Vital Link

HEMOPHILIA OF INDIANA

...For Hoosiers Living with a Bleeding Disorder

July 2017

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

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2017 Annual Meeting

It is almost that time again! The 2017 Annual Meeting will be held at the Crown Plaza Hotel Indianapolis-Aiport on August 5th and 6th. The event will open with an incredible general session featuring Dr. Amy Shapiro, Dr . Anne Greist, and Jen Maahs, PNP. The afternoon will be filled with breakout sessions whose topics range from Self Care advocacy, Aging With Hemophilia, presentations by Fit Livin', and Hemophilia...The Female Connection plus many more! Sunday's general session will feature Chris Bombardier, the fist Hemophiliac to summit Mount Everest. Check him out on his website Adventuresofahemophliac.com! Sunday late morning will top off with support group sessions! Get your registrations in now!

Other upcoming events:

August 24-26: National Hemophilia Foundation Annual Meeting.
This year Hemophilia of Indiana (HoII) will be taking a record 67 patients to the NHF Annual Meeting in Chicago, IL. This is an incredible opportunity for patient education and advocacy.

September 9th: 2017 Hemophlia Walk
The 9th Annual Hemophila Walk will be held at the beautiful Fort Harrison State Park on the northeast side of Indianpolis. Last year we had over 30 teams and 300 participants! Let's see if we can increase that this year!!! Get pumped! Registration now available through the Hoii Website!!

September 16th: Polo at Sunset Presented by Fit Livin'.
This year's event will take place on Saturday, September 16th at 1:00pm (Gates open at 11:00am). If you are looking for a family friendly afternoon outing, this is the event for you! Details on the website!

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Go-Bag Word Scramble Game #1

Here's a list of recommended items to be in a go-bag:

1. To help stop or prevent a bleed, you use this: **RFCTAO** _____

2. To clean your work area, you use this: **DTTANNFIISCE** _____

3. When you infuse, you tighten this around your arm: **EINOQRTTUU** _____

4. When anyone infuses you, they should use: **SLGVOE** _____

5. You should also carry this: **ELCL OPENH** _____

6. You should know the phone number of this place: **CHT** _____

7. This is for simple first aid: **CIE AKPC** _____

8. You stick this into a vein when you infuse: **EGINRSY** _____

9. You should know the phone number of this person: **CDOORT** _____

10. Don't forget these for your flashlight: **ABEEIRSTT** _____

2017 Camp Brave Eagle

Camp Brave Eagle was held at the beautiful Camp Crosely in North Webster, IN. Partnering with the Indiana Hemophilia and Thrombosis Center, Inc, (IHTC) the camp hosted 122 kids ages ranging from 7 to 16 years old! The campers included bleeding disorder patients as well as their siblings. The camp is always an incredible opportunity for those with bleeding disorders to be interact with their peers and siblings. The activities included kayaking, fishing, swimming, climbing, arts and crafts, just to name a few! The kids were busy from sun up to sun down! In addition to the activities the staff from the IHTC provided infusion training for not just the kids with bleeding disorders but their siblings were also given the opportunity to ear their "Big Sticks"!

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For more information, please contact us at 317.871.0000

To contact our Pharmacy, please call 317.829.7778

Visit us online at www.ihtc.org and www.facebook.com/IndianaHemophilia

Evolution of Learning: From Print to Person to Social Media

Rita Epstein

In 1988, my 14-month-old son Nathan suffered a traumatic internal bleed that caused our pediatrician to refer us to a hematologist in New York City. At this point, I truly believed that my son only needed a shot of vitamin K. The word hemophilia was in my vocabulary but not in my family history or experience. After all, no one in our family had hemophilia. The pediatric hematologist in New York arrived at the
official diagnosis through repeated lab work. She was not a hemophilia specialist and left us with a very pessimistic prognosis that included head bleeds, permanent injuries, even potential early death.

I went home to read the only reference book I had in my library: a 1957 edition of *Encyclopedia Britannica*. As far as I was concerned, hemophilia was a death sentence.

