

HBDA QUARTERLY NEWSLETTER

Summer Edition 2021

Rick Dinkins, Chairman

Volume 50

Vicki Jackson, Executive Director

Table of Contents

Cover Page

Words from the Chair

Page 2

Camp Clot Not 2021

Page 3

Camp Clot Not 2021

Page 4

Camp Clot Not 2021

Page 5

Camp Clot Not 2021

Page 6

Camp Clot Not 2021

Page 7

Courage in the Time of COVID

Page 10

Camp Harvest 2021 Save the Date

Page 15

2021 Event Dates

Page 17

Golf Tournament Save the Date

Page 18

Back to School Recipes

Page 19

Year End Luncheon Save the Date

Page 20

HBDA Information & Birthdays



Staff

Executive Director

Vicki Jackson

Consumer Relations Manager

Amanda Jennings

Board Members

Rick Dinkins - Chairman

Jared McLaughlin - Vice Chair

Van Rushton - Treasurer

Blake Harris - Board Member

Brian Ward - Past President

Chris Blair - Past President

Words from the Chair

Here's my opening paragraph from the last newsletter:

"Spring is in the air and so is the pollen and every other allergy-contributor in the world! But, it's all better than the "C-Virus" and it feels like that the corner has been turned in the battle against it! I hope so!"

Well, it looks like I jinxed us! As I write this, Alabama and numerous other states are experiencing an outbreak of the Covid variant D and it is wreaking havoc in our day to day lives. For my family, we continue to evaluate our "safe" place and hope we can continue to avoid the virus. That said, we are trying to be flexible and reasonable in our approach to living...easier said than done sometimes.

Flexible, reasonable and adaptable is exactly what Vicki and Amanda have been doing all year and, most recently, with postponing our Annual Meeting till the February/March timeframe. It was a tough decision but in the end, it was the right call. We did not take it lightly nor do so without consultation with our partners and supporting businesses that make Annual Meeting work. We will pause our efforts and begin focusing on the next "big" things."

Family Camp, the Golf Tournament and the annual Year End Luncheon are just around the corner so we will shift gears a bit. We realize that staying flexible is key coupled with a fair degree of risk management in our approach and decision making.

That said, Covid was not a damper for the Camp Clot Not in 2021. We had over 30 campers and from my point of view, it was outstanding. Feedback has been exceptional thanks to leadership of our Camp Director, Libby Hall and a super crop of "LITs" and volunteers who made the week special for all. It was great to see us approach a bit of normalcy, even for a short time.

This year we offered a "grant" for school supplies to our members using our CLOT LINE resources...a first time for us. Over 40 families took advantage of the effort and we were very pleased to offer a "member benefit" for our HBDA community. Great job Vicki and Amanda.

Stay close to the website for the latest HBDA updates and Be Safe.

Rick Dinkins
Chairman



CAMP CLOT NOT 2021

"SCHOOL OF WIZARDRY"

CHILDREN'S HARBOR ON LAKE MARTIN



Many things have changed since the last time that HBDA campers were able to meet for Camp Clot Not! Thanks to an unwelcomed visitor, COVID-19, Camp Clot Not 2020 had to be cancelled. That gave the staff and volunteers extra time to make CCN 2021 an absolutely amazing experience.

We were overjoyed to be able to transform Children's Harbor into a satellite campus of Hogwarts, the ever so famous, School of Wizardry. The Galley was decked out from top to bottom to resemble the Great Hall. The head table was reserved for Professors Dumbledore, McGonagall, and Snape, along with special guests and that pesky Bellatrix LeStrange. She was up to her usual hijinks, and we were forced to keep a watchful eye on her all week. In keeping with the theme of the week, the campers were sorted into their Houses to promote a sense of brotherhood/sisterhood. All of the activities were planned in a way to foster and encourage interaction between the campers and to teach them to work as a team.

Our industry sponsors provided the campers with great educational sessions and each camper was able to take home a goody bag with items donated by our sponsors.

