

# Vital Link



...For Hoosiers Living with a Bleeding Disorder

September 2020

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

Designed by: Kristy McConnell

## Board of Directors

President  
Joseph McKamey

Vice President  
Jason Flora

Treasurer  
Jeffrey Warner

Secretary  
Melissa Breedlove

## Directors

Greg Kil  
Matt Shade  
Corey McSweeney

Legal Counsel  
Bryce H. Bennett, Jr.

## Staff

Scott Ehnes  
Executive Director

Kristy McConnell  
Development and Event  
Director

Angel DiRuzza  
Community Outreach  
Coordinator

Hemophilia of Indiana  
6910 N. Shadeland Ave.  
Suite 140  
Indianapolis, IN 46220  
(317) 570-0039  
(800) 241-2873  
www.hoii.org

## 2020 Hemophilia of Indiana's Virtual Annual Meeting

Annual Meeting is usually one of our largest patients events and held over the course of a weekend at a local hotel, but thanks to COVID-19, changes had to be made. On Saturday, August 15th, Hemophilia of Indiana held its first ever Virtual Annual Meeting. Although we would of much preferred to be able to see all of our patients and families in person, it was a fun morning to see everyone's faces on the computer screen!

The Virtual Annual Meeting started with a two part general session. The first part was an incredible presentation by Patrick James Lynch, Founder & CEO of Believe Limited. Hemophilia of Indiana was proud to be the first Chapter to partner with Believe Limited with a viewing of its newest documentary "Let's Talk Mental Health". The documentary is an immersive journey through the lives of five members of the U.S. bleeding disorders community, as they open their hearts and lives to show how we can gain strength through struggle, and that perhaps we aren't so different after all. Produced in partnership with Mental Health Too, the film is intended to spark conversation, increase awareness and decrease stigma of mental health disorders within the bleeding disorders community. Following the viewing, participants enjoyed a recap of the documentary by Patrick James Lynch as well as a nice mental health discussion by Debbie de la Riva, a licensed professional counselor and a Q & A session. For the second part, it was the return of "Happy Hour" with Angel DiRuzza and Jennifer Maahs with their special guests Dr. Amy Shapiro and Dr. Anne Greist. Dr. Shapiro and Dr. Greist discussed in the impact of COVID-19 on the bleeding disorders community and answered participants questions. It was an informative and fun program and always enjoyable to hear from two experts. Following the general session, our participants were able to meet with our industry sponsors in a round robin breakout rooms.

(Continued..)

The afternoon portion of the Virtual Annual Meeting provided multiple educational presentations hosted by our industry sponsors and staff from the Indiana Hemophilia & Thrombosis Center. It was an incredible afternoon of education and community engagement. Hemophilia of Indiana was able to record the 2nd part of the general session as well as the sessions presented by staff from the IHTC and these are now available to view on the Hemophilia of Indiana's Facebook page and the IHTC website ([www.ihtc.org](http://www.ihtc.org)). Hemophilia of Indiana would like to thank all of the participants that joined us for a great day of education and all of our sponsors that made the Virtual Annual Meeting possible! We are looking forward to an in-person Annual Meeting in 2021! Go to [www.hoii.org](http://www.hoii.org) for more information!

**Thank you to all of our 2020 Virtual Annual Meeting Sponsors!!!**  
**Title Sponsors:**



**Exhibiting Sponsors:**

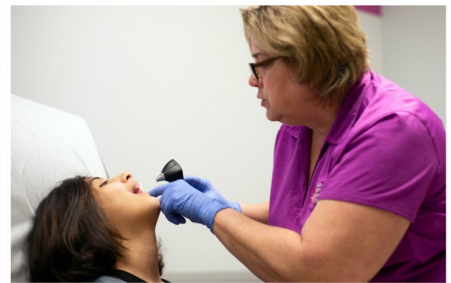




Indiana  
Hemophilia  
& Thrombosis  
Center

# COMPREHENSIVE BLEEDING DISORDER CARE ALL AT ONE CENTER

*All members of IHTC's clinical care team have extensive experience and deep expertise in bleeding disorders. This offers our patients the comfort and convenience of having every aspect of their bleeding disorder care all in one location.*



