

# Vital Link

HEMOPHILIA  
OF INDIANA

...For Hoosiers Living with a Bleeding Disorder

April 2019

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

Designed by: Kristy McConnell

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## Washington Days

Hemophilia of Indiana, Indiana Hemophilia & Thrombosis Center and several members of Indiana's bleeding disorders community were proud to participate in this year's Washington Days in Washington D.C. Washing Days, hosted by the National Hemophilia Foundation, had over 450 representatives and 48 states advocating on behalf of the bleeding disorders community. The Indiana team was excited to meet with the staff of various U.S. Representatives and Senators to advocate and tell "our stories". The bleeding disorders community asks all Members of Congress to support policies that ensure access to comprehensive insurance and health care services that are needed for healthy and productive lives. The major "asks" for the this year's Washington Day's meetings were in support of protecting pre-existing conditions, increase legislation regarding short-term insurance plans. Support federal hemophilia programs at CDC, HRSA, and NIH that support the bleeding disorders community. HRSA Maternal and Child Health Bureau Hemophilia Program provides funding to hemophilia treatment centers and allows participation in the 340B Program and support of comprehensive care services.



TELL YOUR STORY.  
ADVOCATE. DONATE.

MARCH 1 - APRIL 17

THE  
2019  
NHF **REDTIE**  
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FOR ALL BLEEDING DISORDERS



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INDIANA  
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# COMPREHENSIVE BLEEDING DISORDER CARE ALL AT ONE CENTER

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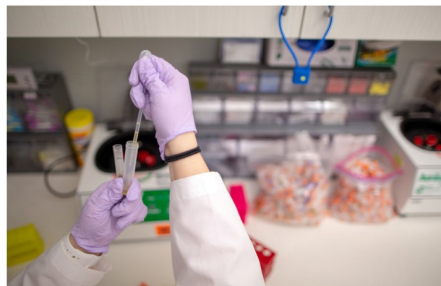
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**Registered Dietician**

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**Indiana's only Center of Excellence for bleeding & clotting disorders**

*The state's only federally-designated Hemophilia Treatment Center and the first HTC in the U.S. to receive national medical home certification*



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# Hearts for Hemophilia “Tiaras & Bow Ties” Winter Gala

The 29th Annual Hearts for Hemophilia “Tiaras & Bow Ties” Winter Galawas held Friday, February 8th at the Historic Union Station Grand Ballroom at the Crowne Plaza Hotel Downtown Indianapolis. Our guests looked their finest in their tiaras and bow ties! The event included dinner, a live and silent auction, a casino, and dancing to the music of Stella Luna and the Satellites! The special guest speaker this year was Lisa Swaney. Lisa and her family are members of Indiana’s bleeding disorders community. Lisa also leads Hemophilia of Indiana’s Moms In Action support group and did an incredible job telling “her family’s story” and giving the guests a glimpse into the life of a person living with a bleeding disorders. All proceeds from the Gala benefit the many programs and services offered by Hemophilia of Indiana to the bleeding disorders community. These programs include emergency financial assistance, educational programs, MedicAlert ID program, Camp Brave Eagle, and the Doug Thompson Teen Leadership Camp. Hemophilia of Indiana would like to thank our title sponsors the Indiana Hemophilia & Thrombosis Center and Takeda. Other sponsors include Bayer Healthcare, Cook Medical, Katz Sapper & Miller, Flora Legal Group, General Hotels Corporation, Novo Nordisk, Sharp Investments, Pfizer, CSL Behring, Aptevo, Waypoint Global, and Republic National Distributing Company. Mark your calendar for next year’s Hearts for Hemophilia Gala to be held February 7th, 2020! For more pictures from the Event go to Hemophilia of Indiana’s Facebook page!!





Go beyond 86°F—**Novoeight®**  
can help you get there

A recombinant factor VIII to  
prevent and control bleeding in  
people with hemophilia A

*Julian, 25 years old, lives with hemophilia A.*



Up to  
**104°F**  
for up to  
**3 months**

Please see Prescribing Information  
for complete product storage conditions.