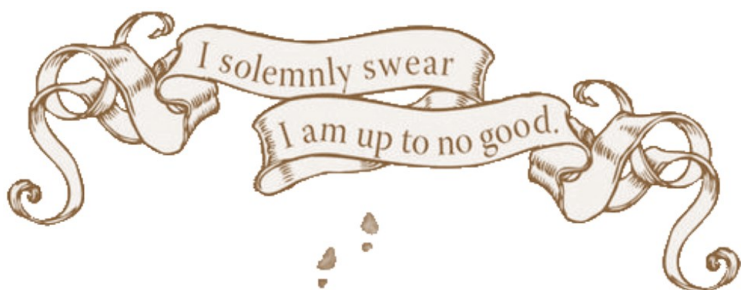
One of the challenges that we faced this year was in the staffing arena. We were blessed to have three young men from Samford University School of Physical Therapy volunteer to be counsellors. They did an outstanding job. Any task that was asked of them, was met with a smile and enthusiasm.

Our LIT program this year was a new experience for us, as well as the LIT's. All of our LIT's were in their first year of the program. We were blown away by how well they adjusted and interacted with the campers. It is always quite a shock to the LIT's when they realize just how much work goes into a successful camp and this year was no exception. The level to which each of them rose was impressive. These young leaders in training have a bright future ahead of them.

At the conclusion of camp, each camper was presented with a yearbook, their diploma, and a commemorative Hogwarts Welcome Letter.

We look forward to our next Camp Clot Not. See you in 2022!

- Professor McGonagall



CAMP CLOT NOT 2021



HBDA was on a mission to create a wonderfully magical and safe experience for all campers. As campers arrived, they were transported from the 9 and $\frac{3}{4}$ platform to the magical world of the Lake Martin Hogwarts campus. During their first day, students ran through the 9 and $\frac{3}{4}$ platform to Diagon Alley to await the Sorting Hat Ceremony at Hogwarts. Once all students had arrived, everyone gathered in the Great Hall to be sorted into their prospective houses via the famously enchanted Sorting Hat. During the Sorting Hat Ceremony, students were lined up, and their names read aloud. Each student then sat in the official chair and the hat was placed on their head to determine which house they would be in. Promptly thereafter, students were advised of the Triwizard Tournament and the House Points.

For the unfamiliar Muggles reading this, the Triwizard Tournament consisted of three challenges which required each House to work together as a team in order to complete.

Of course, given the enchanting nature of Hogwarts, things change without warning. Therefore, not only were the teams required to work together, they were also required to work with other Wizards and Muggles from other teams depending on the challenge. The challenges required full group participation, communication, teamwork and determination.

Students worked exceptionally hard during their "Potions Class" to ensure their success in the Tournament. This included, but was not limited to, wand making which also fashioned as *LUMOS* aka a muggle flashlight to be used during the Tournament.

Midway through the week, students took a break from the tournament by having a fun amazing day on the lake tubing, swimming, boat riding and turning life vests into diapers on the island. After dinner in the Great Hall, students grabbed blankets/pillows/mattresses and gathered for movie night. I must say, this was one of my favorite activities – who can beat watching a movie underneath the magical floating star ceiling?!

In addition to receiving points based on completing said challenges, houses were awarded daily points based on positive observations throughout each day which ultimately determined who won the House Cup. Although all of teams put forth an exceptional effort, THE MUGGLES ultimately triumphed in winning the House Cup with 1,930 points. In second place, the Beauxbatons with 1,914 points. In third place, Gryffindor with 1,910 points. In fourth place, Slytherin with 1,480 points.

Last but certainly not least, I would like to send a special thank you to my LITs who ROCKED this year. Kris, Evan, Cole, Will, Chelynn, Troy, Nathan and Cameron – thank you all for your hard work, positive can-do attitudes and truly taking a leadership role this year.

