

HBDA QUARTERLY NEWSLETTER

Spring Edition 2021

Rick Dinkins, Chairman

Volume 49

Vicki Jackson, Executive Director

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Words from the Chair

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

We continue to monitor the Covid rules for large gatherings along with the staff at Children's Harbor as we prepare for a "normal" summer for HBDA. Vicki, Amanda, and a host of volunteers are busy preparing and we will press on until we are told to stop...I have faith that this will work itself out and we can get back to business as usual--with a nod to being safe and smart about our efforts. Vicki will update us all as we move towards Camp Clot Not kickoff.... stay tuned for more information from HBDA. All of us look forward to renewing, in person, the bonds of friendship.

Our Industry Partners have been great during all of this, and we appreciate their efforts in keeping us all up to date on new and exciting products and services. We are fortunate to have them on the HBDA team, and the Board and I look forward to seeing all of them again, too!

One area we continue to focus on is our "Outreach" to families and individuals who can benefit from our services who may not know about HBDA. We continue to look for ways to improve our current efforts and we solicit your help in this endeavor. Please share your ideas, thoughts and even contact information of those we can help...we would appreciate it very much.

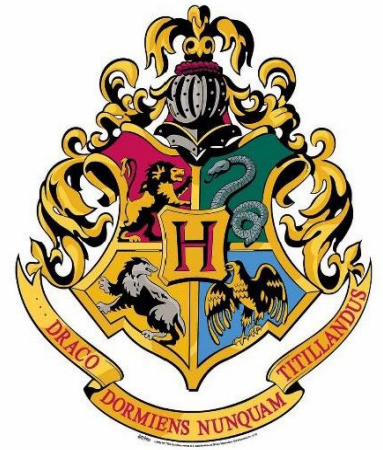
By the time you receive this, summer will be right around the corner and hopefully we will all have the "Clot Not" buzz on....let's hope so!

Best to All and Be Safe.

Rick Dinkins
Chairman



Camp Clot Not goes to Hogwarts!



Pack your bags and get ready to hop on the Hogwarts Express to Children's Harbor to have a wickedly magical time at Camp Clot Not!

More information, including the application will be available very soon!



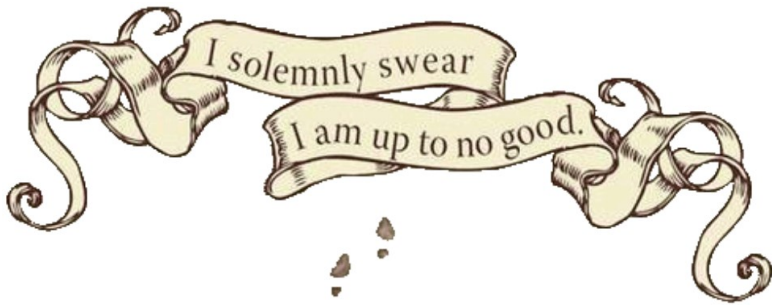
When: July 24 – 29, 2021

Where: Children's Harbor on Lake Martin



Keep an eye out on your inbox for more information coming soon!

Calling All
Campers !!!!!



Prepare yourself for a magical trip to Hogwarts for
Camp Clot Not 2021!

Applications have been sent, so please make sure you fill it out and
send it back in as soon as possible!

Mischief Managed!



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
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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



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HBDA Annual Meeting 2021

The HBDA Annual Meeting will be held at the Embassy Suites Hotel and Conference Center in Montgomery, AL. Information and registration forms will be sent out in the next few months.
Make plans now to attend!

Date: August 20 - 22, 2021



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What to Expect:

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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.





Save the Date
For HBDA's



Family Educational Weekend

Mark your Calendars for

October 22 - 24, 2021

Keep an eye out for more information
coming to your inbox soon!

This will be a wonderful weekend full of
fellowship and education!



