Vital Link

HEMOPHILIA OF INDIANA

...For Hoosiers Living with a Bleeding Disorder

December 2018

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

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2018 Year In Review

As we approach the end of 2018, it is always good to reflect back upon the year. 2018 was another great year for Hemophilia of Indiana! Hemophilia of Indiana (HOII) was able to provide more than 1300 members and families within the bleeding disorders community with assistance, educational, and advocacy opportunities. This is made possible by our fundraising events, private donors, and industry partnerships. The year started with the Hearts for Hemophilia "Mad Hatter's Ball" with over 220 in attendance and an incredible and moving program with Zachary Crabtree as our keynote speakers. Washington Days in March provided the HOII staff, IHTC representatives, and patient advocates the opportunity meet with report with Senators and State Representatives to advocate on behalf of the bleeding disorders community. Topics discussed included the importance of no lifetime caps on medical insurance and denial for medical insurance based on pre-existing conditions. The Bowling Marathon was revamped and now is the Bowling for Bleeding Disorders event! This event included an education program and fundraiser for the Judy Moore Scholarship Program. We had 20 teams and over 85 participants! The Judy Moore Scholarship Program is one of HOII proudest achievements. We are extremely pleased that the amount awarded in 2018 was another record high of $30,000.00 to 10 incredible individuals! The Course for the Cure Golf Outing took place in June and the weather was picture perfect. Twenty six teams participated followed by a silent and live auction! The Annual Meeting was held in August and it was another year of record attendance with over 260 individuals and families! The weekend was kicked off with incredible speakers from the Indiana Hemophilia & Thrombosis Center and the National Hemophilia Foundation. The day successfully continued with a variety of important educational topics and concluded with the Awards dinner. The weather may not have cooperated, but overall the 2018 Unite For Bleeding Disorders was a huge success and we reached our goal of $60,000.00!! There were over 7 teams that raised over $1000.00 and are already excited for the 2019 UNITE for Bleeding Disorders Walk! It was the 10th Anniversary of the Fit Livin' Thanksgivin' Day Run and another HOII event that had a record attendance! There were over 520 runners and walkers!. The last event of the year was the Year End Education Event. The families attended enjoyed a delicious lunch, crafts, and a fun visit from Santa! Hemophilia of Indiana would like to say a big thank you to all that participated in all of our events and a special thank you to all of our donors! 2019 is going to be even better! Go to www.hoii.org for details on all of our programs and events!


START / FINISH


#THXRUN
START / FINISH
#THXRUN
10TH ANNIVERSARY!!!
THANKSGIVING DAY - NOVEMBER 22ND!
WWW.FITLIVIN.COM


4290


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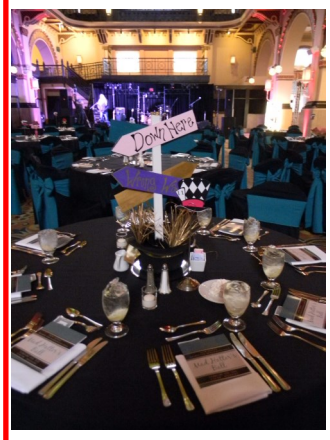
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HEMOPHILIA OF INDIANA
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www.hoii.org
Judy Moore Scholarship Recipients
$30,000.00
Thirty Thousand and 00/100
dollars
Hemophilia of Indiana