**Pediatric Hematologists**

**Adult Hematologists**

**Nurse Practitioners**

**Physician Assistants**

**Nurses**

**Physical Therapists**

**Dental Hygienists**

**Pharmacy Team**

**Psychologist**

**Genetic Counselor**

**Research**

**Social Workers**

**Registered Dietician**

**Career & School Counselors**

**Patient Insurance Coordinators**

**Child Life Specialist**



**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*



8326 Naab Road • Indianapolis, IN 46260 • 317.871.0000 • [www.ihtc.org](http://www.ihtc.org)



# GO SEEK. GO EXPLORE. GO AHEAD.

PEOPLE LIKE YOU. STORIES LIKE YOURS.  
Explore more at [HEMLIBRAjourney.com](https://HEMLIBRAjourney.com)



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

#### 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**.





**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  
©2018 Genentech, Inc. All rights reserved.

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



© 2019 Genentech USA, Inc. All rights reserved. EMI/061818/0106a(2)  
HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan.  
The HEMLIBRA logo is a trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan.  
The Genentech logo is a registered trademark of Genentech, Inc.  
All other trademarks are the property of their respective owners.

**Genentech**  
A Member of the Roche Group

## 2020 Unite for Bleeding Disorders Walk

The Unite for Bleeding Disorders Walk was held on Saturday, September 12th at the beautiful Fort Harrison State Park. Following all guidelines set forth by the Indiana Department of Health, participants practiced social distancing and wore masks. The overall look of the event might have been different this year, but the Unite theme was still going strong! It was an enjoyable morning celebrating the bleeding disorders community and supporting Hemophilia of Indiana! Congratulations to “Emiliano’s Advocate’s” and their team captain, Carolyn Salazar for being the Top Fundraising Team! A huge thank you to all of our local sponsors for their participation and support!!

We are already planning for the 2021 Unite for Bleeding Disorders Walk and can’t wait for everyone to join us in person!





## 2020 Course to a Cure Golf Outing

The 2020 Course to a Cure Golf Outing was held on Monday, August 24th! This is the 36th year for the Course to a Cure Golf Outing (normally held in June, but postponed due to COVID-19) and is held at the beautiful Maple Creek Golf & Country Club in Indianapolis, IN.

This year, we had 29 teams that participated and donated to Hemophilia of Indiana. The event had a little bit of a different look this year due to social distancing and the wearing of masks, but was still a successful day of fundraising and community support! Hemophilia of Indiana would like to thank all who donated and especially our sponsors that are vital to the success of the event!

Please note masks were removed for picture purposes only!







No actual patients depicted.

**ADYNOVATE**  
[Antihemophilic Factor  
(Recombinant), PEGylated]

REAL LIFE. REAL BLEED PROTECTION.\*

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

## HEMOPHILIA A IS A PIECE OF YOU. NOT ALL OF YOU.

ADYNOVATE® is a treatment that can be personalized to fit your lifestyle so you have more time to spend doing the other things that also make you, you. It has a simple, twice-weekly dosing schedule on the same 2 days every week.<sup>1,2</sup>

\*In clinical trials, ADYNOVATE demonstrated the ability to help prevent bleeding episodes using a prophylaxis regimen.

### ADYNOVATE twice-weekly prophylaxis prevented or reduced the number of bleeds<sup>2</sup>

ADYNOVATE was proven in 2 pivotal clinical trials to prevent or reduce the number of bleeding episodes in children and adults when used regularly (prophylaxis)<sup>2</sup>

- **Children Under 12 Years:** This study evaluated the efficacy of ADYNOVATE twice-weekly prophylaxis and determined the ability to treat bleeding episodes for 6 months in 66 children under 12 years old who received 40–60 IU/kg of ADYNOVATE prophylaxis treatment<sup>2</sup>
  - During the 6-month study in children under 12, those receiving twice-weekly prophylaxis treatment experienced a median<sup>1</sup> overall ABR<sup>1</sup> of 2.0
  - 0 bleeds in 38% (25 out of 66 patients) during 6 months on twice-weekly prophylaxis

<sup>1</sup>Median is defined as the middle number in a list of numbers arranged in numerical order.