## PORTABILITY

Novoeight® can be stored:

Up to  
**104°F**  
for up to  
**3 months**

Up to  
**86°F**  
for up to  
**12 months**

Longest room temperature storage time  
after reconstitution—**up to 4 hours**  
**at up to 86°F<sup>a</sup>**

Highest storage temperature after  
reconstitution—**up to 104°F for**  
**up to 2 hours<sup>a</sup>**

<sup>a</sup>Compared with other recombinant FVIII products.  
Please see Prescribing Information for complete product  
storage conditions.



## SAFETY

**0 INHIBITORS**

were confirmed in one of the  
largest clinical trial programs with<sup>b</sup>

**225** previously treated patients

receiving

**88,000** infusions

<sup>b</sup>People with previous inhibitors and those new to  
treatment were not included in the trial. People with  
hemophilia A may develop inhibitors to factor VIII.



## BLEED CONTROL

**89%**

of adults and  
adolescents  
aged 12-65

**95%**

of children  
aged 0-11

Bleeds treated with 1 or 2 infusions

## Indications and Usage

Novoeight® (Antihemophilic Factor [Recombinant]) is an injectable medicine used to control and prevent bleeding in people with hemophilia A. Your healthcare provider may give you Novoeight when you have surgery.

Novoeight® is not used to treat von Willebrand Disease.

## Important Safety Information

You should not use Novoeight® if you are allergic to factor VIII or any of the other ingredients of Novoeight® or if you are allergic to hamster proteins.

Call your healthcare provider right away and stop treatment if you get any of the following signs of an allergic reaction: rashes or hives, difficulty breathing or swallowing, tightness of the chest, swelling of the lips and tongue, light-headedness, dizziness or loss of consciousness, pale and cold skin, fast heartbeat, or red or swollen face or hands.

Before taking Novoeight®, you should tell your healthcare provider if you have or have had any medical conditions, take any medicines (including

non-prescription medicines and dietary supplements), are nursing, pregnant or planning to become pregnant, or have been told that you have inhibitors to factor VIII.

Your body can make antibodies called “inhibitors” against Novoeight®, which may stop Novoeight® from working properly. Call your healthcare provider right away if your bleeding does not stop after taking Novoeight®.

Common side effects of Novoeight® include swelling or itching at the location of injection, changes in liver tests, and fever.

**Please see Brief Summary of Prescribing Information on following page.**

Novoeight® is a prescription medication.

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

**Visit [Novoeight104.com](http://Novoeight104.com) today to learn more.**



Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.

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**novoeight®**  
Antihemophilic Factor  
(Recombinant)



# novoeight®

## Antihemophilic Factor (Recombinant)

### Brief Summary information about Novoeight® Antihemophilic Factor (Recombinant)

#### Rx Only

This information is not comprehensive.

- Talk to your healthcare provider or pharmacist
- Visit [www.novo-pi.com/novoeight.pdf](http://www.novo-pi.com/novoeight.pdf) to obtain the FDA-approved product labeling
- Call 1-844-30-eight

#### Read the Patient Product Information and the Instructions For Use that come with Novoeight® before you start taking this medicine and each time you get a refill. There may be new information.

This Patient Product Information does not take the place of talking with your healthcare provider about your medical condition or treatment. If you have questions about Novoeight® after reading this information, ask your healthcare provider.

#### What is the most important information I need to know about Novoeight®?

##### Do not attempt to do an infusion 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 Novoeight® so that your treatment will work best for you.

#### What is Novoeight®?

Novoeight® is an injectable medicine used to replace clotting factor VIII that is missing in patients with hemophilia A. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally. Novoeight® is used to control and prevent bleeding in people with hemophilia A.

Your healthcare provider may give you Novoeight® when you have surgery.

Novoeight® is not used to treat von Willebrand Disease.

#### Who should not use Novoeight®?

You should not use Novoeight® if you

- are allergic to factor VIII or any of the other ingredients of Novoeight®
- if you are allergic to hamster proteins

Tell your healthcare provider if you are pregnant or nursing because Novoeight® might not be right for you.

