Vital Link

HEMOPHILIA OF INDIANA

...For Hoosiers Living with a Bleeding Disorder

September 2023

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

Designed by: Kristy McConnell

Hemophilia of Indiana
6910 N. Shadeland Ave.
Suite 140
Indianapolis, IN 46220
(317) 570-0039
(800) 241-2873
www.hoii.org

2023 Hemophilia of Indiana Annual Meeting

The 2023 Annual Meeting took place on August 12th & 13th at the Crowne Plaza Hotel - Indianapolis Airport. The Annual Meeting is Hemophilia of Indiana's largest consumer gathering and includes a weekend of education and support for the bleeding disorders community. The event began Saturday morning with a two part general session by staff from the Indiana Hemophilia & Thrombosis Center. New treatments were discussed in the first half and the second half was fun and interactive and gave participants the chance to talk one on one with members of the multi-disciplinary teams from the Indiana Hemophilia & Thrombosis Center. Saturday afternoon's breakout session included topics such as joint health, the importance of proper dental care and nutrition, women and their bleeding disorder issues, staying active, insurance information, and the importance of mental health care. Saturday evening concluded with the Annual Awards dinner and the presenting of the "big check" to the 2023 Judy Moore Memorial Scholarship winners.

Hemophilia of Indiana is proud to acknowledge this year's Award winners:

2023 Volunteer of the Year - Debbie Kinder
2023 Distinguished Business of the Year - Racemaker Productions
2023 President's Award - Dr. Kyle Davis

The 2023 Annual Meeting concluded on Sunday morning with another great interactive presentation on first aid training by several staff members from the Indiana Hemophilia & Thrombosis Center. The support group break out sessions followed the general session. It was a great weekend overall and we are already looking forward to the 2024 Annual Meeting!

2023 Judy Moore Memorial Scholarship

Founded in 2013, the Judy Moore Memorial Scholarship program provides scholarships to members of the bleeding disorders community. 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 bleeding disorders community spanned the HIV/AIDS epidemic, the transition to re-combinant 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. Hemophilia of Indiana is also proud to announce that $46,000 was awarded to following 2023 Judy Moore Memorial Scholarship Winners:

Hery Acosta Acosta
Levi Brush
Tyler Bumbalough
Lauryn Hicks
Clay Kistler
Jackson Kroeger
Mason Moore
Ashlyn Myers
Ashlyn Myers
Jennifer Oldfather
Nicholas Oldfather
Grace Olovich
Samuel Petty
Jack Shade
Elizabeth Williams

Not all of the winners were able to attend the Awards Dinner. A special thank you to Jennifer Littlefield and Sidney Moore for attending and to the entire Judy Moore family for their continued support of the Judy Moore Scholarship Program and Indiana's bleeding disorders community!

Thank you to our
2023 Annual Meeting Sponsors!!!!

Title Sponsors:

Indiana Hemophilia & Thrombosis Center

Takeda

Genentech
A Member of the Roche Group

BIOMARIN®

novo nordisk®

octapharma®

CSL Behring
Biotherapies for Life™

sanofi

Exhibiting Sponsors:

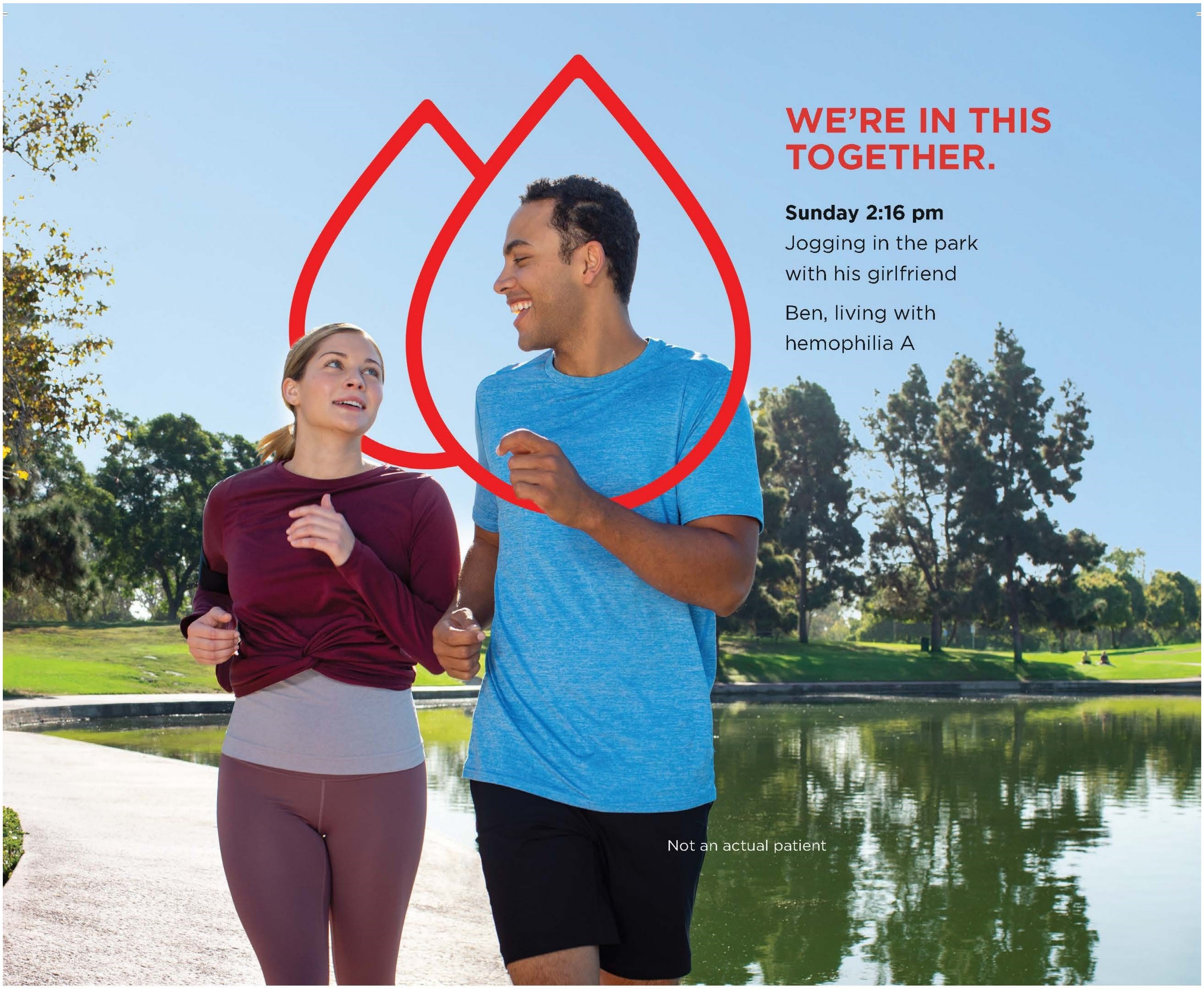
accredo®
Specialty Pharmacy

HEMA Biologics™

Pfizer

CVS specialty®

MEDEXUS PHARMA



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

2023 Doug Thompson Teen Leadership Camp

The Doug Thompson Teen Leadership Camp (DTTLC) is a leadership camp for teens affected with bleeding disorders ages 14-18. DTTLC was created in memory of Hemophilia of Indiana's beloved friend and colleague, Doug Thompson. Doug had a passion for teens and enjoyed working with them during the impressionable years of life. The Doug Thompson Teen Leadership Camp Program was designed to provide teen members of the bleeding disorder community the opportunity to develop and refine life skills while participating in an adventure camp experience. Each year 10 to 15 teen "leaders" are chosen to participate in the teen leadership program. DTTLC has four main goals: To develop self-confidence through challenging activities, to prepare participants to be responsible about their health condition as adults through education and by completing steps necessary to pursue college admission, and to develop their innate ability through reasonable risk-taking through physical activities, and to foster relationships and build a sense of community between young people with bleeding disorders. This year's camp took place at Potato Creek State Park in Northern Indiana. The teens were able to tour the University of Notre Dame campus, kayak, hiking, and much more! A special thanks to this year's sponsors and donors for help making the Doug Thompson Teen Leadership Camp possible!

NATIONAL
BLEEDING DISORDERS
FOUNDATION
Formerly NHF

The National Hemophilia Foundation is Now the National Bleeding Disorders Foundation

National Harbor, MD – August 17, 2023 – The National Hemophilia Foundation (NHF) has officially changed its name to the National Bleeding Disorders Foundation (NBDF). Foundation leaders announced the change alongside advocates and supporters at the 2023 Bleeding Disorders Conference in National Harbor, MD.

The Foundation was established 75 years ago to help people living with hemophilia, but over time has evolved to serve those facing other inheritable blood and bleeding disorders such as von Willebrand disease, rare factor deficiencies, platelet disorders, and more. Through a powerful combination of research, education, and advocacy, NBDF has improved the lives of people and families with many different blood and bleeding disorders.

In recent decades, the Foundation also expanded its focus to include health equity, working to identify and eliminate barriers to care for underserved populations across the U.S. This rebrand aims to address concerns around diversity, inclusion, and equity to ensure every person and family facing an inheritable blood or bleeding disorder has access to the advanced care and support they need — regardless of gender, age, ethnicity, location, or socioeconomic background — so they can achieve their highest level of health.

In addition to the new name, the National Bleeding Disorders Foundation unveiled a new visual identity and logo intended to represent a wide range of inheritable blood and bleeding disorders, as well as a new tagline: Innovate | Educate | Advocate.

“Our new name is one that’s inclusive, trying to represent that entire blood and bleeding disorders community based on our past. We think that this really embraces what we’re going to offer into the future by bringing everybody in and offering them something. No matter what disorder you have, you will find a home in the National Bleeding Disorders Foundation,” said Dr. Len Valentino, CEO.