HEMOPHILIA OF INDIANA

2019 CALENDAR OF EVENTS

Hearts for Hemophilia Gala, *Union Station:* **February 8**

Bowling Marathon, *Pinheads*: **April 14**

World Hemophilia Day: **April 17**

Course to a Cure Golf Outing, *Maple Creek Golf & Country Club*: **June 3**

Camp Brave Eagle, *Camp Crosley:* **June 9-14**

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

Annual Meeting, *Crowne Plaza Airport Hotel*: **August 10-11**

UNITE for Bleeding Disorders Walk *Ft. Harrison State Park*: **September 21**

Thanksgiving Day Run, *Dillon Park*: **November 28**

Year End Educational Program: December 7

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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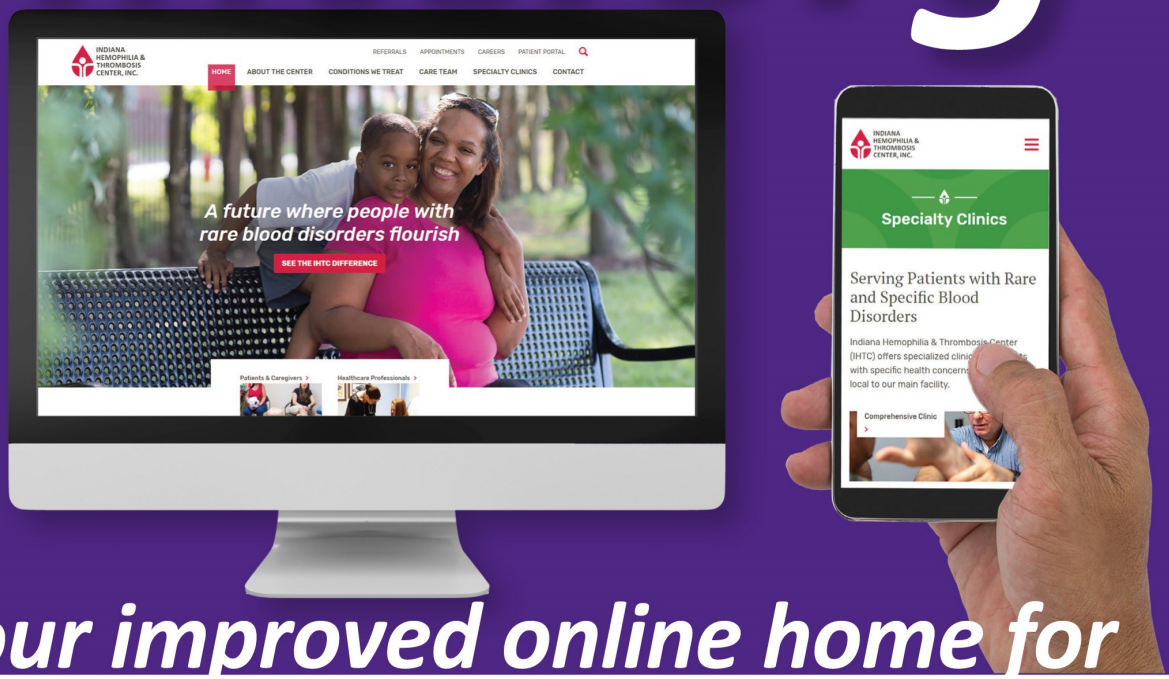
ihtc.org



Your improved online home for rare blood disorder information & resources

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IHTC is 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)
- Outreach clinics across Indiana, education and training for families
- Research to advance care and provide savings to patients and families

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INDIANA HEMOPHILIA & THROMBOSIS CENTER, INC.

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

1998 20 2018 Years

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. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. HEMLIBRA may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). 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.

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

HEMLIBRA
emicizumab-kxwh
injection for subcutaneous use
150 mg/mL

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,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048

For more information, go to 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

HEMLIBRA™
emicizumab-kxwh
injection for subcutaneous use
150 mg/mL

Genentech
A Member of the Roche Group

5 Holiday Travel Tips for Bleeding Disorders Families

Being prepared is key to traveling safely
Author: Ian Landau

One of the joys of the holiday season is visiting with family and friends. But traveling can also be stressful, especially when managing a bleeding disorder. There's a lot to take into account, including safely transporting your child's medication and making sure you stay on top of treatment away from home when your family's normal routine is disrupted.

To help your holiday travels (or travel any time of year) go as smoothly as possible, be sure to prepare in advance. With proper planning, you can enjoy your time away with loved ones and be confident you're doing all you can to keep healthy. Below are a few helpful tips.