<sup>2</sup>ABR=annualized bleed rate, the number of bleeds that occur over a year.

<sup>3</sup>Per-protocol patients were assigned to the prophylactic group and treated with their originally assigned dose for the entire duration of the study.

### ADYNOVATE Important Information

#### 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 (HCP) 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

##### Who should not use ADYNOVATE?

Do not use ADYNOVATE if you:

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

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

##### What should I tell my HCP before using ADYNOVATE?

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 ADYNOVATE passes into your milk and if it can harm your baby.
- Are or 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).

- **Adolescents and Adults 12 Years and Older:** This study evaluated the efficacy of ADYNOVATE in a 6-month study that compared the efficacy of a twice-weekly prophylactic regimen with on-demand treatment and determined hemostatic efficacy in the treatment of bleeding episodes in 137 patients. These adolescents and adults were given either ADYNOVATE prophylaxis twice-weekly at a dose of 40–50 IU/kg (120 patients) or on-demand treatment with ADYNOVATE at a dose of 10–60 IU/kg (17 patients). The primary study goal was to compare ABR between the prophylaxis and on-demand treatment groups<sup>2</sup>
  - 95% reduction in median overall ABR (41.5 median ABR with on-demand [17 patients] vs 1.9 median ABR with prophylaxis [120 patients])
  - 0 bleeds in 40% (40 out of 101 per-protocol<sup>3</sup> patients) during 6 months on twice-weekly prophylaxis

#### What important information do I need to know about 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.
- Do not attempt to infuse yourself with ADYNOVATE unless you have been taught by your HCP or hemophilia center.

#### 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. 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 ADYNOVATE?

- The common side effects of ADYNOVATE are headache and nausea. These are not all the possible side effects with ADYNOVATE. Tell your HCP 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](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.**

**Please see Important Facts about ADYNOVATE on the following page and discuss with your HCP.**

**For Full Prescribing Information, visit [www.adynovate.com](http://www.adynovate.com).**

**References:** 1. Valentino LA. Considerations in individualizing prophylaxis in patients with haemophilia A. *Haemophilia*. 2014;20(5):607–615. 2. ADYNOVATE Prescribing Information.

Copyright © 2019 Takeda Pharmaceutical Company Limited. 300 Shire Way, Lexington, MA 02421. 1-800-828-2088. All rights reserved. TAKEDA and the TAKEDA logo are trademarks or registered trademarks of Takeda Pharmaceutical Company Limited. ADVATE and ADYNOVATE are registered trademarks of Baxalta Incorporated, a Takeda company. S50751 08/19







# 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.ADYNOVATE.com](http://www.ADYNOVATE.com) or 1-877-825-3327.

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.

©2018 Shire US, Inc., Lexington, MA, 02421. All rights reserved. 1-800-828-2088. BAXALTA®, ADVATE®, and ADYNOVATE® are trademarks of Baxalta Incorporated, a wholly owned, indirect subsidiary of Shire plc.

Patented: see <https://www.shire.com/legal-notice/product-patents>

Baxalta US Inc.  
Lexington, MA 02421 USA  
U.S. License No. 2020  
Issued 05/2018

S47033

# The Power of Positivity

Enjoy the benefits of a more beneficial outlook

Author: Ian Landau

**Taking Charge**

At first, the idea that you can be happier or more satisfied by making it a habit to think more positively may seem too good to be true. But there is evidence that by consistently applying techniques that develop positive emotions, experiences and habits, you can indeed improve your self-esteem as well as your overall health—even if you have a challenging chronic condition like a bleeding disorder.

Researchers have found that performing certain practices rewires the brain's neural networks, developing and enhancing strengths like resilience, optimism, courage, perseverance and hope. Your version of happiness is of course unique to you, but by strengthening these mental attributes, research shows you can experience more meaning and fulfillment. Applying these practices won't turn you into Pollyanna. You will experience challenging times and emotions. But by cultivating a more positive outlook, these hard times won't bring you down as hard or for as long.

So how do you begin to enjoy these benefits? Start by trying the simple and proven practices below for three weeks and see how you feel.