#### What should I tell my healthcare provider before I use Novoeight®?

You should tell your healthcare provider if you

- Have or have had any medical conditions.
- Take any medicines, including non-prescription medicines and dietary supplements.
- Are nursing.
- Are pregnant or planning to become pregnant.
- Have been told that you have inhibitors to factor VIII.

#### How should I use Novoeight®?

Treatment with Novoeight® should be started by a healthcare provider who is experienced in the care of patients with hemophilia A.

Novoeight® is given as an injection into the vein.

You may infuse Novoeight® 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 hemophilia treatment center or healthcare provider. Many people with hemophilia A learn to infuse the medicine by themselves or with the help of a family member.

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

You may need to have blood tests done after getting Novoeight® to be sure that your blood level of factor VIII is high enough to clot your blood. This is particularly important if you are having major surgery.

Your healthcare provider will calculate your dose of Novoeight® (in international units, IU) depending on your condition and body weight.

#### Call your healthcare provider right away if your bleeding does not stop after taking Novoeight®.

##### Development of factor VIII inhibitors

Your body can also make antibodies called "inhibitors" against Novoeight®, which may stop Novoeight® from working properly.

If your bleeding is not adequately controlled, it could be due to the development of factor VIII inhibitors. This should be checked by your healthcare provider. You might need a higher dose of Novoeight® or even a different product to control bleeding. Do not increase the total dose of Novoeight® to control your bleeding without consulting your healthcare provider.

##### Use in children

Novoeight® can be used in children. Your healthcare provider will decide the dose of Novoeight® you will receive.

#### If you forget to use Novoeight®

Do not inject a double dose to make up for a forgotten dose. Proceed with the next injections as scheduled and continue as advised by your healthcare provider.

#### If you stop using Novoeight®

If you stop using Novoeight® you are not protected against bleeding. Do not stop using Novoeight® without consulting your healthcare provider.

If you have any further questions on the use of this product, ask your healthcare provider.

#### What if I take too much Novoeight®?

Always take Novoeight® exactly as your healthcare provider has told you. You should check with your healthcare provider if you are not sure. If you inject more Novoeight® than recommended, tell your healthcare provider as soon as possible.

#### What are the possible side effects of Novoeight®?

##### Common Side Effects Include:

- swelling or itching at the location of injection
- changes in liver tests
- fever

##### Other Possible Side Effects:

You could have an allergic reaction to coagulation factor VIII products. **Call your healthcare provider right away and stop treatment if you get any of the following signs of an allergic reaction:**

- rashes including hives
- difficulty breathing, shortness of breath or wheezing
- tightness of the chest or throat, difficulty swallowing
- swelling of the lips and tongue
- light-headedness, dizziness or loss of consciousness
- pale and cold skin, fast heart beat which may be signs of low blood pressure
- red or swollen face or hands

These are not all of the possible side effects from Novoeight®. Ask your healthcare provider for more information. You are encouraged to report side effects to FDA at 1-800-FDA-1088.

Tell your healthcare provider about any side effect that bothers you or that does not go away.

#### What are the Novoeight® dosage strengths?

Novoeight comes in six different dosage strengths. The actual number of international units (IU) of factor VIII in the vial will be imprinted on the label and on the box. The six different strengths are as follows:

- Dosage strength of approximately 250 IU per vial
- Dosage strength of approximately 500 IU per vial
- Dosage strength of approximately 1000 IU per vial
- Dosage strength of approximately 1500 IU per vial
- Dosage strength of approximately 2000 IU per vial
- Dosage strength of approximately 3000 IU per vial

Always check the actual dosage strength printed on the label to make sure you are using the strength prescribed by your doctor.

#### How should I store Novoeight®?

##### Prior to Reconstitution:

Store in original package in order to protect from light. Do not freeze Novoeight®.

Novoeight® vials can be stored in the refrigerator (36°F to 46°F [2°C to 8°C]) for up to 30 months or up to the expiration date. During the 30 month shelf life, the product may be kept at room temperature up to 86°F (30°C) for no longer than 12 months, **or** up to 104°F (40°C) for no longer than 3 months.

