THE WINNING SPIRIT

Fall 2020

EASTERN PENNSYLVANIA
HEMOPHILIA FOUNDATION

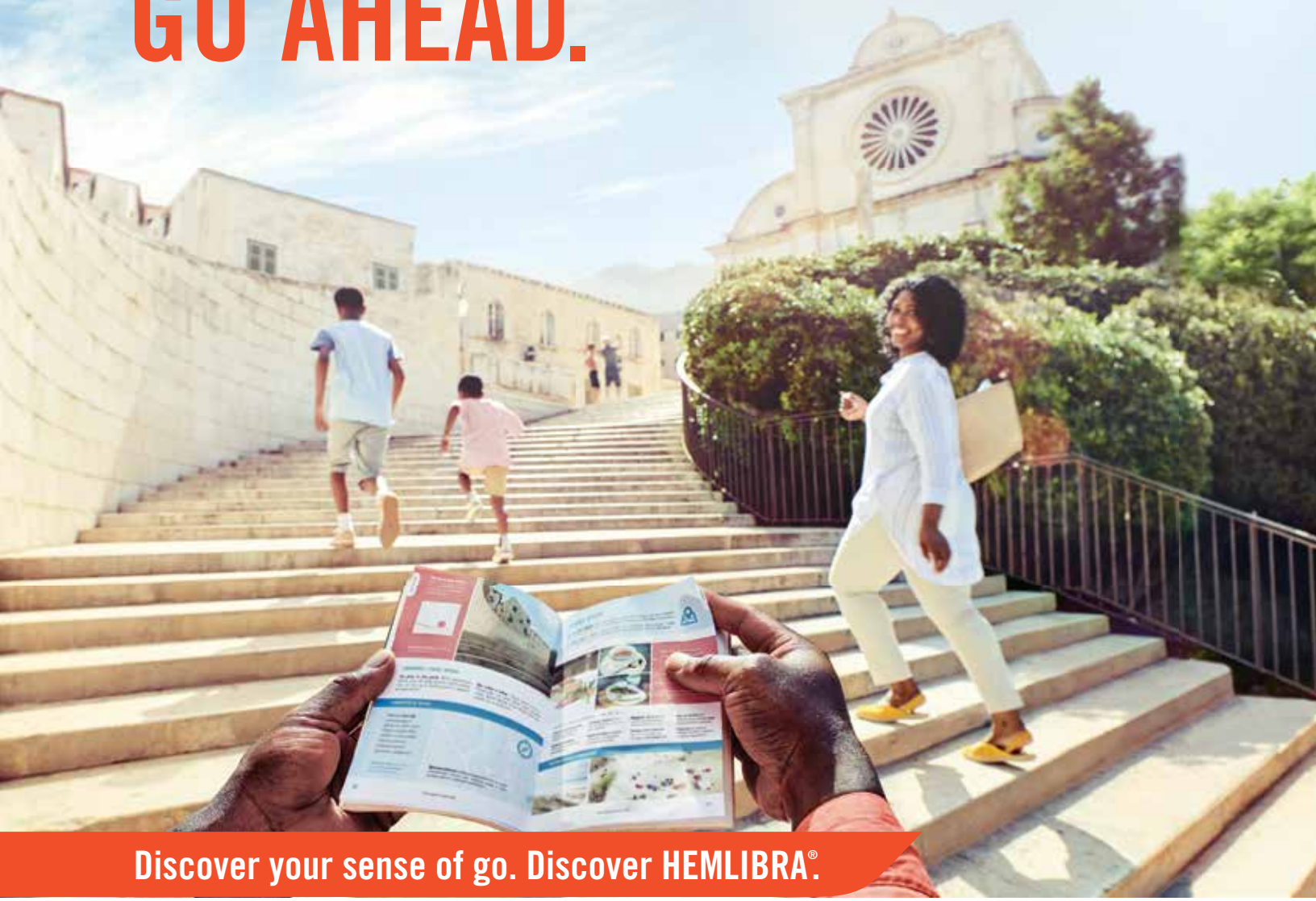
41 Counties. 1 Mission.