## 1) Practice gratitude

As anyone with a bleeding disorder (or a caregiver of someone with a bleeding disorder) knows, life isn't always rosy. But if you consistently choose to focus on the negative, your brain gets in the groove of looking for reasons to be gloomy. You can retrain your brain to look for good instead. To do this, develop your capacity for gratitude.

Each day, think of three positive moments that happened and write them down. You can make these as broad as you like. Talking with a friend, listening to a song you like, and eating a yummy dinner are all fair game. At first, you may struggle to come up with three, but as the days pass and you train your brain to look for the good that's happened, it will get easier. Even if **you're coping with a bleed or another setback**, there are always a few positive things to discover in your day.

## 2) Expand on a positive experience

Pick one good moment from your day and spend a few minutes recalling it in writing. Capture the details of the experience. Research has found that visualizing and writing



down such positive events enhances the brain's ability to establish them as positive memories to draw on later.

### 3) Exercise

You already know consistent exercise is key for overall health and helps manage symptoms of bleeding disorders like joint pain. But the positive effects of exercise go further. Physical activity has neurological as well as physical benefits. Studies show that exercise enhances mood by boosting levels of feel-good brain chemicals like endorphins. In addition to feeling better, exercise helps ward off positivity-sapping emotions and experiences like stress, depression and anxiety. To reap the rewards, aim for the recommended 30 minutes a day of moderate-intensity activity. Everything from walking, jogging, bike riding, dancing or gardening is good.

### 4) Meditate

Although it's more mainstream than ever, meditation can be daunting to get started with for some. Practicing meditation teaches us to more fully experience the present moment. Without being overwhelmed by thoughts of the past or the future, our minds can relax a bit. Allowing thoughts, feelings and sensations to arise in our minds, and accepting them for what they are without judgment, helps promote a sense of overall contentment that carries over into life in general. Start with just a few minutes a day of meditation (e.g., focusing on the rising and falling of your breath) and build to longer sessions.

### 5) Perform random acts of kindness

Over time, regularly doing uncomplicated kind gestures requiring minimal effort on your part can have a big impact on your well-being—and on the outlooks of the recipients of your acts of kindness. Evidence shows such acts build optimism and hope in yourself and reinforce the positive impact you can have on your own quality of life while also improving the lives of others.

This may seem the most difficult practice to accomplish every day, but again, think broadly. Bring up your neighbor's trash cans from the street when you grab your own. Buy coffee for the person behind you in line or pick up lunch for a co-worker. Bake cookies for your hemophilia treatment center's staff or your child's teacher. Send an email or text to someone simply saying you appreciate them. There are endless ways to bring a little joy to others, and enjoy it while you're doing so. For more ideas, visit [randomactsofkindness.org](http://randomactsofkindness.org).



## Exploring the science behind gene therapy research

Gene therapy research has the potential to bring an entirely new option to people with specific genetic conditions. Many gene therapies are in clinical trials to evaluate the possible risks and benefits for a range of conditions, including hemophilia. HemDifferently is here with gene therapy education, providing accurate information in a way you can understand.

Let's explore gene therapy together at **HemDifferently.com**

No gene therapies for hemophilia have been approved for use or determined to be safe or effective.

**BIOMARIN**

©2020 BioMarin Pharmaceutical Inc. All Rights Reserved. MMRCGTH0037 0620



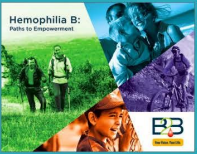
## Exciting Updates - Virtual Educational Dinners

We are excited to announce that we will be partnering with some of our industry sponsors to bring you some virtual educational “dinners” in the fourth quarter of 2020. You will be able to find information about any upcoming virtual events on the HOII website events calendar ([www.hoii.org/events](http://www.hoii.org/events)) and on Facebook or Instagram pages (@HemoIndy). We hope you will join us virtually and we look forward to seeing you all live and in person soon!

