

# HBDA QUARTERLY NEWSLETTER

Winter Edition 2018

Volume 40

Rick Dinkins, Chairman

Vicki Jackson, Executive Director

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## Staff

Executive Director

**Vicki Jackson**

Consumer Relations Manager

**Amanda Jennings**



Hemophilia and Bleeding  
Disorders of Alabama, Inc.

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Van Rushton

Rick Vasil

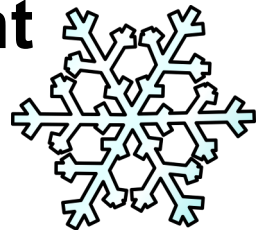
Brian Ward - Past President

Chris Blair - Past President

## Year End Luncheon and Display Event



**December 8, 2018**  
**Capital City Club**





# YEAR END LUNCHEON

HBDA would like to thank all of our members, board, and Industry partners for a successful 2018 and a great beginning to 2019!

The Year End Luncheon was a wonderful way to close out 2018. 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 2019 a great year for our members. Thank you for your continued support and we look forward to seeing everyone soon at the HBDA Annual Meeting!





# HBDA ANNUAL MEETING 2019

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 sent out in the next few weeks.

Make plans now to attend!

**Date: April 26 - 28, 2019**



## Event Quote:

Coming together is a beginning;

Keeping together is progress;

Working together is success.

- Edward Everett Hale



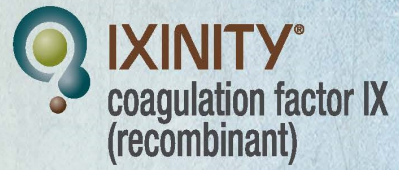
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AUBURN-OPELIKA  
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## What to Expect:

- \* Top Keynote Speakers
- \* Exhibits/Displays from Industry Partners
- \* Current Educational Information
- \* Inspirational and Interactive Sessions







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# WORDS FROM THE BOARD

In this world that we live in, I cannot help but feel extremely blessed. My wife and I are blessed to have our children with hemophilia in a time when there are treatment options. My kids are blessed to be able to run around and play like their friends and not worry about having a bleed. They are like normal children. We treat them like normal children minus the weekly infusion that happens Saturday mornings. My 2-year-old woke up from his nap earlier this week and wouldn't put any weight on his left leg. Naturally we quickly worried about his joint and decided to give him an extra infusion. Within hours he was running around like nothing happened. I continually ask myself why we are so blessed. We were told just after having our first child with hemophilia that God gave us exactly what he intended to with this son. I believe it. He was sent to us exactly how he was supposed to be. I can't help but think how life might be different had we not had a child with hemophilia. A different world has been opened up to us because of it. I also find myself blessed with many friends in the hemophilia community. Many of you have become friends that we worry about or pray about and love to see at HBDA events. I am not diminishing the struggles and unique challenges each of you have. I am, however, saying that we should recognize the good that comes from our experiences and our struggles as well as the support and progress that is available. We live in an exciting time. I want the best for each of you. God is great. I pray that he blesses each of you.

Sincerely,

Jared McLaughlin



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# HBDA GOLF TOURNAMENT

We were honored to have one of our biggest supporters, Dr. David Bronner, on hand to help raise awareness and money for Alabama's bleeding disorders community.

We would like to thank Dr. Bronner as well as our wonderful Industry Partners for making our Golf Tournament a huge success! We would also like to thank Doug Amos and Charlie Trotman for hosting their radio show from the golf course and for promoting our event and our organization!