- Bellatrix LeStrange

CAMP CLOT NOT 2021



CAMP CLOT NOT AWARDS 2021



Abi D - Courage Award



Christian G - Courage Award



Chelynn P - Branch Award



Jack M - Branch Award



Makenzie C - Branch Award



Bentley G - Branch Award



Cameron J - Branch Award



Maddie S - Branch Award



Nathan S - Branch Award



Bethalyn B - Branch Award



Christian B - Branch Award



Andy H - Big Stick Award



Dylan W - Big Stick Award



Alanna B - Big Stick Award



Porter M - Big Stick Award



Noah G - Big Stick Award

CAMP CLOT NOT AWARDS 2021

Leader in Training Awards



Camper Awards



Mischief Managed!



"COURAGE IN THE TIME OF COVID"

COURAGE ['kərij] NOUN
The ability to do something that frightens one.
Strength in the face of pain or grief.

We are living in a time that demands great courage. We often wake up to dreadful news affecting our way of life and the lives of those we love.

I never thought, in my lifetime, I would face a pandemic like we are experiencing with Covid. I feel sure we all know someone who has overcome this terrible virus, and sadly, most of us have known someone who has died from it. I pray for those brave (and often unrecognized) heroes that wake up with the courage to face another day. They put themselves in harm's way tend to the needs of their fellow human beings.

There are nurses, physicians, respiratory therapists and other clinicians across the world, who are risking their own health and safety to save the lives of those whose lungs are so wracked by COVID-19 that they are unable to breathe. There are likewise countless people, from teachers to food workers to social service providers, who are taking risks to attend to those who are especially vulnerable to this pandemic.

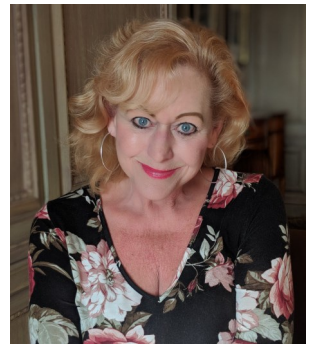
Many of them are afraid, but they press on because they have committed themselves to care for the sick and the vulnerable. This commitment to care, this love, does not remove their fear. Rather, it fuels and sustains their courage.

Did you know, the original definition of courage, when it first came into the English language — was from the Latin word for, meaning heart.

That makes sense to me. It takes someone with a mighty big heart to get up everyday and provide care to those who are sick.

Take time to thank these brave, amazing caregivers. They are courage in action!

Stay well and be blessed! – Leslie Bailey



www.firstchoiceiv.com
1-866-665-3244

First Choice Home Infusion/Specialty Pharmacy

Dedicated partner in infusion and specialty pharmacy services

- At home delivery
- Personalized service
- HTC coordination
- Dedicated pharmacist support
- Home nursing coordination
- All needed supplies
- Nurse educators
- Insurance support services
- Copay assistance programs

Need more information? Call, text, or email

Mark Osborne
615-351-3604
mark@firstchoiceiv.com

JD Weir, RN
251-604-8832
john@firstchoiceiv.com

Shannon Kelley, RN
205-389-3201
shannon@firstchoiceiv.com

Make First Choice your first choice

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. People who use activated prothrombin complex concentrate (aPCC; Feiba®) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots.

These serious side effects include:

- **Thrombotic microangiopathy (TMA)**, a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs
- **Blood clots (thrombotic events)**, which may form in blood vessels in your arm, leg, lung, or head

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 

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 or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised: 10/2018



HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan.
The HEMLIBRA logo is a registered 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.
©2020 Genentech USA, Inc. All rights reserved. M-US-00007357(v1.0) 09/20

Genentech
A Member of the Roche Group



Don't run out of time.

**The deadline is fast approaching to make reservations to be a part of HBDA's
Weekend of Fellowship and Enlightenment at this year's
"Camp Harvest" Family Educational Weekend!
October 22-24,2021 at Children's Harbor.**

**It's a time to catch up on what is happening and what WILL be happening in
the world of bleeding disorders, with informative sessions from industry
partners and top keynote speakers.**

**Plus, you will have time to re-connect and bond with your HBDA Family and
Industry Representatives.**

**It is an opportunity to be part of some of HBDA's favorite Fall traditions:
Family Portraits, hot chocolate and cider around a roaring campfire, arts and
crafts, our annual Family pumpkin carving contest for bragging rights and so
much more!**

Registration deadline is September 24th...don't miss it!



