

# HBDA QUARTERLY NEWSLETTER

Winter Edition 2019

Volume 44

Rick Dinkins, Chairman

Vicki Jackson, Executive Director

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HBDA Information

## Staff

Executive Director

**Vicki Jackson**

Consumer Relations Manager

**Amanda Jennings**



Hemophilia and Bleeding  
Disorders of Alabama, Inc.

## Board Members

Rick Dinkins - Chairman

Jared McLaughlin - Treasurer

Rick Vasil - Secretary

Ron Dickerson, Sr.

Van Rushton

Brian Ward - Past President

Chris Blair - Past President

## Year End Luncheon and Display Event

December 14, 2019  
Embassy Suites Montgomery





# YEAR END LUNCHEON 2019

HBDA would like to thank all of our members, board, and Industry partners for a successful 2019 and a great beginning to 2020!

The Year End Luncheon was a wonderful way to close out 2019. It brought together many of our members and sponsors together for fellowship as well as education on what the new year would bring for HBDA and our community.

We look forward to working with all of our sponsors to make 2020 a great year for our members. Thank you for your continued support and we look forward to seeing everyone at the HBDA Annual Meeting in April!



HAPPY NEW YEAR  
2020

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# UPCOMING HBDA EVENTS

<u>Event Name</u>	<u>Event Date</u>	<u>Event Location</u>
Annual Meeting	April 24 - 26, 2020	Marriott Auburn/Opelika
HBDA Advocacy Day	May 2020	Montgomery, Alabama
Camp Clot Not	June 13 - 18, 2020	Children's Harbor on Lake Martin
Camp Harvest	October 23 - 25, 2020	Children's Harbor on Lake Martin
Golf Tournament	November 2020	Robert Trent Jones Prattville
Year End Luncheon	December 12, 2020	Embassy Suites Montgomery

There will also be many Educational Dinners throughout the state during the course of the year. Please keep an eye on your email and our website for updates about dinners near you!

Attendance at all events and educational dinners is very important for us to continue to provide up-to-date information and support from our industry partners. If you have any questions about any of these events, please email us at [hbdaeevents@gmail.com](mailto:hbdaeevents@gmail.com) or call us at 334-478-7822.



## New HEAD-TO-HEAD Pharmacokinetic (PK) Study Data

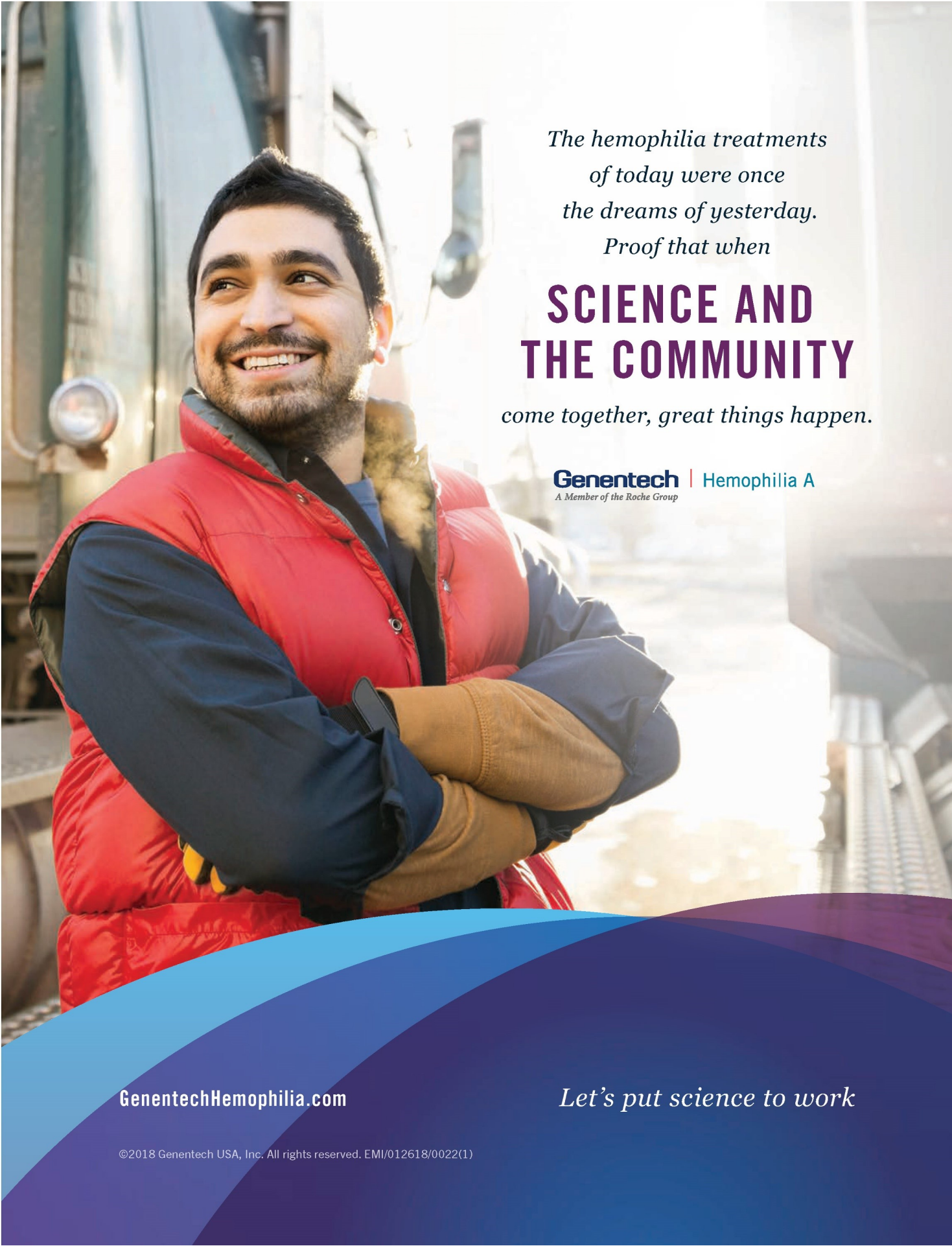
See half-life, clearance and other PK data from the crossover study comparing **Jivi**® and **Eloctate**®