I immediately and thankfully called the hemophilia hotline that was in my local phone book—the second book I referred to after the encyclopedia! Tom Harrington, "guru" of Hemophilia Association of New York (HANY) at that time, called me back within seconds and would not get off the phone until he updated me on 30 years of changes in the medical field. He connected me to the Regional Hemophilia Treatment Center at Cornell Medical Center, where Dr. Margaret Hilgartner protected and advocated for "her children." Tom also connected me to Isabel Brach, social worker extraordinaire at HANY. These wonderful people not only changed our lives, but I believe saved them. They talked me off the ledge.

Soon, support and information gathering and sharing began in full force, as well as a sense of collaboration and hope. In 1990, Laurie Kelley was just beginning to publish a small newsletter, PEN (in those days, the *Parent Exchange Newsletter*).
Her articles, and the opportunity for me to write articles, were enormously reassuring. Then came the books! *Raising a Child with Hemophilia* connected so many families with hemophilia in the United States. Many more books followed over the years, for adults and children.

Our children now had storybooks about kids just like them. They were prepared for a slightly less typical medical journey than most children experienced. They could share these books in their classrooms. Our children felt special—after all, books were being written about them!

New York Hospital–Cornell Medical Center created workshops, social gatherings, and mentoring groups for parents. All of a sudden, we were nodding our heads in agreement, making eye contact, giving hugs, and watching our children thrive. We could observe older children with hemophilia who were healthy. We could reach out and support newer members. Our children were not alone.

National Hemophilia Foundation annual conferences became more family and child centered. There were workshops just for children. Industry stepped up to create programs, supplies, and information that were more and more user friendly. There were smiles and laughter when we all met. There was hope.

Then, in 2004, came social media. I respect and use social media. I consider myself technologically comfortable when researching, meeting people, and communicating on social media. But there's a difference between reading people's posts of despair, confusion, and fear, and hearing them on the phone or being there to hug them and tell them it's going to be all right. I remember calling some of my seasoned hemophilia moms early on and literally describing the bump, limp, and pain. We were all available day or night.

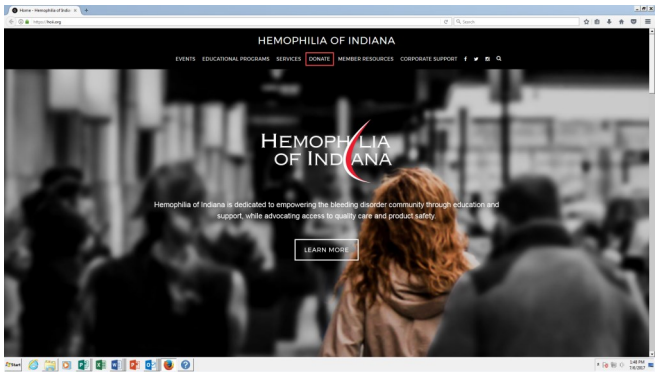
Certainly, social media has a place in our hemophilia world. We are now able to support our families internationally. Through Facebook, emails, and other social media options, families all over the world can share their experiences and look for support. Our village has become much larger. We are now able to respond to a parent's moment of utter despair in almost real time.

The Internet is filled with the good, the bad, and the ugly about hemophilia. As always, it's imperative that we become educated consumers. We need to keep asking the hard questions: Do I have the right to advocate for my child and request a different protocol? Can I change medical facilities? Can I explore insurance coverage that meets my child's unique needs? We need to feel entitled to call and reach out to our doctors and nurses with questions and concerns. Parents have personal experiences,but the medical community has research and cutting-edge information. And we have the right to reach out directly to the pharmaceutical companies. For example, some of my more informative discussions have been with patient representatives in those companies.

We also need to continue to reach out in person and through published books. When our children are diagnosed, we have the opportunity to become active in our local organizations. We can be present.

We all react to the diagnosis differently in our personal journeys. We need printed materials based on research and experience. We need each other. Ultimately, we need human contact. Living with a bleeding disorder is not a journey for the faint of heart. It takes courage and requires human support. Social media allows us to connect through time and space. We are 21st-century families and have so many more options than our children did years ago.