1. Bring a travel letter

A travel letter is a brief explanation of your child's bleeding disorder and a description of the medications and supplies you have with you and why you need them. Your hemophilia treatment center (HTC) or your hematologist can provide you this letter. The travel letter is not only useful for airport security, but it's also helpful should you need to visit a doctor or the emergency room

2. When flying, keep medicine and infusion supplies in a carry-on bag

Don't put medicine in checked luggage. Stay organized, and make it easier to get through airport security, by stowing all your supplies in a dedicated "medical travel bag." And don't forget to pack a sharps disposal container.

3. If you're traveling out of state, check your insurance coverage

Your insurance plan probably doesn't have restrictions on coverage outside of your local area, but it's always better to double-check before you travel rather than be surprised.

4. Know the closest HTC to your destination

Should you need medical help while you're far from home, you'll want to know where to go. The Centers for Disease Control and Prevention has a list of US HTCs. Your home HTC can connect with the HTC staff at your destination before your trip to pass along your information and alert them to your travel plans.

5. Stay on top of treatment

Before you travel, talk with your treatment team to devise a medication schedule for while you're away. Based on where you're going and what activities you have planned, your team may advise you to change your typical routine. Visits with relatives and friends are full of activities, but it's important to stick to the schedule. Alerting your hosts in advance that you may need to take some time out from the fun to help your child infuse helps to set expectations for your visit. And don't forget to update your treatment log.

Bon voyage!

**Article published on www.hemaware.org

Learn. Explore. Connect With Our Hemophilia Community on **Facebook**.

Our Hemophilia Community

Find us on **Facebook.com/OurHemophiliaCommunity**

Printed in USA/March 2011

Pfizer

UNLOCKING YOUR SELF-POTENTIAL

ONLY ADVATE® HAS 15 YEARS OF EXPERIENCE IN THE REAL WORLD AS A RECOMBINANT FACTOR VIII[1]

- Proven in a pivotal clinical trial to reduce the number of bleeding episodes in children and adults when used prophylactically[2]*
- Third-generation full-length molecule, similar to the factor VIII that occurs naturally in the body[1,2]

*Multicenter, open-label, prospective, randomized, 2-arm controlled trial of 53 previously treated patients with severe to moderately severe hemophilia A. Two different ADVATE prophylaxis regimens (standard, 20-40 IU/kg every 48 hours, or pharmacokinetic-driven, 20-80 IU/kg every 72 hours) were compared with on-demand treatment. Patients underwent 6 months of on-demand treatment before 12 months of prophylaxis.[2]

The market leader in hemophilia A treatment
(Based on 2016 data published July 2017)[3]

Learn more at ADVATE.com

ADVATE Important Information

What is ADVATE?

- ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia).
- ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A. Your healthcare provider (HCP) may give you ADVATE when you have surgery.
- ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADVATE?

Do not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

Tell your HCP if you are pregnant or breastfeeding because ADVATE may not be right for you.

What should I tell my HCP before using ADVATE?

Tell your HCP 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 ADVATE passes into your milk and if it can harm your baby.
- Are or become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What important information do I need to know about ADVATE?

- You can have an allergic reaction to ADVATE. Call your HCP 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.
- Do not attempt to infuse yourself with ADVATE unless you have been taught by your HCP or hemophilia center.

What else should I know about ADVATE 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 ADVATE from working properly. Talk with your HCP to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

What are possible side effects of ADVATE?

- Side effects that have been reported with ADVATE include: cough, headache, joint swelling/aching, sore throat, fever, itching, unusual taste, dizziness, hematoma, abdominal pain, hot flashes, swelling of legs, diarrhea, chills, runny nose/congestion, nausea/vomiting, sweating, and rash. Tell your HCP about any side effects that bother you or do not go away or if your bleeding does not stop after taking ADVATE.

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.

For additional safety information, please see Important Facts about ADVATE on the following page and discuss with your HCP.

For Full Prescribing Information, visit www.ADVATE.com.