GO SEEK. GO EXPLORE.

GO AHEAD.

PEOPLE LIKE YOU. STORIES LIKE YOURS.

Explore more at 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**.

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

EASTERN PENNSYLVANIA HEMOPHILIA FOUNDATION

41 Counties. 1 Mission.

Serving the Hemophilia and vWD Community.

National Hemophilia Foundation
for all bleeding and clotting disorders

Proud Member HFA

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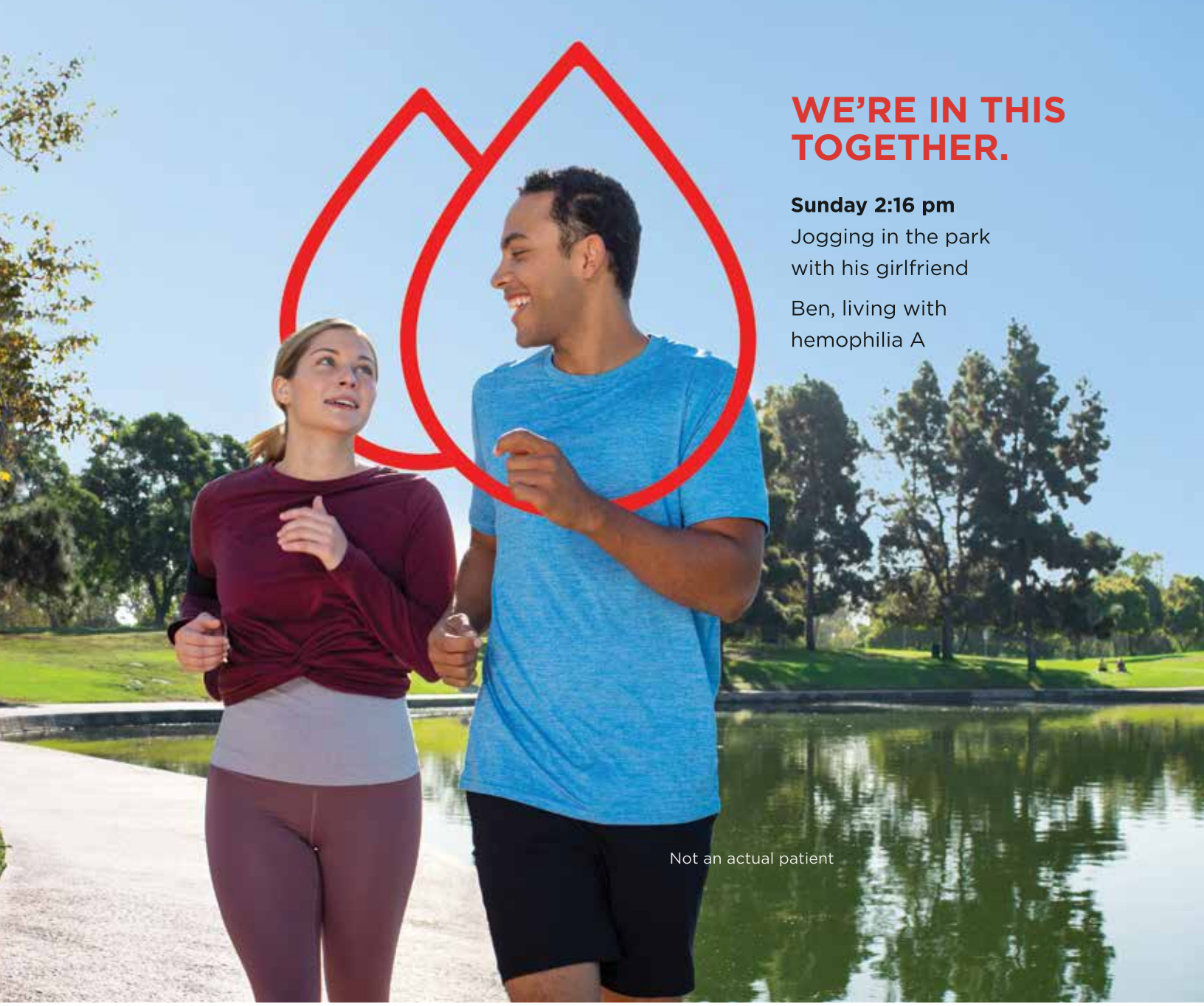


Let's make today brilliant.

Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world, is stronger than ever.

bleedingdisorders.com

Takeda

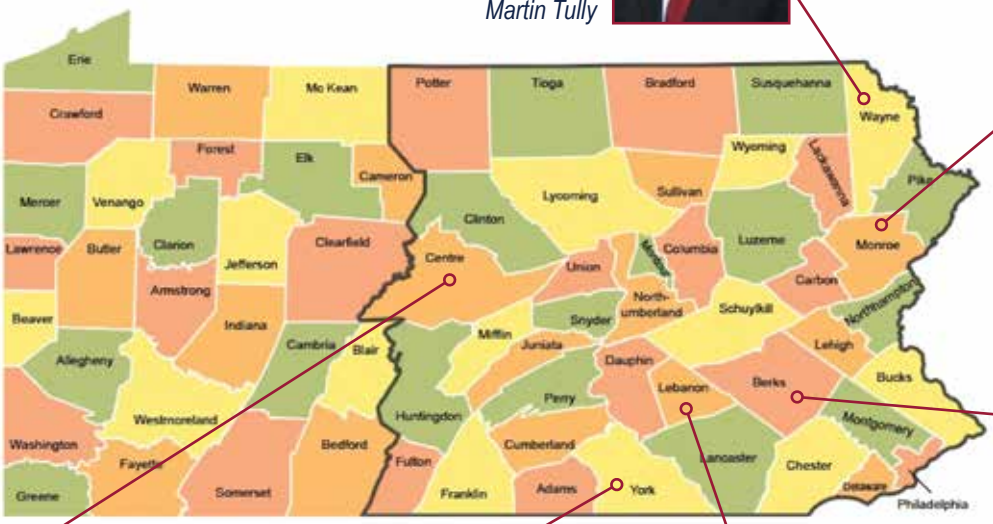
ADVOCACY UPDATE
ADVOCACY AMBASSADORS

The EPHF Advocacy Ambassador program is in full force. We have had meetings with legislators and their respective ambassadors throughout our coverage area. We discuss issues affecting our community and the ambassadors share their personal stories. Our hope is to both educate and develop strong relationships with our representatives and senators.

We invite you to join our advocacy team. The goal is to have ambassadors throughout our 41 counties. For more information, please contact Curt Krouse at (484) 445-4282.

Wayne County
Representative Jonathan Fritz
Advocacy Ambassador
Martin Tully

Monroe County
Senator Mario Scavello
Advocacy Ambassadors
Nancy, Nicole and Callie Padilla



Centre County
Senator Jake Corman
Advocacy Ambassador
Marisa Ferger

York County
Senator Kristin Phillips-Hill
Advocacy Ambassador
Ryan Nicolaisen

Lebanon County
Representative Frank Ryan
Advocacy Ambassador
Frank Lentini

Berks County
Senator Judith Schwank
Advocacy Ambassador
Christopher Templin

Managing the Transition From Childhood to Adolescence

Guiding Preteens With Hemophilia

For more information, visit b2byourvoice.com to download *Navigating The Preteen Years.*

This content is brought to you by Pfizer.

Parents of a preteen with hemophilia may have concerns about preparing a child for life with a chronic condition. During the preteen years, children spend time away from family, attend school, and experience additional social influences. This is when children begin to form their own ideas and opinions. Preteens may be exposed to peer pressure to engage in risky behavior and/or forego treatment, making open communication essential.

