

# Vital Link



...For Hoosiers Living with a Bleeding Disorder

December 2021

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

Designed by: Kristy McConnell

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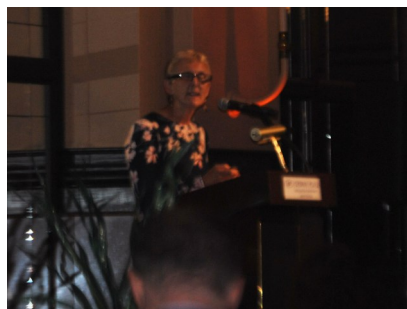
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## A Year In Review

2021 may not have looked like what we thought it would, but definitely better than 2020! Hemophilia of Indiana was able to have all of our events in person this year (following all safety protocols) and the goal is to continue to have in person events in 2022! There were some exceptions as Washington Days, HFA Symposium, and NHF's Bleeding Disorder Conference were virtual. Holl's event calendar started in April with the Bowling for Bleeding Disorders. It was a great turn out and a lot of money was raised for the Judy Moore Scholarship Program. This summer turned into the "Summer of Events" and started with the Course to a Cure Golf Outing the beginning of June, followed by Camp Brave Eagle and Polo at Sunset. For the first time in its 31 year history, the Hearts for Hemophilia Gala was moved from the winter to the end of July. The Annual Meeting was held in August and was immediately followed by the Unite for Bleeding Disorders Walk. The year concluded with the FitLivin THXRUN on Thanksgiving Morning and the Year End Education Event in December. Hemophilia of Indiana would like to thank all of our community members, donors, and sponsors that help make 2021 such an incredible year! Planning is already well underway for 2022 with lots of exciting fundraising and education events! Check out Hemophilia of Indiana's website ([www.hoii.org](http://www.hoii.org)) and social media pages for information regarding upcoming events and programs! The Board of Director's and Staff of Hemophilia of Indiana would like to wish everyone Happy Holidays and a very Happy New Year!!

# A Photo Year In Review!!





Indiana  
Hemophilia  
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From our compassionate staff, robust resources, and commitment to tailored treatment, you and your family will find comfort in IHTC's leading approach to a lifetime of quality hemophilia care.

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The Indiana Hemophilia & Thrombosis Center (IHTC) is the state's only federally-designated Hemophilia Treatment Center and the first HTC in the U.S. to receive national medical home certification. We offer comprehensive bleeding disorder care, all at one center. All members of IHTC's clinical care team have extensive experience and deep expertise in bleeding disorders. This offers our patients the comfort and convenience of having every aspect of their bleeding disorder care all in one location. [Visit \*\*ihc.org\*\*](http://ihc.org)



**NATIONAL HEMOPHILIA FOUNDATION**  
*for all bleeding disorders*

## **WHAT YOU NEED TO KNOW ABOUT THE NEW SKILLED NURSING FACILITY (SNF) LAW**

Starting October 1, 2021, SNFs can bill separately for hemophilia and other inherited bleeding disorder treatments administered to Medicare beneficiaries needing care in a SNF. This change allows the SNF to either provide the bleeding disorder treatment(s) themselves or contract with a third-party such as an HTC or specialty pharmacy.

Medicare covers short-term stays (less than 100 days) in SNFs. SNFs are paid a prospectively determined daily rate for all SNF services provided to patients covered under a Medicare Part A stay. This bundled payment includes nursing and therapy components, drugs, supplies, and equipment, in addition to a room/board and administration component to cover the cost of a typical patient. Prior to the passage of the Hemophilia SNF Access Act, very few SNFs would admit patients with bleeding disorders because the bundled payment rate did not adequately cover the cost of clotting factor therapies.

Under current law, Medicare allows for certain costly, highly specialized services that SNFs do not typically provide to be billed separately. As of October 1, bleeding disorder treatments have been added to this list. Separate billing under Medicare Part B for bleeding disorder treatments for SNF patients will rectify a long-standing problem for our community and will facilitate placing an individual with a bleeding disorder in a SNF, provided they meet the clinical criteria for placement.

