

# Vital Link



## ...For Hoosiers Living with a Bleeding Disorder

March 2024

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## **2024 Washington Days**

On March 6-8, an Indiana team made up of staff from Hemophilia of Indiana and Indiana Hemophilia & Thrombosis Center and community members headed to Washington DC to be a part of the National Bleeding Disorders Foundation (NBDF)'s 2024 Washington Days! NBDF's Washington Days is an opportunity for people affected by a bleeding disorder to advocate for issues that are important to them. This year hundreds of volunteer advocates from across the United States met with legislators and staff to discuss this year's issues. This year we were advocating on behalf of the "Help Ensure Lower Patient (HELP) Copays Act (S. 1375 / H.R. 830). The HELP Act has been introduced to ensure accumulator adjustor programs do not prevent copay assistance programs from accounting against a patient's out-of-pocket costs. Nearly all (99.6%) of copay assistance is used for brand-name drugs that do not have generic alternatives such as bleeding disorders medication. Under accumulator adjustor programs, most patients are caught off guard several months into the plan year when their financial assistance has run out and they are faced with bills for the full cost of their medication which, can easily run into thousands of dollars. In addition to the support for the HELP Copays Act, our team is calling on Members of Congress to sign a letter to the Department of Health and Human Services (HHS) requesting enhanced enforcement of current essential health benefits (EHB) policies that would prevent narrow formularies that don't cover treatments for all bleeding disorders. Narrow formularies are when health plans significantly limit the medications they cover. An example is a health plan only covering one type of factor medication for ALL bleeding disorders. This letter is to ask HHS to enforce their regulation that requires plans to cover recommended drug treatments regimens that "treat all disease states". **How can you help??** You can help the bleeding disorders community by contacting your federal representatives and ask them to support the above issues!! If you help finding out who your elected officials are go to <https://www.hemophilia.org/advocacy> on NBDF's website.

**Our Indiana team would like to thank the offices and staff of Congressman Andre Carson, Congresswoman Victoria Sparts, Congressman Larry Buchon, Congressman Jim Baird, Senator Young, and Senator Braun for meeting with our team and allowing us to advocate on behalf of bleeding disorders community of Indiana!**



## Washington Days



NATIONAL BLEEDING DISORDERS FOUNDATION

NEARLY ALL - 99.6 PERCENT - OF COPAY ASSISTANCE IS USED FOR BRAND-NAME DRUGS THAT DO NOT HAVE GENERIC ALTERNATIVES.

MANY OF AMERICA'S MOST VULNERABLE PATIENTS RELY ON ONE OR MORE HIGH-COST MEDICATION EVERY DAY.



## Washington Days



NATIONAL BLEEDING DISORDERS FOUNDATION

WHEN HEALTH PLANS AND PHARMACY BENEFIT MANAGERS EXCLUDE COPAY ASSISTANCE PAYMENTS FROM COUNTING TOWARD A PATIENT'S OUT-OF-COST, THE HEALTH PLAN ESSENTIALLY GETS PAID TWICE.



## Washington Days



NATIONAL BLEEDING DISORDERS FOUNDATION

UNDER ACCUMULATOR ADJUSTOR PROGRAMS, MOST PATIENTS ARE CAUGHT OFF-GUARD SEVERAL MONTHS INTO THE PLAN YEAR WHEN THEIR FINANCIAL ASSISTANCE HAS RUN OUT, AND THEY ARE FACED WITH BILLS FOR THE FULL COST OF THEIR MEDICATION, WHICH CAN EASILY RUN INTO THE THOUSANDS OF DOLLARS.



## 2024 SCHOLARSHIP OPPORTUNITIES!!!

Applications are now being accepted for the 2024/2025 Judy Moore Memorial Scholarship Program and the 2024/2025 Ed Magoni Memorial 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](http://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 applicants that provides the best combination of a creative and persuasive essay, excellent recommendations, and superior academic standing.

Submission deadline for both scholarships is May 27, 2024. 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](mailto:adiruzza@hoii.org) with any questions.

Additional scholarship opportunities are also listed the above website.