References: 1. Grillberger L, Kreil TR, Nasr S, Reiter M. Emerging trends in plasma-free manufacturing of recombinant protein therapeutics expressed in mammalian cells. *Biotechnol J.* 2009;4(2):186-201. **2.** ADVATE Prescribing Information. **3.** The Marketing Research Bureau, Inc. The plasma proteins market in the United States. 2016.

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ADVATE
[Antihemophilic Factor (Recombinant)]

ADVATE
[Antihemophilic Factor (Recombinant)]

Important facts about

ADVATE [Antihemophilic Factor (Recombinant)]

This leaflet summarizes important information about ADVATE. 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 ADVATE. If you have any questions after reading this, ask your healthcare provider.

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

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 ADVATE so that your treatment will work best for you.

What is ADVATE?

ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia). The product does not contain plasma or albumin. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A.

Your healthcare provider may give you ADVATE when you have surgery. ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

Who should not use ADVATE?

You should not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

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

How should I use ADVATE?

ADVATE is given directly into the bloodstream.

You may infuse ADVATE 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 ADVATE by themselves or with the help of a family member.

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

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

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

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

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 ADVATE passes into your milk and if it can harm your baby.
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Side effects that have been reported with ADVATE include:

cough	headache	joint swelling/aching
sore throat	fever	itching
unusual taste	dizziness	hematoma
abdominal pain	hot flashes	swelling of legs
diarrhea	chills	runny nose/congestion
nausea/vomiting	sweating	rash

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 ADVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADVATE 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 ADVATE 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 ADVATE for a condition for which it is not prescribed. Do not share ADVATE 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 ADVATE. The FDA approved product labeling can be found at www.ADVATE.com or 1-888-4-ADVATE.

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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Publication: PEN 11.18
Column: As I See It

Article

Be a Part of Making Tough Decisions Now

Steve Place

I have lived for 64 years with mild hemophilia and have voluminous experience, from which I came to my own rock-solid conclusions about how someone with a bleeding disorder can participate in sports and other potentially life-changing activities.

One experience was a significant life change at age 10, when I sustained a serious head injury. I felt able to ride my bike with no hands. Sand and a quick moment of unbalance tossed me off my bike, and my head hit the pavement hard. I got myself up and walked back home with my bike. My sister saw me and screamed. That's when I felt a huge lump on my forehead and knew I was in trouble. Our doctor, who made house calls, wrapped my head with a pressure bandage and told my parents to give me two aspirin every four hours and added that if I made it through the night, I probably would be all right. Aspirin and all, I survived.

All of a sudden, I was prohibited from participating in contact sports. This is tough for a 10-year-old boy. Although I was always the smallest kid in my class and the last to be chosen at sports, it still hurt. Fortunately, my mom and dad and sister were very supportive, and we got through it together. They steered me to other avenues that led me to a happy, healthy, and productive life. I thank God every day for my hemophilia!

I look back and wish I could have accepted at age 10 what I strongly believe about my bleeding disorder today. I went from "Boo-hoo, I can't do certain things!" to "Drop back, punt, and come up with a new plan."

Now that may sound a bit harsh, but the sooner we accept our limitations in life and pursue the best and safest path, the better off our lives and our families' lives will be. Yes, we must think about our families, too; it's not all about the person with hemophilia. Every person with a bleeding disorder has affected and will continue to affect the lives of those we love most. Our bleeds seem to come at the most inconvenient times, for us and for them!

It was traumatic when at age 10, I had to stop doing the things my buddies were doing. But here I am today, happy, married for 40 years with two daughters, successful, and in excellent health. I am physically active in my daily pursuits. I am a professional handyman and sole proprietor, and I work daily with all types of sharp tools, both power and manual. Safety and thinking through a job are paramount. Knee pads and elbow/forearm protection are vitally important. The most dangerous tool in my toolbox is a dull blade.

I treat on demand and prior to some potential bleeding situations. I have 95% mobility in all of my joints. The only time I infuse, apart from surgery, is when I make a mistake.