A **ONCE-WEEKLY** TREATMENT OPTION FOR HEMOPHILIA B.



HOW DOES
THIS FACTOR IN?

To find out about a prescription
option, talk to your doctor or visit
[OnceWeeklyForHemophiliaB.com](https://www.OnceWeeklyForHemophiliaB.com)



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.

No actual patients depicted.

ADYNOVATE twice-weekly prophylaxis prevented or reduced the number of bleeds²

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 treatment²
 - During the 6-month study in children under 12, those receiving twice-weekly prophylaxis treatment experienced a median¹ overall ABR[†] of 2.0
 - 0 bleeds in 38% (25 out of 66 patients) during 6 months on twice-weekly prophylaxis

¹Median 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.

²Per-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 groups²
 - 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

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.

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





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.

©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



Explore **HEAD-TO-HEAD** Pharmacokinetic (PK) Study Data

See half-life, clearance and other
PK data from the crossover study
comparing **Jivi®** and **Eloctate®**

Visit **PKStudies.com** to find out more.

► **Pharmacokinetics** is the study of the activity
of drugs in the body over a period of time.

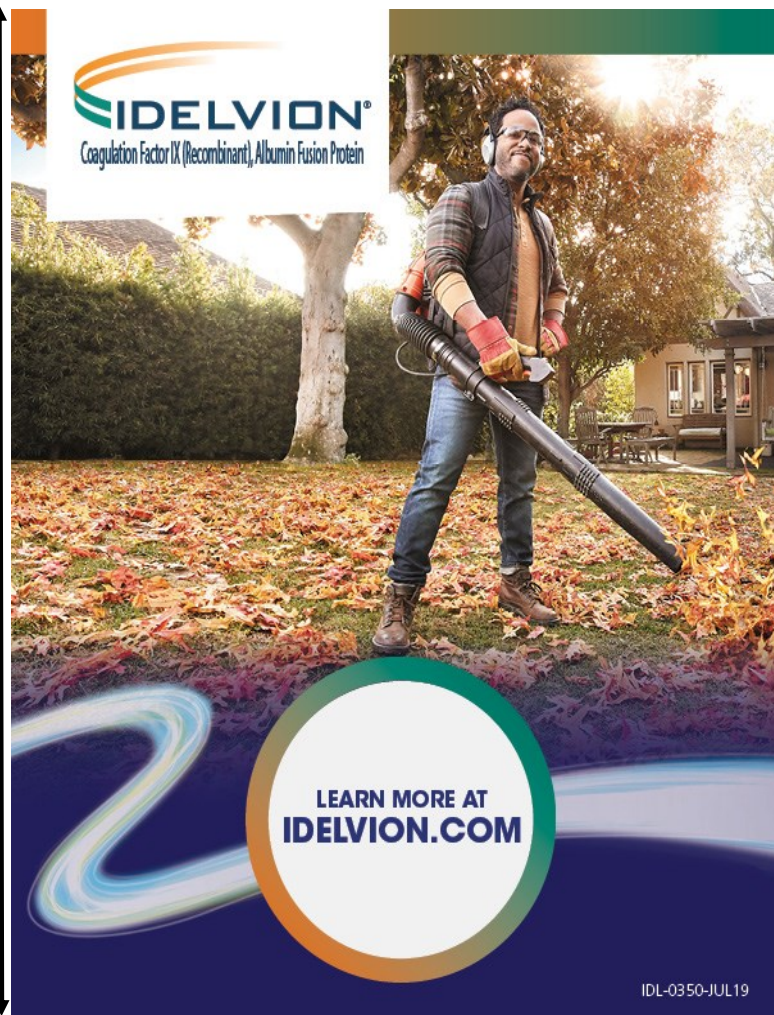
©2020 Bayer. All rights reserved. All trademarks are the property of their respective owner. Printed in the USA 01/20 PP-JW-US-1008-1

Jivi
antihemophilic factor
(recombinant) PEGylated-augl
LET'S GO

**** 2021 EVENTS ****

<u>Date of Event:</u>	<u>Event:</u>	<u>Event Location:</u>
October 22 - 24, 2021	Camp Harvest	Children's Harbor
November 12, 2021	Golf Tournament	Robert Trent Jones
December 11, 2021	Year End Luncheon	Embassy Suites Mgm

More information will be coming out soon!