**Q: Does this law only apply to hemophilia treatments?**

**A:** No, the change in the law applies to treatments for all inherited bleeding disorders including but not limited to those needed to treat hemophilia A, hemophilia B, and Von Willebrand disease (VWD). While the bill included hemophilia in its name, it included all inherited bleeding disorders. CMS has published the list of product codes ([J-codes](#)) that can be billed separately under Medicare Part B.

**Q: Is it only clotting factor treatments that are included?**

**A:** No, this change allows for all treatment modalities used to treat an inherited bleeding disorder.

**Q: What happens when a new treatment or therapy comes to market?**

**A:** The Secretary of HHS has the authority to expand the list of products that can be billed separately. In addition, during the annual rulemaking for the Medicare SNF benefit, NHF can recommend additions or other changes as part of the comment

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*for all bleeding disorders*

process. Any new FDA approved treatment that becomes available during that year will be included in our annual comment letter that will be made publicly available. So, while not immediate, the new treatment is expected to be included in the law.

Q: Who does the law apply to?

A: This law only applies to Medicare beneficiaries following a qualified hospital stay of at least three days (72 hours). Bleeding disorder beneficiaries are likely to use this benefit following surgery or a prolonged inpatient hospital stay. However, coverage under state Medicaid programs and private insurers varies with some allowing for treatments to be billed separately at a rehabilitation/nursing facility. If you are currently insured by private insurance and/or Medicaid and have concerns about placement please contact Marla Feinstein ([mfeinstein@hemophilia.org](mailto:mfeinstein@hemophilia.org)).

Q: How long will Medicare allow a beneficiary to stay at a SNF?

A: Medicare only pays SNF care for up to 100 days. During that time, beneficiaries are expected to show improvements to return to their activities of daily living.

Q: Are SNFs now required to admit Medicare beneficiaries with a bleeding disorder?

A: No, patients will need to meet the clinical criteria for a SNF admission. With passage of the Hemophilia SNF Access Act, the SNF will be adequately reimbursed for the costly treatments needed by patients with bleeding disorders, removing a major barrier to SNF care. NHF believes this should be sufficient to alleviate concerns that SNFs have had in accepting bleeding disorder beneficiaries.

Q: How will SNF billing work now?

A: SNFs will be able to bill for bleeding disorder treatments the same way they are billing for other Part B excluded services like chemotherapy and prosthetics. The SNF will know their billing methods for these excluded services. It is important to note that co-pays for beneficiaries will be required.

NHF will be updating this document as more information becomes available. If you have any additional questions or need assistance getting an individual into a SNF, please contact Marla Feinstein at [mfeinstein@hemophilia.org](mailto:mfeinstein@hemophilia.org).

## 13th Annual FitLivin THXRUN

The 13th Annual FitLivin THXRUN was held Thanksgiving Morning at Dr. James A Dillon Park in Noblesville, IN. This year's Run had over 300 walkers and runners! The THXRUN is a 4 mile and 1.5 mile run and/or walk. There is also a free 1/4 mile Kids run prior to the start of the THXRUN! The proceeds from this years Run benefiting the Judy Moore Scholarship Program! Did you know that the FitLivin THXRUN was started 13 years ago in the backyard of community members Kasey and Matt Shade?? The Run started with just under 50 participants and has grown tremendously over the years! Hemophilia of Indiana would like to thank everyone that registered, participated, and donated to this years FitLivin THXRUN!! To see more pictures from the THXRUN go to [www.fitlivinthanksgivin.com](http://www.fitlivinthanksgivin.com)!



**SAVE THE DATE**

*Hearts for Hemophilia  
"Fire & Ice" Gala*

**JANUARY 28, 2022  
6:30 PM**

**Crowne Plaza Indianapolis-Downtown  
123 West Louisiana St / Indianapolis**

IN HEMOPHILIA,  
THERE'S ONE THING  
YOU CAN COUNT ON



INNOVATION FROM  
NOVO NORDISK

## We strive to help improve the lives of people with hemophilia

For 30 years, Novo Nordisk has been a driving force for people living with rare bleeding disorders. We take pride in striving for innovative solutions to help improve patients' lives. This motivates us to uphold the highest standards in our product research and development. This vital research is just the beginning of our commitment in hemophilia.