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)

Kid-Friendly Breakfast Sushi

Ingredients:

- Banana
- Greek Yogurt
- Fruity Pebbles Cereal
- Blackberries

Directions:

1. Begin peeling the banana
2. Using a butter knife, spread a layer of Greek yogurt on the outside surface of the banana
3. Place your fruity pebbles in a shallow dish. Roll your banana in the Fruity Pebbles, until fully coated.
4. Place banana on a plate. Slice into "sushi" sized pieces. Arrange and top with blackberries

[Kid Friendly Breakfast Sushi Recipe - Raising Whasians](#)



DIY Air Dry Play Dough for Kids

When I tried this DIY for the first time I was blown away. It's the perfect compound to make keepsakes. You can add the color directly into the clay or leave it white and paint it once it dries. So many kid friendly activity options!

MATERIALS:

1. Food coloring
2. 1 3/4 - 2 cups of corn starch
3. 1 cup of white glue
4. 1 tablespoon white vinegar
5. 1 tablespoon baby oil
6. 1 teaspoon of lotion (a little less is better)

INSTRUCTIONS:

1. Add all ingredients together in a bowl. Mix together well.
2. Wait until your mixture balls up together. Touch the clay to see if it is too sticky.
3. If still sticky, keep mixing and add a little bit of corn starch.
4. Grab your mixture and start to knead. Work the clay until it hardens a bit and has more structure. (Usually about 5 minutes)
5. If you wish to color your clay, add the food coloring of choice to the clay and knead until the color is distributed throughout.
6. Once you've created your masterpiece, leave your clay to dry for 24-48 hours (depending on its thickness). It should dry nice and hard!

[AIR DRY CLAY DIY — MOTHERCOULD](#)



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!



WHAT PARENTS SHOULD KNOW ABOUT TELEHEALTH APPOINTMENTS

Families welcome virtual visits for convenient bleeding disorders care

Author: Christina Frank

Michelle Culpepper usually has to drive her son Jayden 45 minutes each way from their home in Farmington, Michigan, to Ann Arbor for his checkups. Jayden, 4, has severe hemophilia A.

For a recent visit, however, the two simply had to walk to their TV room and hook up Culpepper's laptop to the television.

Telehealth visits—in which healthcare services are provided remotely via telecommunications technology—were being offered by some providers before the pandemic, but their popularity has skyrocketed since lockdown orders were put in place across the country in the spring.

Setting Up

Laura McGinity, a licensed master social worker at the University of Michigan Medical Center, says the staff at her office had talked about offering virtual visits to their patients with bleeding disorders, but it wasn't until COVID-19 hit that they got things up and running. "We had to ramp it up pretty quickly," she says. "We had a fast learning curve, and the patients did, too." Once the technical details were ironed out, the visits went smoothly and have been well received by patients and their families, McGinity says.

Although a physical exam isn't possible during a telehealth visit, patients are able to describe their symptoms and show their providers any areas of concern. (A bleed or an injury that a provider wants to assess further may necessitate an in-person visit.)

McGinity points out that telehealth visits are ideal for people living a long distance from their hemophilia treatment centers (HTCs) and for children who may be anxious about going to a doctor's office. She suggests that parents try to find a quiet area to sit during the visit, make sure their child is well rested and not hungry, and maybe have some crayons and paper available for the child to doodle on if he or she tends to get antsy.

Recognizing the Value

Culpepper especially appreciates how all of the providers involved in her son's care were able to be present on her screen at the same time. "The doctor was there, the nurse was there, the physical therapist was there, and there was an intern as well," she says. "When you're in an office, they take turns and you may have to repeat things. I really like that they were all hearing the same thing at the same time."

Culpepper still values in-person visits—and they remain necessary at least annually for physical therapy evaluations and collection of laboratory data—but she is grateful for the option to do a televisit with her son when possible.

"Sometimes the doctors do need to physically see him, to follow up if he has a bleed or if we have a concern with a joint," she says. "But if a virtual checkup is something that could potentially be done every other visit or something like that, I think it would be great."