We all want to be the best parents we can be for our kids. Good, tough prodding and steering today can result in a wonderful life later on for them. I made a very strong, positive personal decision that has guided my life for the last 50-plus years. I decided that I will respect my disorder, but I will not be afraid of it. I will determine what I *will* do, and what I will not do. I basically took charge of my life.

Stephen is 64 and has been married for 40 years. He has two adult daughters, and works 50 hours a week. He is active in his church, both teaching and leading. He believes that life is great, especially when "I respect my disease, but am not afraid of it." scplace122@comcast.net

5 Ways to Foster Independence in Your Teen with a Bleeding Disorder

Here's how to help your adolescent child take the necessary steps toward becoming an adult

Author: Donna Behen

If you have a child with a bleeding disorder, the teen years can be challenging. It's a time when adolescents are naturally looking to separate themselves from their parents and take on more responsibility. But after years of being so involved in managing your child's bleeding disorder, it can be hard to step back and give him or her the freedom and independence teens need as they grow toward adulthood.

How can you help teens with bleeding disorders become more independent and empower them to take charge of their health? Here are some suggestions:

1. Hand over all treatment responsibilities

Ideally, a teenager will have already taken one of the biggest steps toward independence, which is learning how to self-infuse. But in addition to that important milestone, teens should be handling a lot of the other aspects of their treatment, including knowing the details of their medication, being responsible for their own treatment log and eventually taking on the task of ordering their medication.

2. Stay positive

Whether it's helping your child transition to managing his or her medical appointments schedule, recognize the signs of a bleed, or cope with a medical emergency, your attitude can make all the difference.

"Let your child know that you are confident that they can take on these new responsibilities, and that you're there to consult or help in any way that they might need," says Mary Alvord, PhD, a child clinical psychologist in private practice in Rockville and Chevy Chase, Maryland.

What's important is not only what you say, says Alvord, but even more so, what you do. "You can model that something is challenging but also problem-solve out loud about how you will approach the issue," she says.
"This approach can counter those 'I *can't*' thoughts that teens can be susceptible to, and provide the powerful message to your teen that, they *can* try, and they *can* do it, with help," says Alvord, author of *Conquer Negative Thinking for Teens*.

3. Teach teens to advocate for themselves
Encourage your child to start taking a more active role in his or her own healthcare by speaking up and asking questions of hemophilia treatment center (HTC) team members or his or her primary care doctor. Once children are high school-aged, they should be able to make their own doctor's appointments and order their own factor and infusion supplies.
The more people can advocate for themselves and learn to communicate what they need, the more they feel in control of their healthcare, says Alvord. "We also know that being proactive and asking for help are strengths that factor into resilience," she says.
According to a recent study, teens who have a medical condition may be better prepared to transition from pediatric care to adult care while taking charge of their own healthcare than teens who don't have a medical issue. When psychologists at the University of Georgia studied 494 older adolescent and young adult patients, they found that those with a chronic condition were more self-supporting in completing health-related tasks and were less reliant on input from their parents.

4. Sign up for camp
A week at overnight camp is when many adolescents with bleeding disorders learn to take a bigger role in managing their own health. Not only do they become more comfortable and confident with self-infusing, they also gain independence by being away from home for several days. Many kids who are active in camp go from being campers to counselors, which teaches them responsibility and leadership skills. There are more than 50 overnight summer camps in 37 states for young people with bleeding disorders, and the cost is usually covered by your local chapter. It's not too early to start planning for next summer. Find a camp near you by contacting your local chapter or HTC, or search NHF's online camp locator< https://www.hemophilia.org/Community-Resources/Locate-a-Camp-Near-You-0>.

5. Encourage your teen to connect with other young adults
Adolescents need role models and mentors, and talking to other teens and young adults who have bleeding disorders can help them feel much more comfortable about their changing role.