We will continue our research and connect with people with hemophilia and health care professionals to ensure we understand and respond to the specific needs of the hemophilia community.

With a rich history, Novo Nordisk remains at the forefront of discovery. We are poised to continue to develop innovative solutions that can help improve the lives of people with hemophilia in the future.

Please visit [www.rarebleedingdisorders.com](http://www.rarebleedingdisorders.com)  
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## Change the way you picture living with Glanzmann's thrombasthenia

### Novo Nordisk is changing the way people like Cathy write their stories

That's why we are continuously seeking new ways to help support and educate the bleeding disorders community. Because, at Novo Nordisk, we're always committed to helping you make your potential possible.

Connect with us at [Facebook.com/ChangingHemophilia](https://Facebook.com/ChangingHemophilia)

Cathy has Glanzmann's thrombasthenia  
with refractoriness to platelets.

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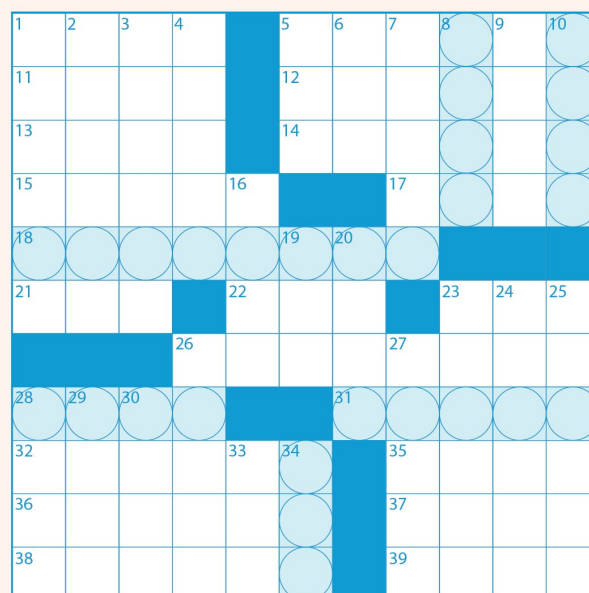
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**CAN YOU SOLVE**

# FOR A DIFFERENT HEMOPHILIA A

**« TREATMENT? »**

Test your HEMLIBRA knowledge



## ACROSS

1. Wine barrel
5. Deep fissures
11. Mideast gulf port
12. District
13. Ripped
14. Familiar with
15. Mean
17. Roost
18. The #1 prescribed prophylaxis for hemophilia A\*

\*According to IQVIA claims data from various insurance plan types from October 2019 to November 2020 and accounts for usage in prophylaxis settings in the US.

21. Calendar divs.
22. Regret
23. Banquet hosts (abbr.)
26. International travel necessity
28. Check out the \_\_\_\_\_ treated bleeds data with HEMLIBRA
31. Number of dosing options HEMLIBRA offers

\* Number of people with hemophilia A treated as of February 2021.

32. Small hole in lace cloth
35. Central Plains tribe
36. Melodic
37. Towering
38. Reduce
39. Spanish cheers

## DOWN

1. Memorable, as an earworm
2. Devotee
3. Medical fluids
4. Prepare to propose, perhaps
5. PC's "brain"
6. Owns
7. Concert venue
8. See Medication Guide or talk to your doctor about potential \_\_\_\_\_ effects
9. Winter hrs. in Denver and El Paso
10. HEMLIBRA is the only prophylactic treatment offered this way under the skin

16. Pre-Euro currency in Italy
19. Subway alternative
20. Relax
23. Human
24. New Orleans cuisine
25. Mentally prepares
26. Collared shirts
27. Instagram post
28. Ardent enthusiasm
29. Brontë heroine Jane
30. Old Portuguese coins
33. Opposite of WNW
34. \_\_\_\_\_ thousand patients have been treated with HEMLIBRA worldwide†