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# Correcting the Record on Copay Assistance and Accumulator Adjustment Policies

## MYTH

**Copay assistance provided by pharmaceutical manufacturers keeps drug prices high, by incentivizing the use of high-cost treatments instead of lower cost generic equivalents.**



## FACT

Copay accumulator adjustment policies (CAAPs) largely target specialty medications for which there are generally no generic equivalents available. In fact, data shows that for all commercial market claims for specialty medications where copay assistance was used, only 3.4% of those claims were for a product that may have a generic alternative available.<sup>1</sup> If copay assistance programs were intended to drive patients away from generic alternatives, then this share would be significantly higher.

The truth is that copay assistance is a critical lifeline that helps ensure the most vulnerable patients can access their needed medications. When barriers prevent patients from accessing these medications, it ends up costing the health system more money due to complications and worsening health outcomes. Research has found that the cost of patients not receiving optimal medication therapy is over \$528 billion each year in the United States.<sup>2</sup>

## MYTH

**Copay assistance enables patients to circumvent plan design and go right to the highest-cost drugs.**



## FACT

Patients taking specialty medications must first go through utilization management (UM) protocols imposed by their health plan, such as prior authorization and step therapy, before being granted access to the medication their doctor has prescribed. It is only *after* receiving approval for his/her medication from the health plan that patients can request copay assistance.

## MYTH

**If patients don't like accumulator policies, they should be better health care consumers and choose a health plan that works better for them.**



## FACT

When it comes to choosing a health plan, most patients do not have a choice. Plans with copay accumulators are either all that is offered, or all they can afford. For many Americans, it all comes down to the cost of the premium, and sadly, the lowest premium plans come with the highest out-of-pocket cost burden. In fact, many employers only offer high deductible health plans (HDHPs) which can require a deductible of up to \$8,700 – which many patients cannot afford without assistance.

With more than 80% of commercially insured plans having copay accumulator policies, millions of Americans are insured, but left unable to exercise their health plan benefits to get the medications they need.<sup>3</sup>



# Correcting the Record on Copay Assistance and Accumulator Adjustment Policies

## MYTH

When patients are allowed to use copay assistance, they have less “skin in the game.”



## FACT

**Patients living with chronic illnesses don't have the luxury of forgoing certain health care treatments and services.** Copay assistance helps shoulder the increasingly high burden of out-of-pocket costs for needed medicines.

In recent years, **patients are being forced to pay more out of pocket than ever before.** More than half of all Americans are now in HDHPs, and the average deductible has increased 90% since 2015.<sup>45</sup> While 56% of Americans report being unable to cover an unexpected expense of over \$1,000, Affordable Care Act (ACA)-compliant plans are allowed to charge \$8,700 out of pocket for an individual and \$17,400 for a family in 2022.<sup>67</sup> **This is not a matter of choosing smarter – it is an impossible financial situation.**

## MYTH

Internal Revenue Service (IRS) guidance stands in the way of the Centers for Medicare & Medicaid Services (CMS) disallowing copay accumulator adjustor policies.



## FACT

This is a misreading of the IRS guidance. **Although critics often point to 2004 IRS informal guidance as preventing CAAP bans, the guidance does no such thing.**

The IRS informal guidance itself does not address copay assistance at all. What's more, the 2004 informal guidance predated patient cost-sharing protections that were set in the ACA, prior to the emergence of accumulator adjustor policies.

The IRS has since clarified its position on the use of copay cards for enrollees on a HDHP paired with a health savings account (HSA) that wish to contribute to their HSA, stating that the enrollee is only required to meet the minimum deductible to be considered to have met their financial responsibility. **Claiming IRS rules block copay help from counting towards a patient's deductible is simply untrue and harms America's most vulnerable patients.**

To set the record straight, **CMS should require that insurers and pharmacy benefit managers (PBMs) count all copayments made by or on behalf of an enrollee toward that enrollee's annual deductible and out-of-pocket limit.** CMS can do this in their annual updated guidance, known as the Notice of Benefit and Payment Parameters (NBPP), which informs health insurance plan design and implementation.