If you choose to store Novoeight® at room temperature:

- Note the date that the product is removed from refrigeration on the box.
- Do not return the product to the refrigerator.
- Do not use after 12 months if stored up to 86°F (30°C) **or** after 3 months if stored up to 104°F (40°C) **or** the expiration date listed on the vial, whichever is earlier.

Do not use this medicine after the expiration date which is on the outer carton and the vial. The expiration date refers to the last day of that month.

##### After Reconstitution (mixing the dry powder in the vial with the diluent):

The reconstituted Novoeight® should appear clear to slightly unclear without particles.

The reconstituted Novoeight® should be used immediately.

If you cannot use the Novoeight® immediately after it is mixed, it must be used within 4 hours when stored at ≤ 86°F (30°C) or within 2 hours when stored between 86°F (30°C) to 104°F (40°C). Store the reconstituted product in the vial.

Keep this medicine out of the sight and out of reach of children.

#### What else should I know about Novoeight® and hemophilia A?

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

For more information about Novoeight®, please call Novo Nordisk at 1-844-30-EIGHT.

Revised: 05/2018

Novoeight® is a registered trademark of Novo Nordisk Health Care AG.

Patent Information: <http://novonordisk-us.com/patients/products/product-patents.html>

Manufactured by:  
Novo Nordisk A/S  
DK-2880 Bagsvaerd, Denmark

**More detailed information is available upon request.**

Available by prescription only.

For information about Novoeight® contact:  
Novo Nordisk Inc.  
800 Scudders Mill Road  
Plainsboro, NJ 08536, USA

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US18NEGT00039 6/2018







## 7 Superpowers of Bleeding Disorders Moms and Dads

Having a child with a bleeding disorder can unleash a host of superhuman qualities

### Family Matters

**Bionic inner strength** so you can be your child's fiercest advocate.

**Supernatural precision** at accessing tiny veins to infuse your child's factor.

**Awe-inspiring nerves of steel** to stay calm and collected when you're infusing your child.

**Herculean multitasking skills** to juggle everything on your to-do list—from making appointments for the hemophilia treatment center to filing insurance claims to meeting with teachers and school nurses.

**Enhanced surveillance skills** to immediately identify a potentially dangerous activity and quickly intervene before an accident happens.

**Extrasensory perception** at recognizing when something isn't right and your child may be at risk for a serious bleed.

**Amazing resilience** to cope with the day-to-day stresses of raising a child with a bleeding disorder and stay positive and hopeful for your child's future.



**NOW APPROVED**

**FOR PEOPLE WITH HEMOPHILIA A WITH  
OR WITHOUT FACTOR VIII INHIBITORS**

**GO SEEK. GO EXPLORE. GO AHEAD.**

**Discover your sense of go. Discover HEMLIBRA®.**

**HEMLIBRA.com**

#### **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 | 150  
injection for subcutaneous use | 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

HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan  
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For more information, go to [www.HEMLIBRA.com](http://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



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# Keep It Up: Tips for Sticking to Your Exercise Plan

Getting moving in the first place is a great start. Here's how to keep yourself on a roll

## [Fitness & Nutrition](#)

Forget New Year's, anytime is a good time to make a resolution to get fitter. As you've heard over and over (and over...), regular exercise has numerous health benefits, ranging from reduced risk of heart attack, stroke, cancer and diabetes to better memory and overall brain function. Exercise also strengthens muscles and bones, providing better joint support, which is critical for people with bleeding disorders of any age because stronger muscles and bones help prevent bleeds and help you recover quicker from bleeds. So, good for you for getting active. The trick now is to keep yourself motivated so that exercise becomes a regular habit and you don't backslide into inactivity. The following tips and ideas can help keep your exercise routine fun and less, well, routine:

### **Take it slow and steady**

Even if you're feeling super motivated in the early days of a new workout regimen, don't jump in too quickly. As you ramp up your activity you don't want to get injured or increase your risk of a bleed, which will force you onto the sidelines for a spell. Second, trying to do too much too early is a good way to burn yourself out mentally. Better to rein it in a little and leave yourself with plenty of physical and mental energy for the long haul.