Preteens are building life experience and taking steps toward independence, and it is important that parents set limits. Preteens may not handle their impulses and desires maturely.[1] Guiding a child to make the right choices can help prepare him or her for the future and the many similar decisions he or she will make. Parents should find a balance between giving a child space to grow and setting boundaries.[1]

Adolescence lasts longer today than in the past; children begin puberty earlier and leave home later. This gives parents and children more time to learn how to negotiate the transition to independence.[2]

Proactivity is Crucial

Dr. Thomas Truncale ranks proactivity as the most important factor when managing hemophilia. Anticipating needs and putting together a plan ahead of time can have benefits when treating hemophilia, addressing parenting issues, and in seeking education.

Proactively educating children about hemophilia can improve their ability one day to begin managing their own medical care. At a young age, children can gather infusion supplies or even decide on the infusion site. This involvement can help prepare them for self-infusing. Dr. Truncale recommends that families attend summer camps where older children mentor younger children.

> "Encourage your child to focus on what he or she can do, not what they can't do."
>
> — Thomas Truncale
> DO, MPH

Education helps children living with hemophilia learn to make the right decisions. If a bleed occurs, proper education may help the child identify it as soon as possible so it can be treated early.

Dr. Truncale adds that proactivity should extend to school, church, and community. Create a package of educational information for the school nurse, teachers, church personnel, babysitters, and other families. Ask the hemophilia care team for materials available for this purpose, and don't forget to add relevant personal contact information.

Reference: 1. Cassis FRMY. *Psychosocial Care for People With Hemophilia.* Montréal, Québec: World Federation of Hemophilia; 2007. **2.** Irish Haemophilia Society. Transition. https://haemophilia.ie/living-with-haemophilia/parents-of-children-with-bleeding-disorders/the-bridge-of-transition-for-adolescents-with-bleeding-disorders/. Accessed September 17, 2019.

PATIENT AFFAIRS LIAISONS

Patient Affairs Liaisons are Pfizer employees who are dedicated solely to providing support to the community. Your Pfizer Patient Affairs Liaison is available to help you access the support and information you need. To find your Patient Affairs Liaison, go to hemophiliavillage.com/support/patient-affairs-liaison-finder or call Pfizer Hemophilia Connect at 1.844.989.HEMO (4366).

PP-HEM-USA-1254

November 2019

Pfizer

2020-21 SCHOLARSHIP RECIPIENTS

Eastern PA is thrilled to award college scholarships to each of the talented students below.

Hajar Abusief
Freshman
New York University

Nickolas Azzarano
Sophomore
Rochester Institute of Technology

Uyen Duong
Freshman
Pennsylvania College of Health Sciences

Johanna Graser
Sophomore
La Salle University

Kataryna Iannuzzi
Freshman
Rowan College at Burlington County

Michael Iannuzzi
Freshman
Rowan College at Burlington County

Rylee Knepper
Freshman
Lancaster Bible College

Nadine Lampe
Sophomore
University of Southern California

Noelle Lampe
Senior
Loyola Marymount University

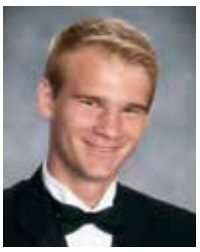
Elisa Macera
Sophomore
University of Delaware

Jenna Oliviero
Senior
Alvernia University

Tori Robbins
Junior
Stockton University

Trevor Robbins
Senior
Stockton University

Hallie Seidel
Senior
West Chester University



Andrew Snyder
Senior
Villanova University

Jacqueline Torres
Sophomore
Community College of Philadelphia

Cory Witmer
Junior
Alvernia University

Ryan Zhao
Sophomore
University of California Berkeley

SENIOR SPOTLIGHT

JENNA OLIVIERO

ALVERNIA UNIVERSITY

WHAT IS YOUR MAJOR AT ALVERNIA UNIVERSITY?