## REFERENCES

- 1 <https://www.iqvia.com/locations/united-states/library/fact-sheets/evaluation-of-co-pay-card-utilization>
- 2 [https://www.sciencedaily.com/releases/2018/04/180402160613.htm?utm\\_source=H2Rminutes](https://www.sciencedaily.com/releases/2018/04/180402160613.htm?utm_source=H2Rminutes)
- 3 <https://www.ajmc.com/view/contributor-providers-and-patients-push-back-payers-push-forward-co-pay-mitigation-programs>
- 4 <https://www.hemophilia.org/sites/default/files/document/files/NHE - National Patients and Caregivers Survey on Copay Assistance %28Key Findings%29.pdf>
- 5 [https://aidsinstitute.net/documents/2021\\_TAI\\_Double-Dipping\\_Final-031621.pdf](https://aidsinstitute.net/documents/2021_TAI_Double-Dipping_Final-031621.pdf)
- 6 <https://www.cnn.com/2022/01/19/56percent-of-americans-cant-cover-a-1000-emergency-expense-with-savings.html>
- 7 <https://www.healthcare.gov/glossary/out-of-pocket-maximum-limit/>

# Exercising with Hemophilia

People with hemophilia can experience pain, swelling, and bleeding, making it harder to do daily activities. Repeated bleeding in joints and muscles can cause permanent damage.

Doctors and physical therapists recommend that people with hemophilia should get regular exercise. The goal of strength training and conditioning is to increase your strength and improve your health without injuring your joints or muscles.

Making changes to your lifestyle and activities can help reduce chronic joint and muscle pain. Indiana Hemophilia & Thrombosis Center (IHTC) physical therapists can provide step-by-step education to help you make the best choices to improve your quality of life.

**Learn about the care IHTC  
physical therapists provide:**



As the warm weather approaches, time spent outside enjoying sunshine and physical activity will most likely increase.

People with hemophilia should consider the following:

- **Fitness goals:** What do you want to get from exercise?
- **Your care plan:** Follow your treatment plan including prescribed medications. This is important to remember as you increase activity
- **Range of motion:** If it hurts to move in certain ways, talk to a physical therapist about how to change your exercise routine
- **Joint disease or target joints:** Talk to a physical therapist about how this will affect your exercise





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



**June 16-21, 2024**

**YMCA Camp Crosley  
North Webster, IN**

**Register ASAP to secure your spot at camp!!**

**<https://www.ihtc.org/campbraveeagle>**



## 2024 Hearts for Hemophilia “Great Gatsby” Gala

The 2024 Hearts for Hemophilia “Great Gatsby” Gala was held Friday, February 9th at the historic Grand Hall at Union Station, Crowne Plaza Hotel - Downtown Indianapolis. Guests wore their best 1920’s inspired attire and participated in an evening of great food, fun, and most important fundraising and supporting the bleeding disorders community of Indiana! A huge thank you to all that attended, donation, and sponsored this very successful event!! Go to our Facebook (@HemoIndy) to check out more pictures!





**Thank you to our 2024 Hearts for Hemophilia  
“Great Gatsby” Gala Sponsors!!!**

**Title Sponsor:**



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# HEMOPHILIA OF INDIANA

## 2024

### CALENDAR OF EVENTS

**Hearts for Hemophilia Gala: *Union Station*: February 9**

**HFA Symposium: Indianapolis, IN: April 11-14**

**World Hemophilia Day: April 17**

**Bowling for Bleeding Disorders, *Pinheads*: April 21**

**Course to a Cure Golf Outing, *Maple Creek Golf & Country Club*: May 17**

**Camp Brave Eagle, *Camp Crosley*: June 16-21**

**Annual Meeting, *Crowne Plaza Hotel - Indianapolis Airport*:**

**Aug. 17-18\*\* (Date Change!)**

**UNITE for Bleeding Disorders Walk *Ft. Harrison State Park*: Sept. 7**

**NBDF Bleeding Disorder Conference, *Atlanta, GA*: Sept. 12-14**

**NEW Women's Retreat, *Renaissance Hotel-Indianapolis*: Oct. 19-20**

**Thanksgiving Day Run, *Dillon Park*: November 28**

**Year End Educational Program *The Wellington Fishers*: December 7**

***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.***

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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](http://ihtc.org)

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





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## **Mark your Calendars!**

- HFA 2024 Symposium - April 11 - 13
- 2024 Bowling for Bleeding Disorders - April 21
- Course to a Cure - May 17 (New Date!!)

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!!!**