You can help your child connect with young adults in your area by contacting your local NHF chapter to discover what programs are available. Participation in these events can help teens learn to talk much more openly and appropriately about their disorder with friends, and also be more likely to act responsibly and take ownership of their healthcare.

Article courtesy of Hemaware (www.hemaware.org)

7 Healthy Holiday Eating Tips

Enjoy this festive time of year without hurting your health
Author: Donna Behen
Fitness & Nutrition

Making healthy food and beverage choices is a year-round priority for anyone with a bleeding disorder since good nutritional habits are necessary for maintaining an ideal weight, keeping joints healthy and preventing joint bleeds.

But choosing wisely is particularly challenging at this time of year, when a steady stream of family gatherings, neighborhood open houses, office parties and other occasions tempt you with lots of high-calorie foods and drinks. These strategies can help ensure that your holidays are not only happy, but healthy, too.

1. Eat a healthy snack ahead of time.

Showing up to a holiday party with an empty stomach is a surefire way to overdo it at the buffet table. About an hour before you go, have a light meal that's high in protein and fiber (for example, a hard-boiled egg and an apple, or almond butter on whole-grain toast). Taking the edge off your hunger will make it easier for you to resist all the temptations.

2. BYO healthy option

When going to an informal gathering at a friend or family member's house, the best way to make sure you have something nutritious to eat is to bring it yourself. Offer to bring a tray of crudites and dip, a fruit salad or a vegetable side dish.

3. Watch those holiday beverages

It's easy to overdo liquid calories because they don't make you feel as full as an equal number of calories from solid food. And seasonal favorites can pack a lot of calories, sugar and fat. For example, just one 8-ounce cup of eggnog can have as many as 300 calories, nearly 20 grams of fat and a whopping 40 grams of sugar! For a healthier drink, try seltzer with a splash of cranberry juice instead.

4. Limit alcohol

Alcoholic holiday drinks are also often high in calories (an 8-ounce hot buttered rum can have more than 300), plus drinking lowers inhibitions, leading to unhealthy eating choices. Your best strategy is to choose one low-calorie alcoholic drink, like a white wine spritzer, and drink it as slowly as you can.

5. Plan ahead

There's no need to completely avoid the holiday foods you look forward to eating all year. If you watch what you eat earlier in the day, you can save room in your calorie budget for a few of your mom's holiday cookies or your favorite seasonal hors d'oeuvres.