Thanks,  
Angel DiRuzza  
Community Outreach Coordinator/Program Director




**Your Voice. Your Life.**



**DOWNLOAD OR VIEW BOOKS**  
filled with patient stories that can inspire, empower, and educate



**LISTEN TO PODCASTS**  
that capture the voices of the hemophilia B community



**VIEW VIDEOS**  
that feature members of the community sharing their personal experiences

Interested in stories and personal experiences from the hemophilia B community for the hemophilia B community? Turn to B2B.

### Topics include:



**EDUCATING YOUR CHILD'S SCHOOL**  
about hemophilia B



**HEMO 101** for caregivers



**MANAGING RELATIONSHIPS**  
with hemophilia B



**LIFE FOR GIRLS AND WOMEN**  
with hemophilia B

Visit [hemophiliavillage.com](http://hemophiliavillage.com) to check out all that B2B has to offer

# SAY HELLO TO JAMES

He has hemophilia A and has gone through two major surgeries while keeping to his factor regimen with the support of his hemophilia care team

"RECOVERY WAS TOUGH,  
BUT I LEARNED I HAD  
MORE SUPPORT THAN  
*I THOUGHT POSSIBLE.*"



Read stories like James' in  
*Hello Factor* magazine:  
[BleedingDisorders.com](http://BleedingDisorders.com)



Copyright © 2020 Takeda Pharmaceutical Company Limited, 300 Shire Way, Lexington, MA 02421.  
1-800-828-2088. All rights reserved. TAKEDA and the TAKEDA logo are trademarks or registered  
trademarks of Takeda Pharmaceutical Company Limited. US-NON-1257v1.0 06/20





## 2020 Scholarship Winners

The Judy Moore Memorial Scholarship was started in 2013 in memory of Judy Moore, an incredible woman who spent decades supporting the bleeding disorders community for both Hemophilia of Indiana and the Indiana Hemophilia & Thrombosis Center. Scholarships are awarded to members of the Indiana's bleeding disorders community pursuing higher education (includes undergraduate, graduate, or vocational/school educations). The Judy Moore Memorial Scholarship Program since its inception has given away \$123,000 to 43 deserving members of the bleeding disorders community of Indiana. Hemophilia of Indiana and the Judy Moore Memorial Scholarship Committee is honored and excited to announce that this year \$40,000 was awarded to 17 incredible individuals, bringing the 7 year total given to \$163,000 to 60 individuals! Congratulations to the 2020 winners:

Matt Olovich  
Caleb Moser  
Cortland Jackson  
Irvin Castillo  
Peyton Zebrauskas  
Mason Moore

Olivia Hoff  
John Bontrager  
Hanna Alquezada  
Madison Stevens  
Lauryn Hicks  
Mary Lang

Julia Collins  
Kyle Collins  
Max Alter  
Hery Acosta  
Lily Jones

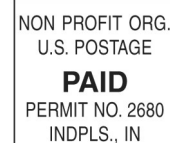
The Ed Magoni Memorial Scholarship was founded in 2019 by Mary Rita and Gary Magoni. Affected with Severe Hemophilia A, unable to fulfill his dream of playing football, Ed transferred his love of athletics into a successful career as a sports journalist. During his career, Ed worked with young, aspiring journalists guiding many of his interns to successful journalism careers. The Ed Magoni Memorial Scholarship was founded by his family to help continue Ed's passion of supporting and encouraging young people in the bleeding disorders community. In 2019, a total \$5,000 were awarded to 3 individuals. Hemophilia of Indiana and the Ed Magoni Memorial Scholarship committee are excited to announce that in 2020 a total of \$5,000 was awarded to 5 individuals bring a two year total to \$10,000 to 7 incredible members of the bleeding disorders community! Congratulations to the 2020 winners:

Tanner Berg      Lauryn Hicks      Kyle Collins      Lily Jones      Hery Acosta

Applications for the 2021 applications will be available February 2021! Please go to [www.hoii.org/member-resources/scholarships](http://www.hoii.org/member-resources/scholarships) for more information!



6910 N. Shadeland Ave., Suite 140  
Indianapolis, IN 46220  
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...

- 2020 Fit Livin' Thanksgiving Day Run - November 26th
- Year End Education Event - December 5th

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

- Check out our social media pages for updates!!!