## SOLUTIONS

Across: 1. cask, 5. chasms, 11. Aden, 12. parish, 13. tone, 14. used to, 15. cruel, 17. nest, 18. HEMLIBRA, 21. yrs, 22. rue, 23. MCS, 26. passport, 28. zero, 31. three, 32. eyelid, 35. Oreo, 36. arose, 37. tall, 38. lessen, 39. cles, 40. Reiss, 33. ESE, 34. ten  
Down: 1. catchy, 2. adore, 3. serums, 4. kneel, 5. CPU, 6. has, 7. arena, 8. side, 9. MSTs, 10. shot, 11. lira, 19. bus, 20. rest, 23. mortal, 24. Creole, 25. steels, 26. polos, 27. photo, 28. zeal, 29. Eyre, 30. Reiss, 33. ESE, 34. ten

Discover more at [HEMLIBRA.com/answers](https://HEMLIBRA.com/answers)

## INDICATION & IMPORTANT SAFETY INFORMATION

### What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

### What is the most important information I should know about HEMLIBRA?

**HEMLIBRA increases the potential for your blood to clot. People who use activated prothrombin complex concentrate (aPCC; Feiba®) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots.**

### These serious side effects include:

- **Thrombotic microangiopathy (TMA)**, a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs
- **Blood clots (thrombotic events)**, which may form in blood vessels in your arm, leg, lung, or head

Please see Brief Summary of Medication Guide on following page for Important Safety Information, including **Serious Side Effects**.



**Medication Guide**  
**HEMLIBRA® (hem-lee-bruh)**  
**(emicizumab-kxwh)**  
**injection, for subcutaneous use**

**What is the most important information I should know about HEMLIBRA?**

**HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.**

**HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:**

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
  - confusion
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - stomach (abdomen) or back pain
  - nausea or vomiting
  - feeling sick
  - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - swelling in arms or legs
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - trouble seeing

**If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.**

See “What are the possible side effects of HEMLIBRA?” for more information about side effects.

**What is HEMLIBRA?**

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

**Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:**

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

**Tell your healthcare provider about all the medicines you take,** including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

**How should I use HEMLIBRA?**

**See the detailed “Instructions for Use” that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.**

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.

- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. **Do not** give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

**What are the possible side effects of HEMLIBRA?**

- See “What is the most important information I should know about HEMLIBRA?”

**The most common side effects of HEMLIBRA include:**

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

**How should I store HEMLIBRA?**

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 86°F (30°C).
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

**Keep HEMLIBRA and all medicines out of the reach of children.**

**General information about the safe and effective use of HEMLIBRA.**

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

**What are the ingredients in HEMLIBRA?**

**Active ingredient:** emicizumab-kxwh

**Inactive ingredients:** L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,  
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For more information, go to [www.HEMLIBRA.com](http://www.HEMLIBRA.com) or call 1-866-HEMLIBRA.  
This Medication Guide has been approved by the U.S. Food and Drug Administration  
Revised: 10/2018



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# Keeping Memory Sharp as You Age Helps You Manage Your Bleeding Disorder

Healthy habits are good for your brain

Author: Lisa Fields

Adults & Aging



Don't assume that as you age, so-called senior moments have to become a part of your future. Sure, everyone misplaces the keys occasionally. But by taking steps to maintain your brain health, you can keep your memory sharp, helping you to continue living independently and enjoying life to the fullest.

Having a bleeding disorder doesn't make you more or less likely to experience age-related memory issues, but no doubt you and your loved ones will feel more confident in your ability to manage your condition if you make brain health a priority.

"If a person truly is serious about it and they're ready to be proactive in taking care of themselves to decrease their odds of memory loss, there are lots of resources," says Sabrina Farina, LMSW, a senior social worker at Gulf States Hemophilia and Thrombophilia Center in Houston.