Rita Epstein has worked in education for over 50 years. Her postgraduate work has been in administration and gifted education. She has been the owner and director of Windsor Academy Educational Campus in upstate New York for almost 20 years. Rita lived in the US Virgin Islands for many years on her sailboat, The Dulcinea. She was involved in creating academically gifted programming in St. Thomas. When her now adult son, Dr. Nathan Rosenblum, was diagnosed with hemophilia in the mid-1980s, Rita became active in the New York State Department of Health Advisory Panel as a consumer representative. She has written for a variety of hemophilia publications and continues to be a strong advocate for education and self-advocacy.



HEMOPHILIA walk SM

Every step makes a difference

ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated] Important Information

Indications

ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNOVATE when you have surgery. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

You should not use ADYNOVATE if you:
- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE [Antihemophilic Factor (Recombinant)]

Tell your healthcare provider if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

You should tell your healthcare provider if you:
- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

Your body may form inhibitors to Factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.

You can have an allergic reaction to ADYNOVATE.
Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

The common side effects of ADYNOVATE are headache and nausea. Tell your healthcare provider about any side effects that bother you or do not go away.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see following page for ADYNOVATE Important Facts.

For full Prescribing Information, visit www.ADYNOVATE.com.

References: 1. ADYNOVATE Prescribing Information. Westlake Village, CA: Baxalta US Inc. **2.** Mullins ES, Stasyshyn O, Alvarez-Román MT, et al. Extended half-life pegylated, full-length recombinant factor VIII for prophylaxis in children with severe haemophilia A. *Haemophilia*. 2016 Nov 27. doi: 10.1111/hae.13119 [Epub ahead of print]. **3.** Data on file; Shire US Inc.

Shire

ADYNOVATE
[Antihemophilic Factor (Recombinant), PEGylated]

Patient Important facts about

ADYNOVATE® [Antihemophilic Factor (Recombinant), PEGylated]

This leaflet summarizes important information about ADYNOVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADYNOVATE. If you have any questions after reading this, ask your healthcare provider.

What is the most important information I need to know about ADYNOVATE?

Do not attempt to do an infusion to yourself unless you have been taught how by your healthcare provider or hemophilia center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing ADYNOVATE so that your treatment will work best for you.

What is ADYNOVATE?

ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNOVATE when you have surgery. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

Who should not use ADYNOVATE?

You should not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE® [Antihemophilic Factor (Recombinant)]

Tell your healthcare provider if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

How should I use ADYNOVATE?

ADYNOVATE is given directly into the bloodstream.

You may infuse ADYNOVATE at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADYNOVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADYNOVATE to use based on your individual weight, level of physical activity, the severity of your hemophilia A, and where you are bleeding.

Reconstituted product (after mixing dry product with wet diluent) must be used within 3 hours and cannot be stored or refrigerated. Discard any ADYNOVATE left in the vial at the end of your infusion as directed by your healthcare professional.

You may have to have blood tests done after getting ADYNOVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

How should I use ADYNOVATE? (cont'd)

Call your healthcare provider right away if your bleeding does not stop after taking ADYNOVATE.

What should I tell my healthcare provider before I use ADYNOVATE?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADYNOVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

What are the possible side effects of ADYNOVATE?

You can have an allergic reaction to ADYNOVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

The common side effects of ADYNOVATE are headache and nausea. Tell your healthcare provider about any side effects that bother you or do not go away.

These are not all the possible side effects with ADYNOVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADYNOVATE and Hemophilia A?

Your body may form inhibitors to Factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.

Medicines are sometimes prescribed for purposes other than those listed here. Do not use ADYNOVATE for a condition for which it is not prescribed. Do not share ADYNOVATE with other people, even if they have the same symptoms that you have.

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADYNOVATE. The FDA-approved product labeling can be found at www.shirecontent.com/PI/PDFs/ADYNOVATE_USA_ENG.pdf or 855-4-ADYNOVATE.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

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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...

- Annual Meeting, Crown Plaza Airport - August 4-6
- NHF Annual Meeting, Chicago, Il -August 24-26
- 2017 Hemophilia Walk, Fort Harrison State Park - September 9th
- Polo At Sunset, Hickory Hall Polo Club - September 16th
- Fit Livin' Thanksgiving Day Run - Noblesville, IN - Nov. 23rd

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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