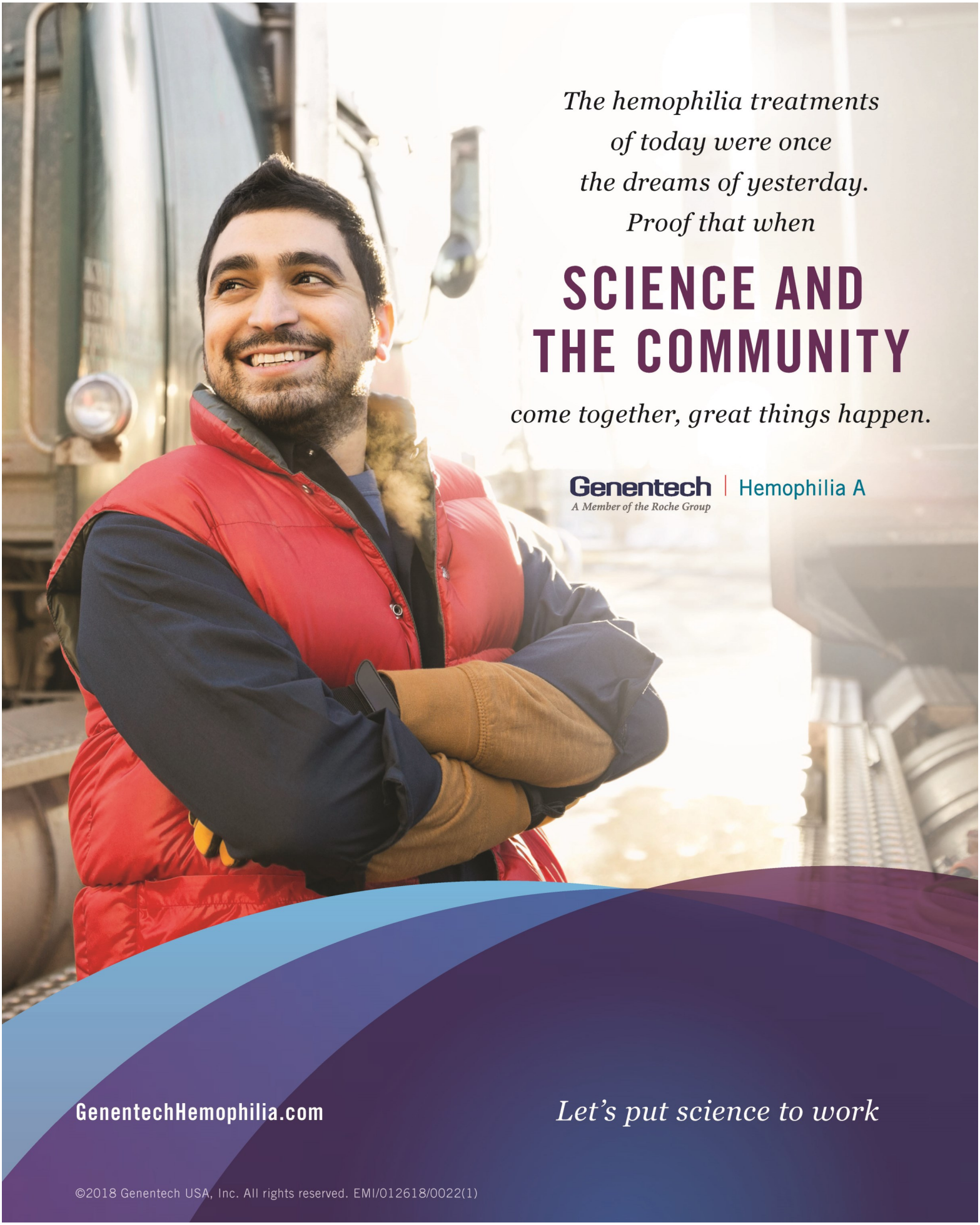
6. Be realistic

If you're trying to lose weight, don't set yourself up for failure by planning to slim down during the holiday season. A better approach is to focus on not gaining any more weight and then get back to your weight-loss regimen once the holidays are over.

7. Don't focus on the food

The holiday season can often seem like one giant eating fest, but there are plenty of healthy, non-eating activities, too. Organize a hike, or plan to meet up with friends at the gym. Offer to take an older friend or family member shopping. Find a volunteer opportunity nearby and spend a few hours on the weekend giving back to others. If you shift the emphasis away from food, you may also end up with a renewed appreciation for the holidays.

Article courtesy of Hemaware (www.hemaware.org)



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!

Greenwood Area:
Topic: **Shire - Topic TBD**
When: Tuesday, February 5th
Time: 6:00pm
Where: Stone Creek Dining
911 N State Rd
Greenwood, IN 46142