Bachelor of Science in Nursing

WHAT IS YOUR GOAL UPON GRADUATION?

My goal is to have a job lined up when I graduate. Right now, I am interested in being an Emergency Room or Trauma ICU Registered Nurse.

WHAT HAS BEEN YOUR FAVORITE EXPERIENCE IN COLLEGE SO FAR?

My favorite experience in college so far is getting involved in our Student Nursing Club on campus in which I have served as President both my junior and senior years. This has allowed me to meet many new people and attend Student Nursing Conventions locally and nationally.

TEMPLE FOOTBALL SIGNS FINAL RECRUIT TO CLASS OF 2020

Football | 9.30.20

PHILADELPHIA – Temple Football head coach Rod Carey announced today that the Owls signed its final recruit to the Class of 2020. Thirteen-year old Jaidyn will fill the final roster spot.

A Philadelphia native, Jaidyn currently attends Sankofa Freedom Charter School. He appeared on the Temple coaches' radar by way of Team IMPACT, a non-profit organization that connects children facing serious and chronic illnesses with college athletic teams in a two-year therapeutic program.

"As soon as I heard about Jaidyn I knew he was Temple TUFF," said Carey. "He fits our core characteristics of being Smart, Tough, and Relentless and serves as an inspiration to all the members of our program."

In his recruitment letter, Jaidyn was informed his "Owl teammates and coaches know [his] commitment to the football program this coming season is sure to be unlike any other." Jaidyn has already taken part in virtual team meetings and will continue to do so until health and safety concerns allow him to attend practices and games.

"As a parent to a child with special health needs," said Jaidyn's mother Sierra, "it is important for me to find programs that are inclusive and safe for Jaidyn. He loves feeling like he is a part of the team and has their support; he can't wait to meet everyone in person!!"

Team IMPACT has created relationships that have enhanced the lives of thousands of courageous children and touched the lives of tens of thousands of student athletes across the country. The team behind Team IMPACT is honored and inspired to continue to expand the long-standing tradition of athletes contributing to something far greater than themselves. The student athletes in the program extend their commitment to their team, to each other, to provide sick children in their local community a profound sense of belonging, by demonstrating their steadfast support for each and every member of the team through adversity both on and off the field.

In the Philadelphia area, Team IMPACT has matched 94 local kids with teams since 2011, and currently has 35 kids matched with teams at 20 colleges and universities, with almost 1,000 student athletes currently supporting local children.

Since its inception in 2011, Team IMPACT has matched over 2,000 children with more than 700 colleges and universities in 48 states, positively impacting more than 60,000 student athletes.

#7 Jaidyn 5-6 135 Philadelphia, PA / Sankofa Freedom Charter

2020 Season: Was the final member of the recruiting class of 2020.

High School: Attends Sankofa Freedom Charter School in Philadelphia, Pa. … the seventh grader's favorite subject is literature.

Personal: Born in Philadelphia … goes by Jai … parents are Sierra and Raheem … has a sister Journey (5) … aspires to be a comedian … list of favorites include: All Dogs Go to Heaven (movie), The Umbrella Academy (TV show), Dairy of a Wimpy Kid / The Melt Down (books), Brooklyn Nets Kyrie Irving (pro team and athlete), Dalessandro's (place to get a cheesesteak), Skai Jackson (celebrity crush).

HTC SPOTLIGHT

INTERVIEW WITH J. NATHAN HAGSTROM, MD, MS

CHAIR OF DEPARTMENT OF PEDICATRICS AT LEHIGH VALLEY HEALTH NETWORK AND PHYSICIAN-IN-CHIEF OF LEHIGH VALLEY REILLY CHILDREN'S HOSPITAL

WHERE ARE YOU ORIGINALLY FROM? WHERE DID YOU ATTEND SCHOOL?