Telehealth Appointment Checklist

Before your child's next telehealth visit, follow these steps:

- **Find a quiet space.** Removing distractions will help you better focus on your physician's guidance.
- **Check your connection.** Log in early so you have time to test the audio and video and troubleshoot if necessary.
- **Set the device down.** Putting your tablet or laptop on a flat surface steadies the camera and frees your hands to show any trouble spots on the body.
- **Add plenty of light.** Turn on lamps or open window shades in front of your face so the doctor can see you more clearly.
- **Have your logs ready.** Your physician can review how your medication is working and adjust treatment as needed.
- **Prepare your questions.** Just like with in-person visits, this ensures you won't forget about what you really want to ask.

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.**

2021 EDUCATIONAL PRESENTATIONS & EVENTS

**** ALL presentations listed below are expected to be in LIVE format with a start time of 6:00 PM for each dinner**

<u>Date of Presentation:</u>	<u>Company Presenting:</u>	<u>City of Presentation:</u>
June 3, 2021	Novo Nordisk	Montgomery, AL
June 8, 2021	Octapharma	Birmingham, AL
June 17, 2021	BioMarin	Birmingham, AL
June 24, 2021	Bayer	Mobile, AL
September 16, 2021	BioMarin	Mobile, AL

LIVE Educational Events 2021

<u>Date of Event:</u>	<u>Event:</u>	<u>Event Location:</u>
July 24 - 29, 2021	Camp Clot Not	Children's Harbor
August 20 - 22, 2021	Annual Meeting	Embassy Suites Mgm
October 22 - 24, 2021	Camp Harvest	Children's Harbor
November 12, 2021	Golf Tournament	Robert Trent Jones Pville
December 11, 2021	Year End Luncheon	Embassy Suites Mgm



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Strength, Support and Community
for People Living with Bleeding Disorders

Factor My Way is a robust patient support program from Octapharma designed for people living with hemophilia A and von Willebrand disease, and for those who care for them. We spoke with you and we listened. The insights we gathered form the foundation of our bleeding disorders patient support program. Built around your needs, Factor My Way includes resources for patients and caregivers, support for those navigating care, reliable educational materials, and uplifting community connection.



Join Today!
factormyway.com/join

Member benefits include:

- ✓ Financial assistance, including free trials and co-pay assistance for eligible patients
- ✓ A dedicated, local Factor My Way Patient Experience Manager, a specialist in dealing with bleeding disorders
- ✓ Access to a wide range of digital programs and events
- ✓ On-demand access to practical and informative educational resources

... and lots more. Membership in Factor My Way is complimentary.
Join the program at factormyway.com/join, or call 1-855-498-4260

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

May

Cayden White
Maxwell McLaughlin
Samuel Wilson
Davie Jane Woods
Bonnie Utterback
Tayla Cooper
Amy Croushorn
Brandon Raber
Libby Hall
Evan Ward
Jack Mason
Jennifer Rose
Tytus Stracener

June

Taylor Renfroe
Chandler Ward
Jhonathan Davis
Al Wilson
Carla Vickery
Carver Bailey
Christian Hall
Hunter Abrams
Jackson Sanders
Alex Leonard
Harmony Pressley
Isabella Sandow
Cole Croushorn
Kim Speer
Anthony Zucco
Tavien Casey
Macey Kelley
Keshawndra Cooper
Haley Jones
Gavin May
Maddie Sanders
Keondre Cooper

July

Rebecca May
Ron Dickerson
Edward Masline
Sarah Blyden
Jordan Cortez
Connie Grammer
Pat Morgan
Christine Chung
Dana Abrams
Nelton Davis
Jeff Tissier
Tera Bradshaw
Rhonda Copous
Andrew Walls
Matthew Watts
Amy Barton
Ann Mitchell
Caitlin Zucco
Brittnee Vasil
Noah Reid Guadalupe
Terrontheon Crayton