Vital Link

...For Hoosiers Living with a Bleeding Disorder

June 2018

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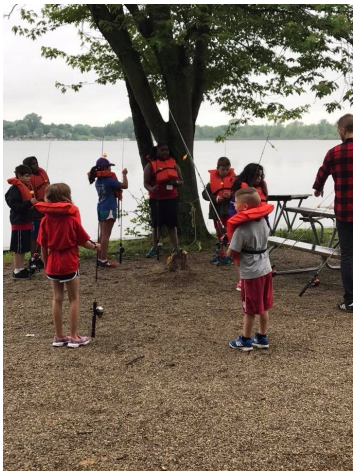
CAMP BRAVE EAGLE
"Where the eagles soar!"

Camp Brave Eagle was started in 1999 by Dr. Amy Shapiro, Medical Director of the Indiana Hemophila and Thrombosis Center. It is a wonderful opportunity for children with bleeding disorders and their siblings to participate in a traditional summer camp experience. The camp encourages self-sufficiency, builds confidence, increases campers' self esteem, and promotes a positive outlook!

This years Camp hosted a record number of 135 campers! The campers were busy from sun up to sun down with kayaking, swimming, canoeing, arts & crafts, fishing, and so much more! In addition to the fun activities, all campers (both those affected by a bleeding disorders and their siblings) are given the opportunity to earn their "Big Stick" by learning how to self infuse from the IHTC!

Hemophilia of Indiana would like to say a very special thank you to all of our Sponsors and donors that make it possible to provide such an incredible experience to our campers!! HoII is focused on using all donations wisely, stretching donation and grant dollars to their fullest extent.!



1998 20 2018 Years

The Indiana Hemophilia and Thrombosis Center has much to celebrate this year—our 20th. Our mission to achieve a future where those with bleeding and blood disorders flourish remains at the heart of what we do. We're so thankful to the patients and their loved ones who have become like family to us over the past two decades. Here's to many more successful and healthy years to come.

Indiana's only Center of Excellence in bleeding disorders

- Comprehensive clinics with our expert multidisciplinary team
- Integrated pharmacy program accessible 24/7
- Nationally renowned for the treatment of bleeding and clotting disorders
- First HTC to receive Medical Home certification (AAAHC)
- Free CME education and 24 hours, 7 days a week consultative services for providers throughout the state
- Outreach clinics across Indiana, education and training for families
- Research to advance care and provide savings to patients and families

For more info, call 317.871.0000
For our Pharmacy, call 317.829.7778
Visit us online at www.ihtc.org

INDIANA HEMOPHILIA & THROMBOSIS CENTER, INC.

HEMOPHILIA OF INDIANA

Unite for Bleeding Disorders

SAVE THE DATE!

Participate. Volunteer. Donate.

Date: Saturday, August 25, 2018
Registration Check-In Time: 8:30am
Walk Start Time: 10:30am
Distance: 3 miles & 1 mile routes
Location: Fort Harrison State Park
Address: 6000 N. Post Rd., Indianapolis, IN 46216

Join us to support the Unite for Bleeding Disorders Walk! We will walk to raise critical FUNDS and AWARENESS for the bleeding disorders community. Your support is greatly appreciated! There will be exhibit booths, a Kid's Zone, and fun for the whole family!

To register, go to **www.hemophilia.org/walk**, select IN-Indianapolis, click "Create a Team" or "Join a Team."

CONTACT US

For more information, please visit **www.hemophilia.org/walk** or contact: Kristy McConnell, Local Walk Manager, at 317-570-0039 or **kmcconnell@hoii.org**

International Study Group Findings Suggest Prophylaxis Could Reduce Hospitalizations for VWD Patients

Researchers from Sweden and the U.S. recently published an article that focused on potential correlations between patients with von Willebrand disease (VWD), hospitalizations and prophylaxis. The authors conducted a retrospective study of inpatients and outpatients, both with and without VWD. Their objective was to investigate the frequency of hospital admittances and determine whether the implementation of a prophylactic treatment regimen is associated with a reduction in hospitalizations.

The lead author of the article was Elena Holm, MD, Department of Translational Medicine, Lund University, Skåne University Hospital in Lund, Sweden. Holm and her colleagues were joined by Thomas Abshire, BloodCenter of Wisconsin and Departments of Pediatrics and Medicine, Blood Research Institute, Medical College of Wisconsin in Milwaukee.