### **Find a buddy or group**

Making your workout a social event has a double benefit: When you intertwine exercise and socializing with friends, it's more fun, plus you're more likely to stick to a regular schedule when friends are relying on you to show up and sweat with them.

### **Don't limit yourself**

When starting out you've likely chosen one activity that speaks to you, be it walking, swimming, cycling or circuit training at the gym. As time goes on, sprinkling in some new activities keeps things fresh. Getting tired of the elliptical machine? Skip it occasionally and do yoga, tai chi or a Zumba class instead.

### **Reward yourself**

Hit 60/90/120 days of exercise? Celebrate with a dinner out, or buy some new workout clothes or gear. It may seem shallow, but if getting to don shiny new shorts, tops or sneakers is motivating, view it as a worthwhile investment in your health.

### **Track your progress**

This is particularly helpful after the first rush of enthusiasm for regular exercise begins to wear off. Seeing how much you've accomplished already pushes you to want to keep adding to your list of achievements. Keep track of your workouts in an exercise app on your smartphone, wear a fitness tracker or log them in a notebook.

### **Don't be too hard on yourself**

If you find your motivation lags after a while of steadily working out, don't worry. It's OK to miss a few workouts and take a break to recharge. Same goes if you miss out on exercise due to illness, a bleed or a hectic schedule. Keep the big picture of your health in mind. A few missed days don't diminish the overall gains you've made. If you fall off the exercise wagon, just jump back on when you're ready and pick up where you left off.

*Get information on the benefits and risks of dozens of sports and other physical activities in the NHF booklet [Playing It Safe – Bleeding Disorders, Sports and Exercise](#).*





**FEEL EMPOWERED**  
to step up to the challenge  
with Jivi®

Are you ready to see what Jivi offers?  
Visit [www.explorejivi.com](http://www.explorejivi.com) to learn more.

**Ask your doctor if Jivi may be right for you.**

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**Jivi**  
antihemophilic factor  
(recombinant) PEGylated-aucI

**LET'S GO**





## SAVE THE DATE!

Participate. Volunteer. Donate.

---

Date: Saturday, September 21, 2019

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](http://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](http://www.hemophilia.org/walk) or contact: Kristy McConnell, Local Walk Manager, at 317-570-0039 or [kmccconnell@hoii.org](mailto:kmccconnell@hoii.org)







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For over 70 years we have been inspired by people like you. Shire is the relentless champion that supports you with pioneering products and programs, while always striving toward our ultimate goal: **a life full of dreams and free of bleeds.**

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[bleedingdisorders.com](http://bleedingdisorders.com)



Annabelle  
Sibling  
Massachusetts

Alex  
Hemophilia A  
Massachusetts

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## **Upcoming Educational Dinners:**

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

**Topic:** CSL Getting' In Game  
**When:** Sunday, May 5th  
**Time:** 12:30 registration, Gates open 12:00pm  
**Where:** Victory Field

**Topic:** Cognitive Conversations  
**When:** Thursday, May 9th  
**Time:** 6:00pm  
**Where:** Giordano's  
4110 E 82nd St  
Indianapolis, IN 46250

# SAVE THE DATE!



**2019 Annual Meeting**

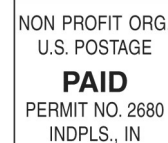
August 10th & August 11th

Crowne Plaza - Indianapolis Airport

2501 South High School Road  
Indianapolis, IN 46241



6910 N. Shadeland Ave., Suite 140  
Indianapolis, IN 46220  
[www.hoii.org](http://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!

Here are some of our upcoming events...

- Course for the Cure Golf Outing - June 3rd, 2019
- Camp Brave Eagle - June 9th - 14th, 2019
- HOII Annual Meeting - August 10th & 11th, 2019
- Unite for Bleeding Disorders Walk - September 21st, 2019

Call our office @ (317) 570-0039 or email Kristy McConnell @ [kmccconnell@hoii.org](mailto:kmccconnell@hoii.org) if you would like to get involved in any of our events!