CLOT Line Assistance Program

Members:

If you are going through a difficult time, please remember, your HBDA family is here for you!

If you have been affected by COVID-19, or if you need assistance purchasing school supplies for your kids, please reach out to us.





Let Us Show You How We Put Patients and Science at the Center of Everything We Do

 **ELOCTATE®**
[Antihemophilic Factor
(Recombinant), Fc Fusion Protein]
www.eloctate.com

 **ALPROLIX®**
[Coagulation Factor IX
(Recombinant), Fc Fusion Protein]
www.alprolix.com



SANOFI GENZYME

1-855-749-4363

HBDA 2021 GOLF TOURNAMENT



Attention All Golfers!
Don't "fore-get" to register
for HBDA's 2021 Golf Tournament!

Registration - 10:00 AM

Lunch - 11:00 AM

Tee Off - 12:00 PM



For more information, please contact us at hbdaevents@gmail.com or call us at 334-478-7822

HBDA's 13th Annual "Tee It Up for Hemophilia" Golf Tournament

November 12, 2021

at one of the jewels in the River Region's crown,
The Robert Trent Jones Golf Trail at Capitol Hill in Prattville, Alabama.

Join us in this fun filled day of golf and probably some good-natured ribbing
between our golfers.

HBDA's tournament is so much more than just golf!

You will have a chance to win fabulous gifts, enjoy an afternoon of spending time
with your friends, a delectable lunch, and awards. To top the day off, we will have
a fabulous wrap up cocktail soiree, and who knows, maybe even say hello to a
celebrity or two!

Stay tuned for more information from HBDA regarding this event!



BACK TO SCHOOL RECIPES

Butterscotch Maple No Bake Cookies



Ingredients

2 cups sugar
1 stick butter
1/2 cup milk
1 cup peanut butter
2 tablespoons maple syrup
3 cups oatmeal
1 cup butterscotch chips
Wax paper for cooling

Directions

In a heavy saucepan over medium-high heat, bring sugar, butter, and milk to a boil.

Boil about a minute, then stir in peanut butter, maple syrup, and oatmeal.

Remove from heat and fold in your chips.

Drop by the tablespoon full on to wax paper to finish cooling (and they'll harden up).

Once cooled, store in an airtight container.

[Butterscotch Maple No Bake Cookies Recipe | Mix and Match Mama](#)

Apple Cider Bundt Cake

Ingredients

1 box of yellow cake mix
2 small boxes instant vanilla pudding
1/2 cup veggie oil
1 cup apple cider, plus a few extra splashes for the frosting
4 eggs
1 cup applesauce
2 tablespoons cinnamon (divided)
1 cup caramel pieces (found on the chocolate chip aisle)
1 cup caramel ice cream topping
1 stick butter, softened
4 cups powdered sugar

Directions

Preheat oven to 350 degrees

Grease (I use Pam) a 10 inch bundt pan

In mixing bowl, combine cake mix, puddings, oil, 1 cup cider, eggs, applesauce and 1 tablespoon cinnamon with electric mixer. Stir in caramel pieces. Pour into prepared bundt pan.

Bake 40-45 minutes or until toothpick inserted comes out clean.

Let cake rest on counter in pan 10 minutes. Then, invert cake onto serving plate to finish cooling. To make the frosting, beat butter, powdered sugar and 2-3 splashes of cider with electric mixer until creamy. Beat in remaining tablespoon of cinnamon. Add more sugar if the frosting is too runny and more cider if it's too thick.

Spoon caramel ice cream topping over cooled cake and then frost with your cider frosting.

If you can't find cider (which you should this time of year) you can use apple juice instead. If you can't find the caramel pieces on the chocolate chip aisle, then unwrap some caramel candy squares and chop them up a bit...they'll work equally as well.