The authors reviewed patient data from two primary groups. The first group encompassed population-based registers from the National Board of Health and Welfare and Statistics Sweden. Data from these registries were incorporated into Sweden's Congenital Bleeding Disorders study. These registries included 2,790 individuals with a diagnosis of VWD between the year 1987 and 2009. They found that VWD patients were admitted to hospitals at a rate 2.3 times higher than the unaffected control groups, and spent on average, 2.0 times as many days as hospitalized inpatients. The most common impetus for these hospitalizations were gastrointestinal (GI) bleeding, menorrhagia (heavy menstrual bleeding) and epistaxis (nose bleeds). Outpatient visits were also twice as common amongst VWD patients.

For the second segment of their research, investigators tapped the von Willebrand Disease Prophylaxis Network (VWD PN), an international study group established to evaluate the prophylactic regimens of patients with VWD. In all, 105 patients from participating treatment centers in North America and Europe were counted in this study, including individuals with type 3 (52%), type 2A (22%), type 1 (12%), type 2B (9%) and other types (4%). As in the registries, GI bleeding was the most common cause of hospitalization. Of the 122 bleed-related hospitalizations reported, 75 occurred prior to the initiation of prophylaxis and 47 after start of prophylaxis, which translates to 712 and 448 events per 1000 patient years. These findings would indicate that significantly fewer hospitalizations occurred after the initiation of a prophylactic treatment regimen.

The authors cited limitations such as a dearth of data on additional variables that could inform study conclusions and a lack of information that could help remove sources of bias or to investigate outcomes related to VWD type or mode of treatment. On the other hand, a major strength of this type research is that general population data fed by national registries allow investigators access to decades worth of healthy control data to match with affected patients, allowing for long term comparisons.

Holm and her fellow investigators also note the potential positive impact of prophylaxis in VWD patients as demonstrated by the VWD PN.

"The VWD PN enrolled the largest cohort using prophylaxis for the management of VWD, concluded the authors. "Prophylaxis using well defined regimens, as in this study, reduced the need for in- and outpatient visits which should translate to increased quality of life for patients and their families."

The article "Bleeding-related Hospitalization in Patients with von Willebrand disease and the Impact of Prophylaxis: Results from National Registers in Sweden Compared with Normal Controls and Participants in the von Willebrand Disease Prophylaxis Network," was published in the February 2018 edition of the journal *Haemophilia.*

2018 Hemophilia of Indiana Annual Meeting

August 11th & 12th
Crowne Plaza Hotel Indianapolis - Airport
Registration Deadline: Monday, July 23rd
Cost: $25.00 per family

Hemophilia of Indiana's Annual Meeting will be held August 11th & 12th designed to provide access to information that will keep the community updated on the status of research, new and improved treatment options, issues regarding health insurance, and other important issues facing the community. It is also a great opportunity to network with others in the bleeding disorders community.

The program begins on Saturday, August 11th, morning with a two-part presentation by staff from the Indiana Hemophilia & Thrombosis Center and the National Hemophilia Foundation. Saturday afternoon consists of several educational breakout sessions. The topics include multiple vWD programs, "How to be a good Consumer", "The Science of Hemophilia : A Changing Landscape", "Clinically Available Novel Sub-Q Agents for Factor 8 Patients", "Living with Hemophilia", and "Exploring Emotional Wellbeing in the Hemophilia Community", and much more!'

On-site child care will be provided for children ages 0-3. Children 4-12 will enjoy a fun filled adventure at the Indianapolis Zoo! Teens, ages 13-17, will enjoy educational programs in the morning and a fun filled afternoon adventure! More details to come!!!

Go to **www.hoii.org/edcationalprograms/annual-meetin**g to register!!!

Publication: PEN 05.18
Column: As I See It

Article

To Play or Not to Play?

Derek Markley

As a father, I will be the first to say that learning about hemophilia leads to a number of questions about the life your son will live. This is highly dependent on your own childhood. Hemophilia mainly affects boys. There are women who suffer from hemophilia and other bleeding disorders, but hemophilia often discriminates. It likes to live in boys.

No one can stereotype exactly what a boy's childhood will look like. Personally, I forecasted my son's future based on my own experiences. We lived out in the country, and growing up, our daughter was happy being outdoors. With a son, I expected that we'd have someone who was simply a replication of me as a child, and also loved being outdoors.

