Vital Link

HEMOPHILIA OF INDIANA

…For Hoosiers Living with a Bleeding Disorder

June 2023

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

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CAMP BRAVE EAGLE
"Where the eagles soar!"

It's camp time again! 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 76 campers earned their big stick! Hemophilia of Indiana would like to thank all of our 2023 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 (HemoIndy) more pictures from the 2023 Camp Brave Eagle!

Thank you!

CAMP BRAVE EAGLE
"Where the eagles soar!"

2023 Camp Sponsors!!

Thank you!

Indiana Hemophilia & Thrombosis Center

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Back to SCHOOL

Are you ready?

It's never too early to start thinking about the school year. The IHTC can help school staff understand your student's bleeding condition.

If you have not already done so, please call the IHTC (317.871.0000) and ask to speak to a school counselor. We can set up an appointment to support you with the following:

- Provide an **individualized health plan** to outline your child's specific medical information
- **Educate school staff** on your student's bleeding condition
- Educate school staff about your student's **social and emotional needs** as they relate to their bleeding disorder

Lets make this the best year yet!

The IHTC wants school to be a place where your child can be his or her best. School staff need to understand the learning needs of students with bleeding disorders. Please contact the IHTC school counselors as soon as possible to ask questions and let us know when meetings are taking place so we can support a successful outcome. Together, we can explore accommodations for your child either under Section 504 or IDEA:

Section 504

Under Section 504 of the Rehabilitation Act of 1973, a student may qualify for accommodations for support in the school environment.

Individuals with Disabilities Act (IDEA)

A student may qualify for special education services for support in the school environment.

Students: Carry/wear your medical ID!

It's very important that students with bleeding disorders always wear their medical ID bracelet or necklace, or carry their information card. In an emergency, school staff will see this vital information as they administer treatment. If you do not already have one of these items, contact an IHTC triage nurse at 317-871-0000.

Emergent Care Card

BLEEDING DISORDER

INDIANA HEMOPHILIA & THROMBOSIS CENTER, INC.

1-877-256-8837

College Checklist

If your student is heading out of state to college or far from home, prepare ahead of time to be sure all their medical needs are met:

- ☐ Locate the nearest HTC, hospital or doctor so that we can communicate medical information
- ☐ Contact the college health services about health needs. They may need education on bleeding conditions as well
- ☐ Prepare for factor or other medication delivery. It should not be delivered to a dorm or PO box! College health services may be able to assist
- ☐ Ensure your student knows their prophylaxis schedule, can self-infuse, log infusions, etc.
- ☐ Be sure your student has a medical insurance card and medical ID

Let's make today brilliant.

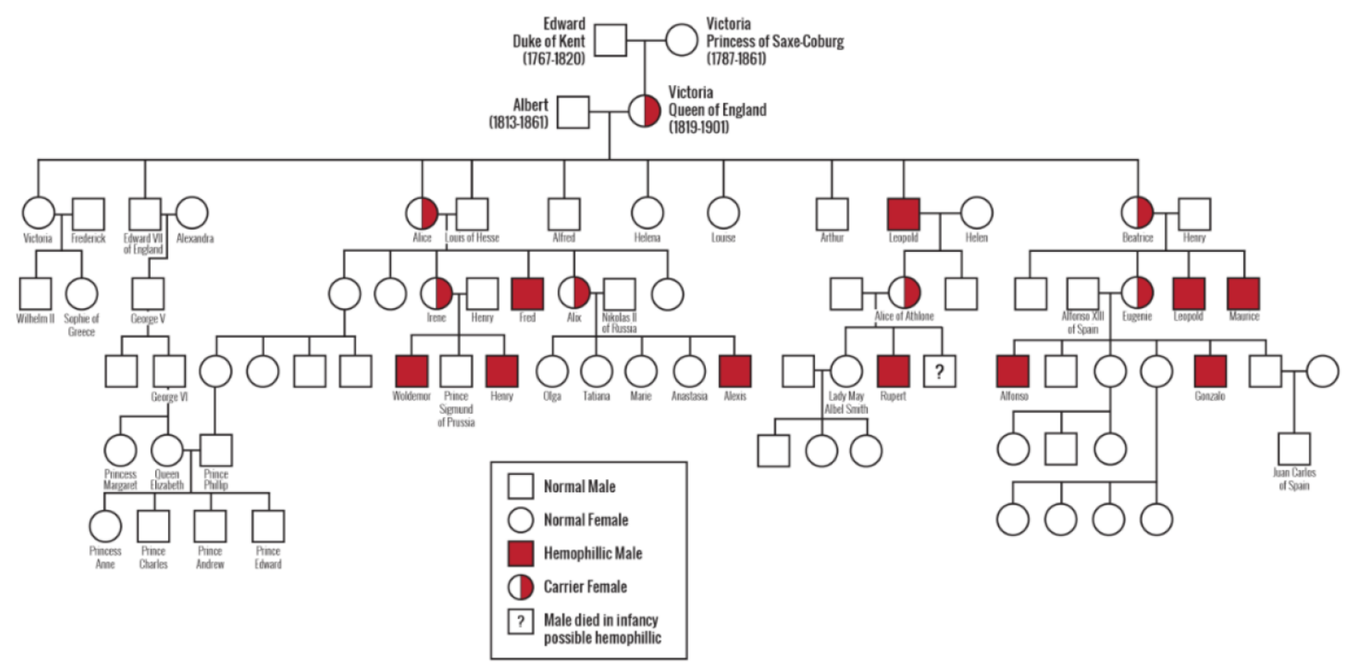
Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world is stronger than ever.