I was born in Bloomington, Indiana and moved to Lancaster County, Pennsylvania when I was nine and then moved to Vermont when I was 15. I attended the University of Vermont for both undergraduate and medical school. After medical school I went to Philadelphia to do my general pediatric and pediatric hematology oncology training at Children's Hospital of Philadelphia. My first faculty position was at the University of Connecticut at their medical school outside of Hartford CT.

WHAT IS YOUR ROLE IN YOUR CURRENT POSITION?

I came to the Lehigh Valley six years ago to be Chair of Pediatrics at LVHN and the Physician-in-Chief at our Children's Hospital. I'm also a physician at the Lehigh Valley Hemophilia Treatment Center, taking care of children and adults with bleeding disorders.

HOW DID YOU BECOME INTERESTED IN BLEEDING DISORDERS?

When I was in medical school, I did an extra year of research in neonatology specifically focusing on vitamin K coagulation factors in newborns. I worked in a coagulations research laboratory and was introduced to different protein biochemical analysis techniques. I fell in love with coagulation and did a two-month laboratory fellowship with Dr. Maureen Andrew in Canada at McMaster and Toronto Hospital for Sick Kids during my final year of medical school. Both of those experiences convinced me to focus my career on hemostasis and thrombosis in newborns and children. At CHOP I had the opportunity to work with Drs. High and Manno, who were tremendous mentors for me, and with Regina Butler who taught me what it means to care for people with hemophilia. CHOP is truly where my interest in hemophilia grew.

WHAT DO YOU THINK ARE THE BIGGEST ISSUES FACING CHILDREN WITH HEMOPHILIA TODAY? HOW HAVE THESE ISSUES CHANGED FROM WHEN YOU FIRST STARTED YOUR CAREER?

HIV and creating recombinant clotting factors were the biggest issues facing the hemophilia community when I first started my career. Today one of the biggest issues is creating treatments that allow for normal living and activities every day while at the same time minimizing the need for injections. Hemlibra has changed our approach to hemophilia care for many people with hemophilia A (factor VIII deficiency). Hopefully similar approaches will be approved for hemophilia B (factor IX deficiency) and other bleeding disorders soon. Another issue facing us today is the cost of treatments and addressing the worldwide need for better treatments; the two are related.

WHAT IS YOUR FAVORITE PART OF YOUR JOB?

Working with wonderful people, those who come to us to seek care and those who provide it. The resiliency, commitment, and compassion I get to see and be a part of every day never stops being inspirational.

WHAT DO YOU LIKE TO DO IN YOUR SPARE TIME?

Music, reading and spending time with my family. I've been playing the guitar and singing since I was a teenager.

IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD?

I want to wish all the best to everyone in the bleeding disorders community and thank them for allowing me to be a part of it.

CSL Behring
Biotherapies for Life®

For adults and children with hemophilia A

REACH HIGHER

With the Long-lasting Protection of AFSTYLA

2x WEEKLY — FDA approved for dosing 2 to 3 times a week

ZERO BLEEDS (median AsBR*) — Regardless of age and dosing schedule

AFSTYLA was studied in 258 adults, adolescents, and children—one of the largest hemophilia A pivotal trial programs to date

*AsBR=Annualized spontaneous bleeding rate.

Ask your doctor if twice-weekly dosing is right for you

Important Safety Information

AFSTYLA is used to treat and control bleeding episodes in people with hemophilia A. Used regularly (prophylaxis), AFSTYLA can reduce the number of bleeding episodes and the risk of joint damage due to bleeding. Your doctor might also give you AFSTYLA before surgical procedures.

AFSTYLA is administered by intravenous injection into the bloodstream, and can be self-administered or administered by a caregiver. Your healthcare provider or hemophilia treatment center will instruct you on how to do an infusion. Carefully follow prescriber instructions regarding dose and infusion schedule, which are based on your weight and the severity of your condition.

Do not use AFSTYLA if you know you are allergic to any of its ingredients, or to hamster proteins. Tell your healthcare provider if you previously had an allergic reaction to any product containing Factor VIII (FVIII), or have been told you have inhibitors to FVIII, as AFSTYLA might not work for you. Inform your healthcare provider of all medical conditions and problems you have, as well as all medications you are taking.