[Caramel Apple Cider Bundt Cake Recipe | Mix and Match Mama](#)

You are invited to attend the:
HBDA Year End Educational and Display Event
December 11, 2021

11 AM – 2 PM
Embassy Suites Hotel Montgomery
300 Tallapoosa Street
Montgomery, AL 36104

Buffet Luncheon
Displays with our Industry Sponsors

Advanced reservations are required by November 26, 2021 for you to be confirmed and included in this event. Walk-ins cannot be accepted, so please plan ahead. A confirmation letter will be sent to you to confirm your reservation. (If you do not receive a confirmation letter within 7 business days of your reservation, please contact us immediately).

Consumer Members may reserve attendance by calling (334) 478-7822 or by emailing your reservation to hbdaeevents@gmail.com. Reservation must include names of all attendees and the ages of all attendees under 18.

Industry Members will be reserved through their sponsorship with an HBDA staff member.

CONSUMER MEMBER

Any person diagnosed with Hemophilia (A or B), vonWillebrand's Disease, or any other bleeding or clotting disorder, including any person who is a diagnosed carrier. Parents or legal guardians of a minor affected consumer member and any other minor family member(s) (people living in the same household) qualify as consumer members. An adult affected consumer member can qualify their minor children and their spouse, significant other OR ONE other adult so long as that adult does not qualify as an industry member, and that they reside in the same household with the affected adult member.

INDUSTRY MEMBER

Any person employed by or representing a pharmaceutical company, specialty pharmacy or any other for-profit business that earns any revenue from serving the bleeding disorders community. All adult members of an industry members' family (people living in the same household) are considered industry members except for any family member affected by a bleeding disorder, as well as any minor siblings living in the same household.

The cost for additional participants, outside the above Membership criteria, will be \$25.00 per person for children under 8 and \$45.00 per person ages 8 and older.



**Hemophilia and Bleeding
Disorders of Alabama, Inc.**

HBDA INFORMATION

Address: 917 W Osceola Street, Wetumpka, AL 36092

Phone: (334) 478-7822

Fax: (334) 478-7824

Website: www.hbda.us

Facebook: www.facebook.com/hbda4u



BIRTHDAY BLESSINGS

August

Amy Blair
Terrell Abrams
Jacob Weaver
Kaitlyn Weaver
Rachel Cooper-Leal
Dylan Ward
Rocisa Moore
Tikila Hawthorne
Seth Kelly
Shelia Baird
Rick Dinkins
Kristopher Lewis
Cannan Dickinson
Lorie Addison
Tara Gerling
Mackenzie Jones
Bella Dickinson
Jeannie McLaughlin
Sean Halloran
Tim Mason
Spring Kane
Ajie Attawia
Heeyeon Chung
Belita Abrams
Christian Blyden
Jason White
Taylor Barton
Stanley Moore
Kileeann Warren
Bethalyn Bailey
Makenzie Clarke
Jeannie Dickerson
Robert Bate
Ericka Caro
VaShette Davis
Garrett May
Chris Blair
Odin Walls

September

Ayden Hoggle
Madison Kelley
Jaxson Kelley
Jared McLaughlin
Jessica Ward
Zachary Pressley
Mark Osborne
Jasmine Hoggle
Larry Grammer
Tabetha McGlinchey
Brayden Cooper
Nyannah Davis
John Masline
Erica Goss
Jaymee Vowell
Cooper Guadalupe
Vicki Jackson
Kristen Blair
Anna Halloran
Abi Dickinson
Lee Hall
Jace McLaughlin
Raley Hoggle
Kristy Roberts
Amber May
Jennifer Mason
JD Weir

October

Scott Weaver
Pat White
Caelum Walls
Nicole Lloyd
Levi McLaughlin
Chance Abrams
Blake Morgan
Gunner Stracener
Joshua Sorrells
Katelyn Erben
Christian Pressley
Micah Champagne
Brent Speer
Justin Clarke
Brian May
Harper Walls
Jonathan Hall
Fallon Howard
Jennifer Harris
Jason Kelley
Andy Hall
Tisha Ward
Ethan Fields
Brandee Cookston