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

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

**Jivi**  
antithrombotic factor  
(recombinant) PEGylated-auct  
LET'S GO





*The hemophilia treatments  
of today were once  
the dreams of yesterday.  
Proof that when*

## **SCIENCE AND THE COMMUNITY**

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*Let's put science to work*

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# WORDS FROM THE BOARD

WOW! 2020 is off to a roaring start as we have just blown through January...way too fast for this "Ole Man!"

The Board and the staff are finalizing the plan for 2020 as well as taking care of the normal beginning of the year administrative work. Vicki and Amanda continue to take care of the day to day business and it's much appreciated by all.

Our Annual Meeting will be held from April 24 - 26 in Opelika, just like last year. A revised agenda for the 2+ days is being worked to allow for a better mix of educational sessions while allowing for some family time in between. As it's finalized, the staff will post it along with registration details and other pertinent information to ensure everyone has an enjoyable AND educational weekend.

The Board is looking at establishing a scholarship program to provide degree/certificate granting educational opportunities. We are excited about this and the goal is to have it in place for 2020-2021 academic period. More to follow.

Finally, Happy New Year and I hope to see most of you in Opelika!

Rick Dinkins



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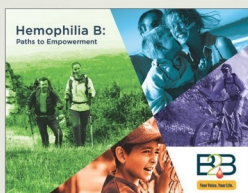
Phone: 866.209.5540

VitalRx is an URAC Accredited Specialty pharmacy with multiple locations. Our mission is to inspire health and well-being to our patients by providing personalized patient centered care for a variety of specialty therapies.



# B2B: Your voice. Your life.

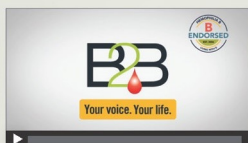
Interested in stories and personal experiences *from* the hemophilia B community *for* the hemophilia B community? Turn to B2B.



**Download or view books**  
filled with patient stories that can inspire, empower, and educate



**Listen to podcasts**  
that capture the voices of the hemophilia B community



**View videos**  
that feature members of the community sharing their personal experiences

**And there's much more, too!**



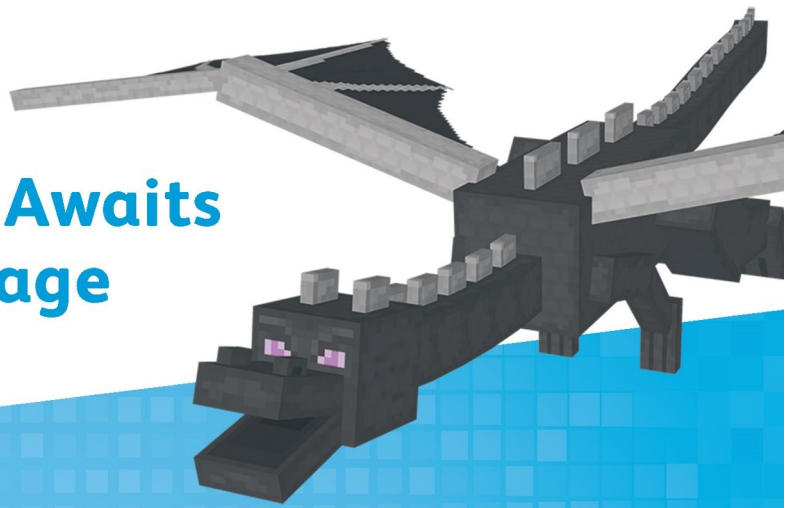
## More topics include . . .

- Educating your child's school about hemophilia B
- Managing relationships with hemophilia B
- HEMO 101 for caregivers
- Life for girls and women with hemophilia B

**VISIT [WWW.HEMOPHILIAVILLAGE.COM](http://WWW.HEMOPHILIAVILLAGE.COM)**  
to explore all B2B materials



# The Ender Dragon Awaits at Hemophilia Village



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**Visit [www.hemophiliavillage.com](http://www.hemophiliavillage.com)** to learn more about  
HEMOCRAFT and start your own adventure

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PP-HEM-USA-1093-01

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Printed in USA/September 2018





# HBDA ANNUAL MEETING 2020

The HBDA Annual Meeting will be held at the Marriott Auburn Opelika Hotel and Conference Center in Opelika, AL. Information and registration forms will be emailed to you in the next few weeks via our Membership Portal on our website. Make plans now to attend!