Immediately stop treatment and contact your healthcare provider if you see signs of an allergic reaction, including a rash or hives, itching, tightness of chest or throat, difficulty breathing, lightheadedness, dizziness, nausea, or a decrease in blood pressure.

Your body can make antibodies, called inhibitors, against FVIII, which could stop AFSTYLA from working properly. You might need to be tested for inhibitors from time to time. Contact your healthcare provider if bleeding does not stop after taking AFSTYLA.

In clinical trials, dizziness and allergic reactions were the most common side effects. However, these are not the only side effects possible. Tell your healthcare provider about any side effect that bothers you or does not go away.

Please see enclosed full prescribing information for AFSTYLA, including patient product information.

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.

You can also report side effects to CSL Behring's Pharmacovigilance Department at 1-866-915-6958.

AFSTYLA®
Antihemophilic Factor (Recombinant), Single Chain

Brief Summary

CSL Behring
Biotherapies for Life®

AFSTYLA®, Antihemophilic Factor (Recombinant), Single Chain
For Intravenous Injection, Powder and Solvent for Injection
Initial U.S. Approval: 2016

BRIEF SUMMARY OF PRESCRIBING INFORMATION
These highlights do not include all the information needed to use AFSTYLA safely and effectively. Please see full prescribing information for AFSTYLA, which has a section with information directed specifically to patients.

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

- Your healthcare provider or hemophilia treatment center will instruct you on how to do an infusion on your own.
- Carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing this medicine.

What is AFSTYLA?

- AFSTYLA is a 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.
- Does not contain human plasma-derived proteins or albumin.
- Your healthcare provider may give you this medicine when you have surgery.
- Is used to treat and control bleeding in all patients with hemophilia A.
- Can reduce the number of bleeding episodes when used regularly (prophylaxis) and reduce the risk of joint damage due to bleeding.
- Is not used to treat von Willebrand disease.

Who should not use AFSTYLA?

You should not use AFSTYLA if you:

- Have had a life-threatening allergic reaction to it in the past.
- Are allergic to its ingredients or to hamster proteins.

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

What should I tell my healthcare provider before using AFSTYLA?

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 hamster proteins.
- Have been told you have inhibitors to Factor VIII (because this medicine may not work for you).

How should I use AFSTYLA?

- Administer directly into the bloodstream.
- Use as ordered by your healthcare provider.
- You should be trained on how to do intravenous injections by your healthcare provider or hemophilia treatment center. Once trained, many patients with hemophilia A are able to inject this medicine by themselves or with the help of a family member.
- Your healthcare provider will tell you how much 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 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 this medicine.

What are the possible side effects of AFSTYLA?

- Allergic reactions may occur. Immediately stop treatment and call your healthcare provider right away if you get a rash or hives, itching, tightness of the chest or throat, difficulty breathing, light-headedness, dizziness, nausea, or decrease in blood pressure.
- Your body may form inhibitors to Factor VIII. An inhibitor is a part of the body's defense system. If you form inhibitors, it may stop this medicine from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.
- Common side effects are dizziness and allergic reactions.
- These are not the only side effects possible. Tell your healthcare provider about any side effect that bothers you or does not go away.

What else should I know about AFSTYLA?

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

Please see full prescribing information, including full FDA-approved patient labeling. For more information, visit www. AFSTYLA.com

Manufactured by:
CSL Behring GmbH
35041 Marburg, Germany

for:
CSL Behring Recombinant Facility AG
Bern 22, Switzerland 3000
US License No. 2009

Distributed by:
CSL Behring LLC
Kankakee, IL 60901 USA

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.

You can also report side effects to CSL Behring's Pharmacovigilance Department at 1-866-915-6958.

Based on December 2019 revision.

