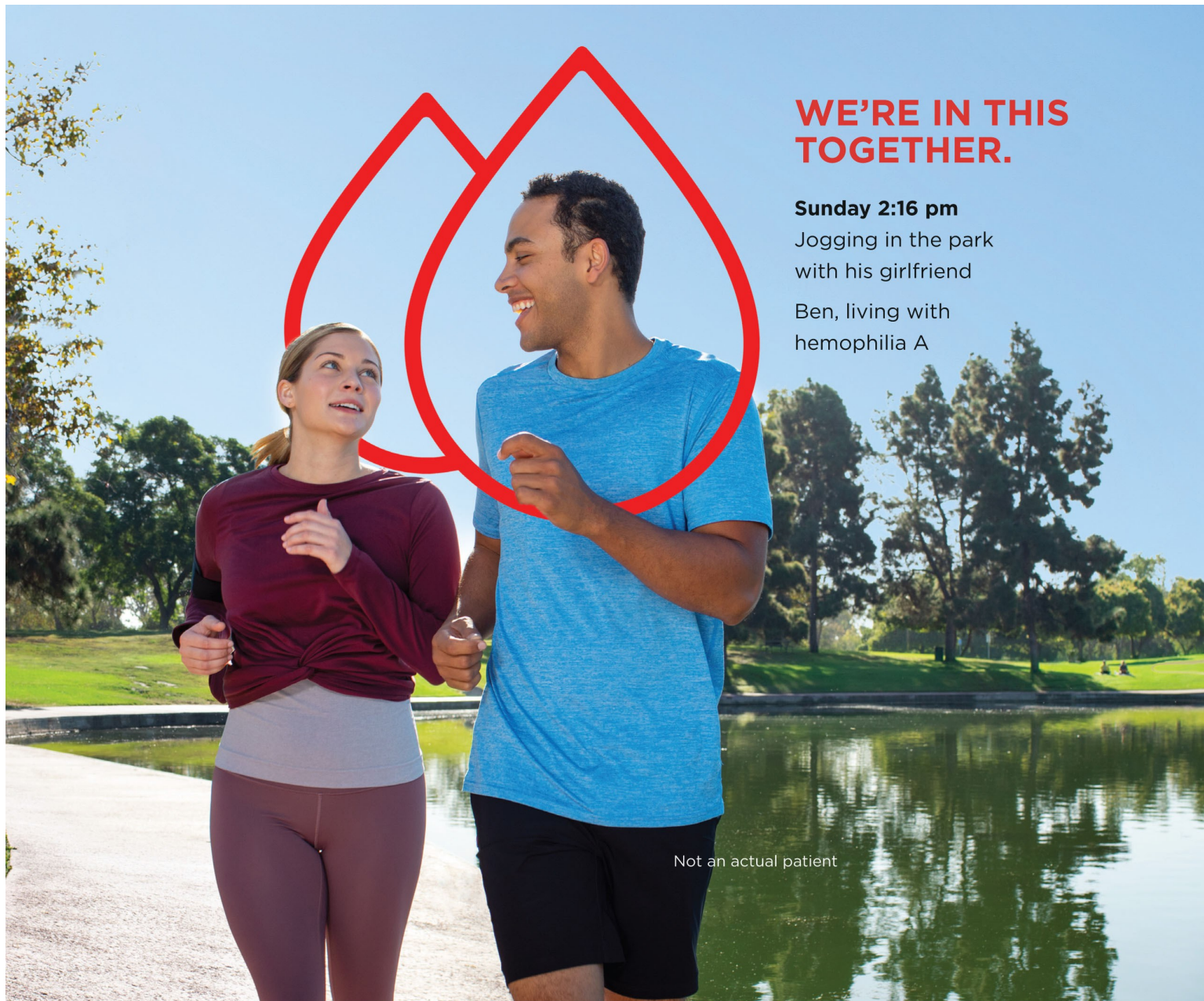
*All participant must be registered!

***Registration deadline Friday, April 8, 2022**

*Contact Kristy McConnell @ kmccconnell@hoii.org or
(317) 570-0039 with any questions!

Presenting Sponsor:





WE'RE IN THIS TOGETHER.

Sunday 2:16 pm

Jogging in the park
with his girlfriend

Ben, living with
hemophilia A

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.

bleedingdisorders.com





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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!

- 2022 Bowling for Bleeding Disorders - April 16th
- 2022 Course to a Cure Golf Outing - June 6th
- 2022 Annual Meeting - August 13th & 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!!!