As NBDF, the organization’s mission will remain the same. It will continue to support a network of over 50 chapters across the country and channel funds into inheritable blood and bleeding disorders research. It will also continue to educate and support families with these disorders — along with the clinicians who care for them — and work to protect and expand access to health care on the state and local level.

In the near future, NBDF will seek ways to harness its resources and networks to help people facing an even broader array of inheritable blood and bleeding disorders, based on the understanding that bleeding disorders *are* blood disorders. Many of these disorders do not yet have a national support and advocacy network, and NBDF will determine how best to fill that role. This new name aligns with that vision for the future. The Foundation’s national and affiliate chapters will play an important role in introducing the rebrand to the community. The strong connections they foster and support they provide at the local level will be key to NBDF’s success.

“Now is the time to better reflect all of those that we serve,” said Dawn Rotellini, COO. “For decades, the Foundation has served the hemophilia community and other conditions, but even though our work supported people and families impacted by ultra-rare blood and bleeding disorders as well as those with von Willebrand disease and more, our name and look did not properly reflect that. I'm so excited to introduce the National Bleeding Disorders Foundation, an organization that can now truly say it’s a home to so many.”

NBDF will continue to roll out the new name and identity in the coming months. NBDF leaders and staff wish to thank the community in advance for their patience during this transition to the new brand. To learn more, visit www.hemophilia.org, or follow the Foundation on its updated social media handles:

- X, formerly known as Twitter: @NBD_Foundation and @NBDFespanol
- LinkedIn: @NationalBleedingDisordersFoundation
- Facebook: @NationalBleedingDisordersFoundation
- TikTok: @natlbdfoundation
- Instagram: @nbd_foundation

General questions about the rebrand can be directed to communications@hemophilia.org.

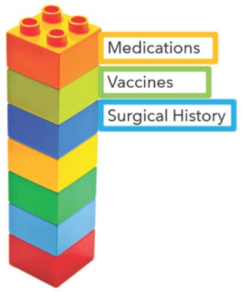
*Original article published on the National Bleeding Disorders Website

New Technology for Patient Care

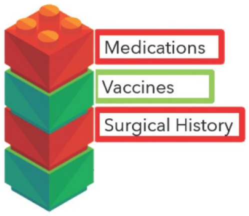
Patient-centered communication is leading the way in new healthcare technology, enabling efficient and quality patient care.

Importance of Shared Information

An Electronic Health Record (EHR) provides a secure way for provider-to-provider communication and patient portal record sharing. All providers use an EHR; they may have different names and look different, but they all function the same and can share information.



Hospital Electronic Health Record (EHR)



Clinic Electronic Health Record

EHRs deliver:
- Efficient care
- Patient-centered communication
- Secure messaging and medication prescribing
- Quick access to patient records
- Better provider-to-provider communication

Patient Portals

Patient portals are a secure place to access personal health information and connect with a care team online. Indiana Hemophilia & Thrombosis Center (IHTC) patients can view personal health care info on the athena patient portal. On-the-go quick needs are available through the app, athenaPatient.

Shared Information

Protecting patient information is important to the IHTC. Patients have the power to choose permissions for record sharing.

Other times patient information could be shared:
- Communication between two providers involved in the patient's care
- Proving a doctor-patient relationship
- Lab/procedures/radiology to the ordering provider

For Example:

A patient's medical information at their primary care center will be shared with their hematologist to allow all healthcare providers to get a better picture of the health care needs.

When a patient in the hospital starts on a new medicine or a new medical problem is found, the patient's clinic can view this information as well.

Use the IHTC's Patient Portal App

- Access personal health information
- Securely message care team members
- View upcoming appointments
- Schedule appointments
- Pay bills

GET IT ON Google Play

Download on the App Store

Or search "**athenaPatient**"
in your mobile device's app store

Indiana
Hemophilia
& Thrombosis
Center

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

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: **Pain Matters**

Pain can affect everyday life for people with hemophilia. Learn about pain management options and tools to help talk about pain with health care providers.

Sponsored by Novo Nordisk

When: Tuesday, October 10th at 5:30pm

Where: Das Dutchman Essenhaus Inn
240 US 20
Middlebury, IN 46540

Topic: **Gene Therapy for Hemophilia**

Presentation on the advances in gene therapy research for hemophilia. Join us for a session which dives into gene therapy for hemophilia, how it works, and the goals of gene therapy.

When: Tuesday, October 17th (time TBD)

Where: Restaurant TBD
Indianapolis, IN

15 YEARS THXRUN

Get your holiday off to a healthy start while supporting the bleeding disorders community of Indiana!!!

When: Thursday, November 23rd

Where: Dr. James A Dillon Park
Noblesville,IN 46060

Time: Free Kids Run - 8:45am
THXRUN - 9:00am

ThxRun.com

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 HTCs, 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

HEMOPHILIA
OF INDIANA

6910 N. Shadeland Ave., Suite 140
Indianapolis, IN 46220
www.hoii.org
(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!

- 2023 FitLivin THXRUN - November 23
- 2023 Year End Education Event - December 2
- 2024 Hearts for Hemophilia Gala - February 9

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!!!