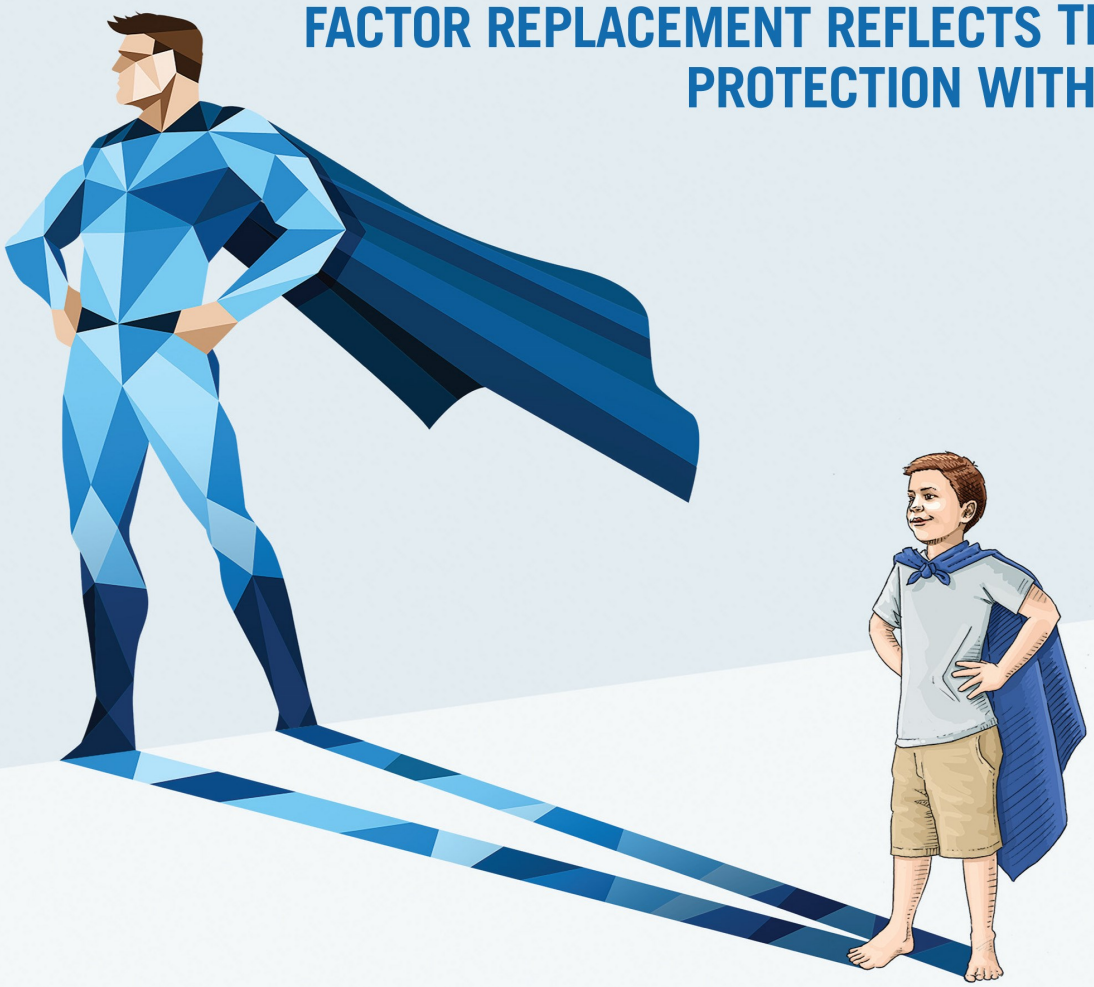
Indianapolis Area:
Topic: **Octapharma - VWD Branded Program**
When: Saturday, March 9th
Time: 1:00pm
Where: Maggiano's Little Italy
3550 E 86th St
Indianapolis, IN 46240

Topic: **Genentech - Topic TBD**
When: Thursday, March 28th
Time: 6:00pm
Where: Restaurant TBD

Location TBD:

Topic: **Shire Hispanic Support Group**
When: Saturday, March 30th
Time: Time TBD
Where: Restaurant TBD

FACTOR REPLACEMENT REFLECTS THE PROTECTION WITHIN



For people with hemophilia, Factor treatment temporarily replaces what's missing.[1,2] With a long track record of proven results, Factor treatment works with your body's natural blood clotting process to form a proper clot.[2-6]

Brought to you by Shire, dedicated to pursuing advancements in hemophilia for more than 70 years.[7]

Stay empowered by the possibilities.

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Shire

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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…

- "Hearts for Hemophilia Tiaras and Bowties Royal Gala - Friday, February, 8th, 2019
- Bowling for Bleeding Disorders - Sunday, April 14th, 2019
- Course for the Cure Golf Outing - Monday, June 3rd, 2019

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!