I like to be outside. As a youth I played outdoors, shot BB guns, fished, and often did things that resulted in falling, tripping, slipping, or sliding. None of this was out of the ordinary. Little boys come back in the house dirty, sweaty, and bleeding sometimes. I was no different.

My fondness for being outdoors also meant that I was constantly playing a sport. My parents enjoyed that, and let me play year-round. Baseball, soccer, and basketball took up most of my year. With all the sports seasons running end-to-end, I picked up a stream of kid injuries, such as broken fingers, twisted ankles, bloody noses, and all manner of bumps, bruises, cuts, and scrapes. Those things were just a fact of life. Rarely was anything bad enough to warrant a trip to the hospital or
24-hour clinic, but we did end up there a couple of times.

How do you raise a boy with hemophilia, based on that kind of a childhood?

Bubba's diagnosis immediately made me confront my own notions about what little boys "should" be able to do. Because of my own childhood, I had an irrational fear that he wouldn't ever have a fully "normal" childhood. I never had to be the kid who sat out of the game, avoided jumping off a slide or tree branch, or shied away from a backyard game of football.

As boys, those are things we're supposed to do, right?

After the diagnosis, my brain was trying to immediately construct a vision of what Bubba's life would look like for his first 18 years. He'd miss everything that had made my childhood fun. He'd always be on the sidelines. He'd never get to enjoy

the benefits, and the associated consequences, of taking the risks that little boys take when playing, fighting, or just being rough-and-tumble kids.

The problem was that I'd already imposed my childhood on Bubba. I guess that's a natural reaction for some fathers. You are given someone you expect to be a little copy of yourself. The idea is that this little person will have to grow up to learn how to be a boy and later a man. Immediately, you begin using your own experiences as a model for how that might look.

Another problem arises when it begins to sink in that everything is not under your control. You didn't get to vote the genetic mutation occurrence up or down. It's something that just happened. It suddenly becomes apparent that you only have an illusion of control.

Life likes to make a point occasionally.

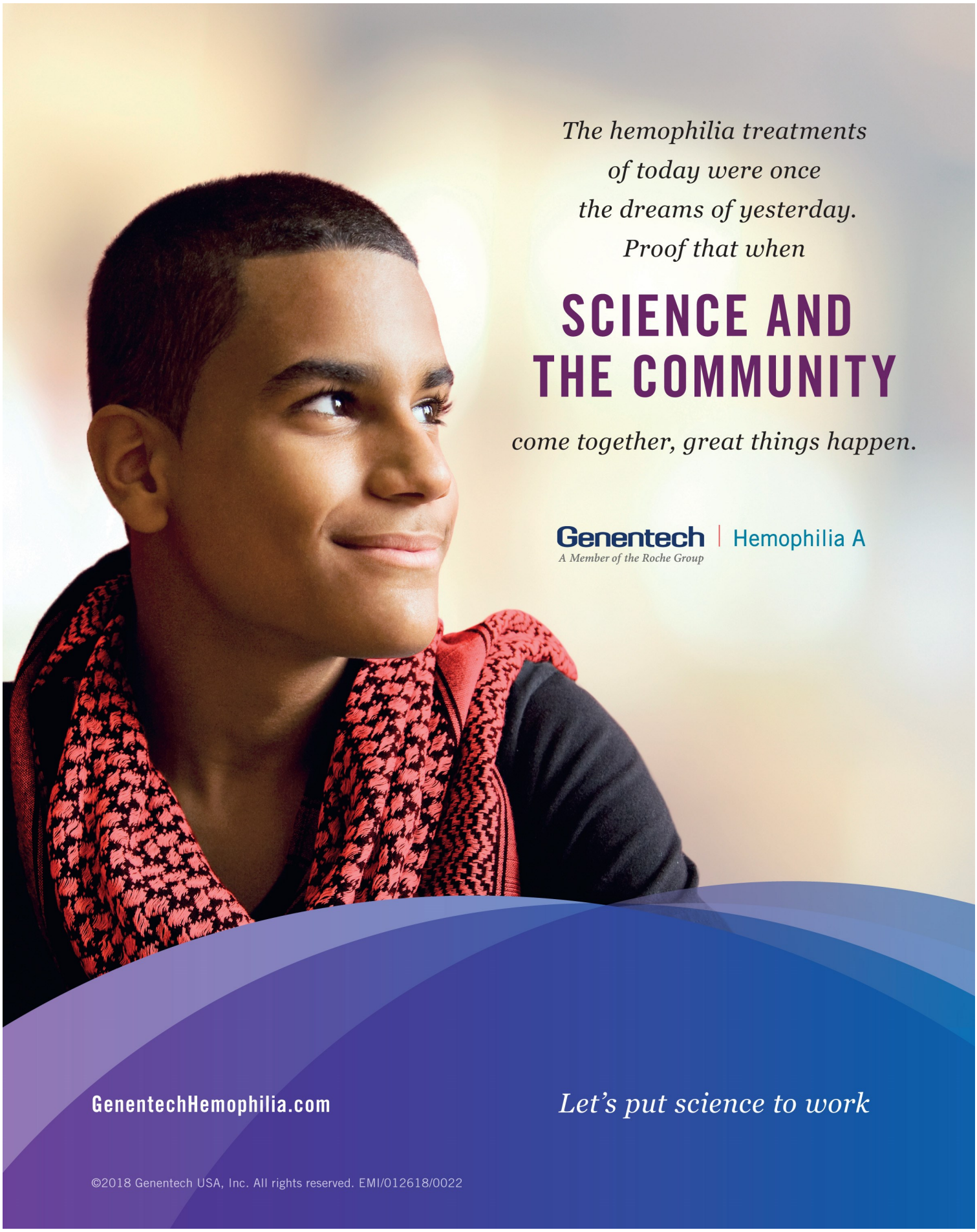
There are times when one of the worst things we can have is an active imagination. Of course, it's fantastic when you're a kid: without an imagination, floors cannot become lava and castles can be constructed with pillows. But grown-up life can turn an imagination against you. This was particularly true for my wife and me in the first few days post-diagnosis, as we tried to envision what life would be like for our son, a boy with blood that does not clot.