## Eat right

Eat whole foods rich in brain-healthy nutrients. Berries, leafy greens, fish, nuts and seeds all contain vitamins, minerals and other compounds that studies show are associated with slower cognitive decline. "It's changing that mind frame from 'oh, this is tasty and delicious' to thinking about how nutrition selections now benefit you," Farina says. "What are the better choices for our bodies and our brains?"

Don't try to take a shortcut to eating well by relying on supposed brain-health dietary supplements. The Global Council on Brain Health, an independent group of experts created by AARP in collaboration with Age UK, **recently concluded** that most older adults don't benefit from such supplements.

## Exercise

Regular physical activity can help keep you fit and mentally sharp by increasing blood flow to the brain, reducing inflammation and strengthening areas of the brain thought to be involved in memory.

“Any type of blood-pumping activity is really good for your brain,” Farina says. “Incorporate activity into a routine schedule, and every day do something to help yourself not be sedentary.”

## Sleep enough

Sleep-deprived people have trouble concentrating and are more likely to make mistakes, especially behind the wheel or when handling machinery. Prioritizing sleep helps boost your cognitive abilities.

“You need between 7.5 and nine hours of sleep,” Farina says. “That’s when your brain regenerates itself and works to help you be healthy neurologically.”

## Avoid stress

Too much stress may hamper your cognitive abilities over time. When possible, skirt stressful situations, and learn coping mechanisms.

“Pick ways that you can decrease your stress and anxiety,” Farina says. “Meditation, deep breathing—all of that helps.”

## Manage your health

If you’re diagnosed with diabetes or another chronic condition, it’s crucial to consider your bleeding disorder while managing that additional disease or complication. Have your hematologist or hemophilia treatment center team communicate with your other specialists. Also consider asking a pharmacist to review your medications, some of which may cause cognitive side effects.

“It’s definitely an extra layer for people with bleeding disorders who are managing other chronic conditions,” Farina says. “It’s like a domino effect: One impacts the other, as far as it eventually impacting our brain.”

## Stay engaged

Maintain social connections as you get older, because isolation may lead to depression or cognitive decline. And challenge yourself intellectually with games such as crossword and sudoku puzzles, which encourage your brain to function optimally.

“Be a lifelong learner, and be curious and willing to be engaged,” Farina says. “These things can stimulate and keep us challenged with our cognitive abilities.”

Find more information about healthy aging at [\*Steps for Living\*](#)



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(Recombinant), GlycoPEGylated

Learn more at  
**[rebinyn.com](http://rebinyn.com)**

# Judy Doyle

Patient advocate

## About Judy

Judy is a Novo Nordisk Hemophilia Community Liaison with 18 years of experience supporting those with bleeding disorders. She loves the passion of the hemophilia community to get things done and not let things stand in their way.

**Hemophilia Community Liaison**  
OH, IN

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# 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](http://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](http://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](mailto:kmccconnell@hoii.org) or (317) 570-0039 with any questions!

**Presenting Sponsor:**



HEMOPHILIA  
OF INDIANA  
2022  
CALENDAR OF EVENTS

Hearts for Hemophilia Gala: *Union Station*: **January 28**

Bowling for Bleeding Disorders, *Pinheads*: **April 16**

World Hemophilia Day: **April 17**

Course to a Cure Golf Outing, *Maple Creek Golf & Country Club*: **June 6**

Camp Brave Eagle, *Camp Crosley*: **June 12-17**

Polo @ Sunset, *Hickory Hall Polo Club*: **TBD**

Annual Meeting, *Location TBD*: **August 13-14**

UNITE for Bleeding Disorders Walk *Ft. Harrison State Park*: **August 20**

NHF Bleeding Disorder Conference, *Houston, TX*: **August 25-27**

Thanksgiving Day Run, *Dillon Park*: **November 24**

Year End Educational Program: **December 4**

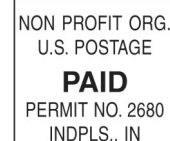
*Our mission:*

*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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(317) 570-0039



\*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 Hearts for Hemophilia Gala - January 28th
- 2022 Bowling for Bleeding Disorders - April 16th

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!!!