**If you have not rejoined HBDA through the member portal, you will NOT receive the registration form. If you have any questions, or are having issues joining, please contact us immediately.**

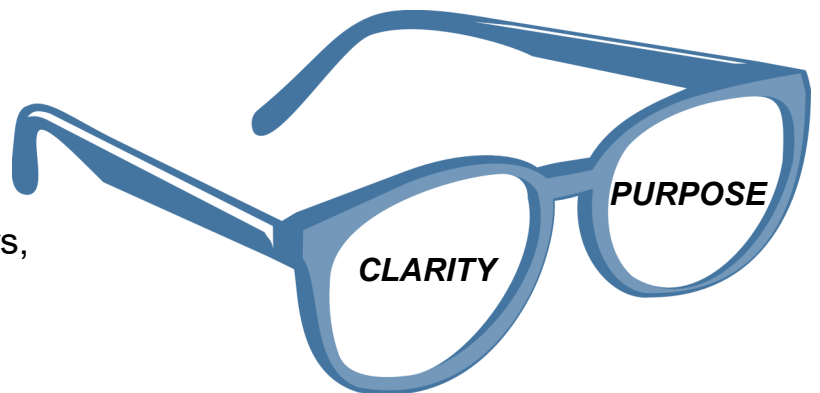
## **Date: April 24 - 26, 2020**



The new year brings thoughts of hope, and images of a slate being wiped clean. With the dawn of a new year **and** a new decade, it has brought a lot of ideas for what we, as an organization, want to accomplish now and for the future.

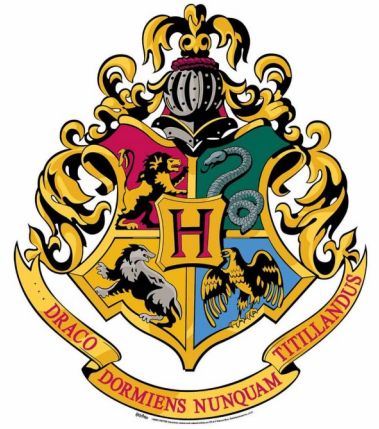
These thoughts and ideas inspired the vision for our Annual Meeting, and for the year ahead... **Clarity and Purpose.**

We certainly hope you will join us for the Annual Meeting to experience what we have planned. We anticipate this new chapter to provide clarity and purpose for our organization, our industry partners, and most importantly ...our members!





# Camp Clot Not goes to Hogwarts!



Mark your calendars because this year, we are travelling to Hogwarts!



**When:** June 13 – 18, 2020  
**Where:** Children's Harbor on Lake Martin



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

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## HBDA Advocacy Day 2020!



HBDA will once again be hosting an Advocacy Day here in Montgomery Alabama. We are still working to solidify a specific date, but we do know that it will be held in May of 2020. Please be on the lookout for more information regarding this event. If you are interested in participating, please let me know, so we can discuss this with you as it draws closer.

Even though this will not be held during Bleeding Disorders Awareness Month or World Hemophilia Day, we will still be planning to wear our red ties as part of the story we will be telling!





# GO SEEK. GO EXPLORE. GO AHEAD.

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#### 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



**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
  - 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

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For more information, go to [www.HEMLIBRA.com](http://www.HEMLIBRA.com) or call 1-866-HEMLIBRA.  
This Medication Guide has been approved by the U.S. Food and Drug Administration  
Revised: 10/2018



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Website: [www.hbda.us](http://www.hbda.us)

Facebook: [www.facebook.com/hbda4u](http://www.facebook.com/hbda4u)



## BIRTHDAY BLESSINGS

### February

Teresa Hall  
Tyler Blair  
Heather Moore  
Paul Wood  
Kensley Moore  
Ty Pitman  
Marcus Hamilton  
Alvin Morgan  
Mallory McLaughlin  
Riley Wood  
Alicia Shipman  
Kristy Lee

### March

Karla Amos  
Danny Wade  
Porter McLaughlin  
Rick Vasil  
Tim Abrams  
Troy Littlejohn  
Barry Sanders  
Brian Ward  
Bryson Botts  
Todd Grayson  
Tarus Ottison  
Nathaniel Killgore  
Ivana Caro  
Mateo Caro  
Traci Renfroe  
Christy Patrick  
Andrew Dickinson  
Karri Botts  
Wendy Mann

### April

Zion Hawkins  
D'Quarius Banks  
Lincoln Zucco  
Tucker Vasil  
Michelle Weaver  
Alleick Shipley  
Jennifer Dickinson  
Lesley Lemarie  
Ivan Caro  
Manny Forde  
Shannon Kelley  
Tristan Martin  
Arianna Hutchings  
Sarah Masline  
Will Dickinson