AFSTYLA® Antihemophilic Factor (Recombinant), Single Chain

GOLF CLASSIC

The Eastern PA Hemophilia Foundation held its annual Golf Classic on Tuesday, September 15 at RiverCrest Golf Club in Phoenixville. Golfers enjoyed the beauty of the course with native grasses, rock walls, cascading waterfalls and deep ravines challenging players of all skill levels. CSL Behring was once again the presenting sponsor, and we thank them for their continued generous support. Special thanks also to Accredo, BioMatrix, Cottrill's, CVS Specialty, Soleo, Visual Communications, Penn Home Infusion, Louis P. Canuso Inc, Axiva Health Solutions, and Novo Nordisk.














No actual patients depicted.

ADYNOVATE
[Antihemophilic Factor (Recombinant), PEGylated]

REAL LIFE. REAL BLEED PROTECTION.*

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.[1,2]

*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[2]

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)[2]

- **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[2]
  - During the 6-month study in children under 12, those receiving twice-weekly prophylaxis treatment experienced a median† overall ABR‡ of 2.0
  - 0 bleeds in 38% (25 out of 66 patients) during 6 months on twice-weekly prophylaxis
- **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[2]
  - 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§ patients) during 6 months on twice-weekly prophylaxis

†Median is defined as the middle number in a list of numbers arranged in numerical order.
‡ABR=annualized bleed rate, the number of bleeds that occur over a year.
§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).

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, 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.

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

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Takeda

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 or 1-877-825-3327.

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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FAMILY CAMP

The Foundation was excited to host Family Camp from September 18-20 at Camp Kweebec in Schwenksville. Friday evening featured a delicious dinner, relaxing massages for parents and teens, and two movies on a giant inflatable outdoor screen. Families enjoyed Doolittle starring Robert Downey, Jr. followed by the inspirational story of Chris Bombardier in Bombardier Blood.

On Saturday, there were plenty of activities, including fishing, canoeing, tennis, street hockey, mini golf, nature walk, kickball, basketball, and arts and crafts. There also were special programs for the tweens and teens. In the evening, Jungle John came to Family Camp with his live reptile show. Everyone was able to see turtles, snakes, and even an alligator. To end the night, there was a dance party with a professional DJ, glow sticks, refreshments, and giveaways. The weekend ended with breakfast on Sunday morning.

SUMMER CONNECTIONS

This summer we were able to get together with our community members in fun and creative ways. On Wednesday, July 8, Dr. Nathan Hagstrom and Carah Tenzer, social worker, from Lehigh Valley Hospital joined us virtually for a Tween Health Program for young girls with bleeding disorders between the ages of 9-13. The Women's Group had a Zoom Happy Hour on Thursday, July 9 with the program *It's Ok to Not Be Ok*. On Thursday, July 23, we met community members at the Cumberland Drive-In Theatre in Newville, PA to watch Bombardier Blood. We were able to safely connect with one another at the first ever drive-in showing of this movie. Thank you to everyone who was able to join us at these events!

ANNUAL MEETING
ADVENTURES IN LEARNING
WOMEN'S RETREAT
NOW VIRTUAL!

PLEASE VISIT WWW.HEMOPHILIASUPPORT.ORG FOR MORE DETAILS

MedicAlert Memberships & IDs

The Eastern PA Hemophilia Foundation provides MedicAlert Memberships and IDs for patients with hemophilia, vWD and other factor deficiencies. To qualify, you must either live in Pennsylvania (Eastern PA's coverage area) or if you live outside the state, then you must be treated at one of the following six Hemophilia Treatment Centers:

- Thomas Jefferson University Hospital
- Hospital of the University of Pennsylvania
- Children's Hospital of Philadelphia
- St. Christopher's Hospital for Children
- Penn State Hershey Medical Center
- Lehigh Valley Hospital – Muhlenberg

Contact Lindsay Frei for more information at 484-445-4282 or lindsayf@hemophiliasupport.org.

MedicAlert FOUNDATION

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