bleedingdisorders.com | Takeda

2023 Bowling for Bleeding Disorders

The 2023 Bowling for Bleeding Disorders event was held March 25th at Pinheads in Fishers, IN. Bowling for Bleeding Disorders is 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, undergrad or postgrad university, or vocational school. Judy Moore's dedication and support of the bleeding disorders community0 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! 10 teams participated and had fun! A special thank you to all of our sponsors including Title Sponsor's Indiana Hemophilia & Thrombosis and Genentech; lane sponsor Novo Nordisk and Octapharma, and CSL Behring and exhibiting sponsors Takeda, Sanofi, and HemaBiologics!



Source: "Hemophilia" by Aronova-Tiuntseva and Herreid

Why Is Hemophilia Called the Royal Disease?

The bleeding disorder changed the course of European history in the 19th and 20th centuries.
Author: Michael Hickey

When it comes to the history of hemophilia, there's a lot to unpack. The public didn't even have a name for the disease until 1928, but hemophilia had a big impact on world affairs even before then — an impact that would give way to its nickname, the "Royal Disease." Its history doesn't start there, though. Far from it: You could go back as far as ancient Egypt to find records of people experiencing irregular bleeds, a symptom of bleeding disorders such as hemophilia.

As for the origins of its royal nickname, you need to go back to the 19th century.

Why Hemophilia Is Called the Royal Disease

Hemophilia's stately moniker comes from its prominent effect on European royalty in the 19th and 20th centuries, affecting English, German, Russian, and Spanish nobility. Queen Victoria of England was a carrier of the disease and passed it along to three of her nine children, one being her son Leopold. She also passed it to her daughters Alice and Beatrice, who then passed it along to their children who married into the royal families of Russia, Spain, and Germany. Historians believe the queen was the one to introduce hemophilia to her bloodline, receiving the bleeding disorder through a spontaneous gene mutation.

Queen Victoria didn't exhibit symptoms, nor did the two daughters she passed hemophilia to. However, her son Leopold dealt with the effects of the disease his whole life. From a very young age, he appeared physically weak, bruised very easily, and was often in pain. He was under constant supervision, as any cuts or bleeds could have had dire consequences.

Treatment didn’t exist at the time, but prominent doctors tried to ease his suffering, including John Wickham Legg, who wrote the famous A Treatise on Haemophilia, which he published in 1872, five years after he stopped attending to Leopold. As a member of the British royal family, Leopold and his condition brought much more attention to hemophilia, which led to an increase in publications in the 1880s and more research toward a cure. Prince Leopold died at age 30 after a minor fall.

How Hemophilia Spread Across Royal Families

Alice’s Family

Queen Victoria’s daughter Alice passed hemophilia to the German and Russian royal families. She married Louis IV, the grand duke of Hesse and by Rhine, a territory in western Germany that existed until 1918. Alice then passed hemophilia on to at least three of her children, one being Princess Alix of Hesse and by Rhine, who later became Empress Alexandra Feodorovna of Russia after marrying Tsar Nicholas II. Alexei, Feodorovna’s child (Alice’s grandson) and heir to the Russian throne, inherited hemophilia and showed symptoms at just months old. His bleeding disorder caused him constant pain, before he and his family were assassinated when he was just 13 years old.

Beatrice’s Family

Queen Victoria’s youngest child, Beatrice, passed hemophilia to the Spanish royal family. Beatrice married Prince Henry of Battenberg, then passed the bleeding disorder on to at least two of their four children. One inheritor of hemophilia was Princess Victoria Eugenie of Battenberg, who later became Queen Victoria Eugenia of Spain through her marriage to King Alfonso XIII.

Eugenie then passed it on to her children, including Alfonso, Prince of Asturias, heir to the Spanish throne; he died at age 31, bleeding to death after a car accident. Eugenie also passed it on to her two daughters, Infantas Beatriz and Maria Cristina of Spain, but none of their descendants have been known to have hemophilia.

Is Hemophilia Still Royal?

There are no known living members of the European royal families or of past dynasties who have hemophilia. However, some point out that with the possibility of silent carriers in many of Victoria’s great-granddaughters, there remains a small chance that the disease could appear again.

Article originally printed in HEMAWARE – April 28, 2023

2023 Course to a Cure

The 2023 Course to a Cure was held on Friday, June 9th at Maple Creek Golf & Country Club. It was a beautiful day for our 28 teams. The Course to a Cure began in 1984 and is a golf outing and fundraiser. Thanks to this year's sponsors, donors, and supporters the 2023 event was a huge success. Hemophilia of Indiana would like to thank the staff at Maple Creek for their efforts in help making the event so successful. A special thank you to the Title Sponsor, the Indiana Hemophilia & Thrombosis Center.

A Special Thank You to Our Title Sponsor!!

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2023 ANNUAL MEETING

AUGUST 12TH & 13TH, 2023

Crown Plaza Hotel - Indianapolis Airport

REGISTER TODAY!!!

WWW.HOII.ORG

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

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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!

- 2023 Annual Meeting - August 12-13
- 2023 FitLivin THXRUN - November 23
- 2023 Year End Education Event - December 2

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!!!