We would soon meet with doctors, nurses, physical therapists, and social workers who would help us manage Bubba's condition and our own fears, insecurities, and concerns. But prior to those incredibly helpful first meetings, we wondered exactly how we were supposed to raise a child who is different. We were desperate for someone to help us make sense of how we'd navigate the coming years.

As parents, we had to make a decision: either let Bubba play, or begin to guide his interests in a direction other than sports. When he started preschool in Tupelo, we learned that his teacher and her husband had lost a child at a young age. During one of our first discussions with this teacher, we found a common ground in our desire to make sure that Bubba was limited as little as possible by hemophilia. His teacher agreed fully, and told us that she and her husband had felt the same way about their son. I still remember her saying that she'd never regret the fact that they had always let him do as much as his medical condition would allow.

Overcoming our initial fears was not easy, nor would those fears disappear immediately when Bubba's first soccer game ended without incident. So much of Bubba's life is defined by the fact that he has hemophilia, but that does not have to be a bad thing. Playing soccer has been great for him, and a few people have even learned more about hemophilia because of his presence. The biggest leap wasn't his to take; it was ours. Our decision to let him play sports ensures that we'll always feel apprehension at game time, but it also means that our son will make valuable memories as a member of a team, and as a little kid having fun on the soccer field.

Derek lives in Saltillo, Mississippi, with his wife Ashley and their children Abbey and Bubba. He is executive director of two University of Mississippi regional campuses and assistant professor in the School of Education. Ashley is a fifth grade math teacher in the Tupelo Public School District.



Upcoming Educational Dinners:

Contact Angel Couch at acouch@hoii.org to register.
Check out our Facebook (@HEMOINDY) page and website for details on educational dinners!

Indianapolis:
Topic: **"Learning from experiences living with Hemophilia B"—**
Speaker Jennifer Maahs
When: Tuesday, July 24th
Time: 6:00pm
Where: **Cooper's Hawk**
3815 E 96th St
Indianapolis, IN 46240

Fishers:
Topic: **Topic TBD**
When: Sunday, July 29th
Time: 2:00pm - 5:00pm
Where: **Top Golf**
9200 E 116th St
Fishers, IN 46037

Future Educational Dinner Dates - Details Coming Soon!

August 21st - Indianapolis

September 6th - Bloomington

September 18th - Middlebury

HEMOPHILIA OF INDIANA

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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!

Here are some of our upcoming events…

- Polo at Sunset, July 13th, 2018
- 2018 Annual Meeting, August 11th & 12th, 2018
- Unite for Bleeding Disorders Walk, August 25th, 2018

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!

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