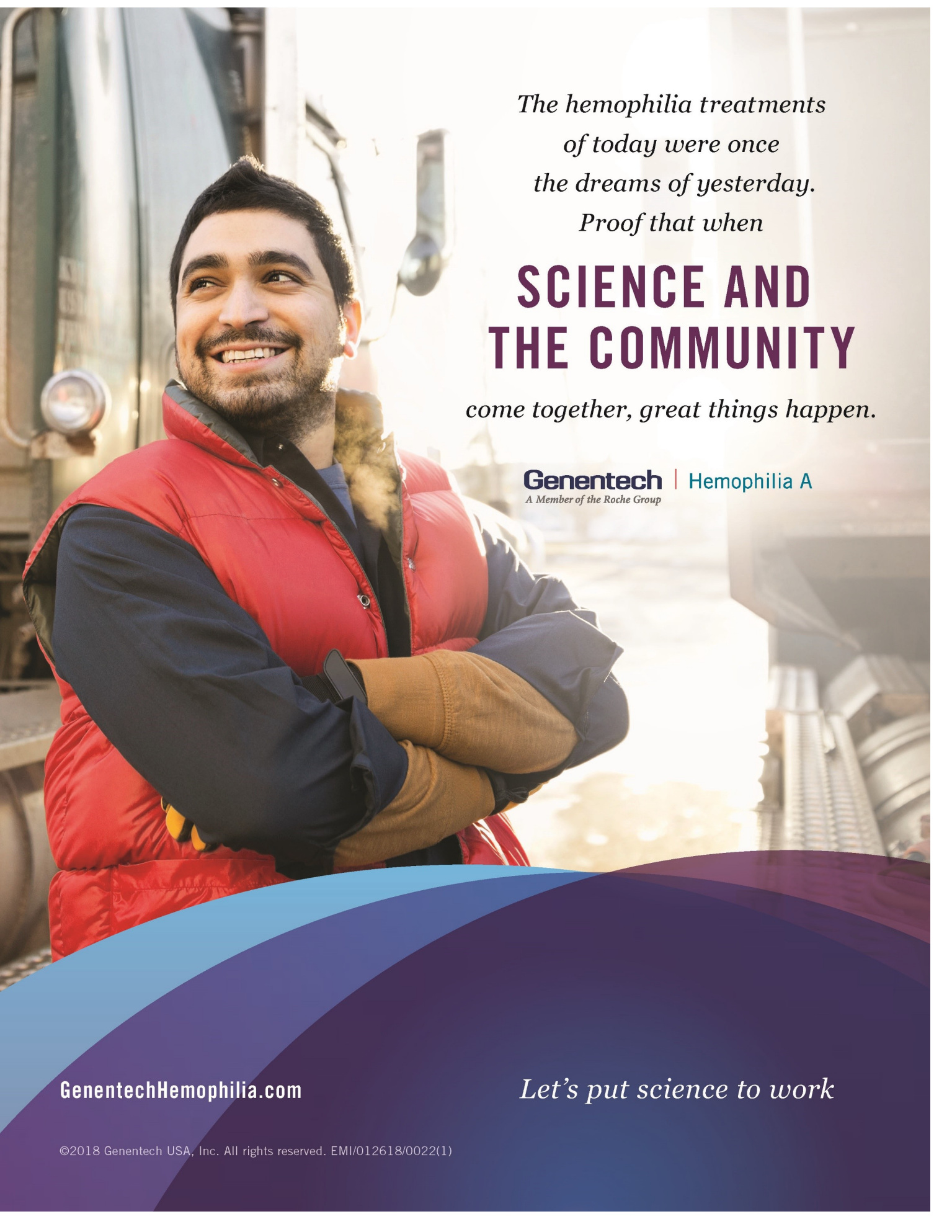
The Robert Trent Jones Golf Course at Capitol Hill was once again the location and we were blessed with fabulous weather and a great turn-out! Our golfers had a blast and we had some fabulous raffle baskets to bid on thanks to some amazing donors!

Pro golfer, Perry Parker was also able to play in our golf tournament again this year. It is always such an honor to have him participate in our tournament and show that Hemophilia does not have to define who you are, it is just what you have.

HBDA is very grateful to the many generous industry partners and volunteers who make this such a huge success! Thank you again, and we look forward to seeing you in 2019!







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

*Proof that when*

## SCIENCE AND THE COMMUNITY

*come together, great things happen.*

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World Hemophilia Day is April 17th!

**HBDA Advocacy Day**

**When: April 17, 2019**

**Where: Alabama State Capitol  
in Montgomery, Alabama**



Coming together is a beginning;  
keeping together is progress;  
working together is success.

- Edward Everett Hale

Keep an eye out for more information on how you and your family can participate in this community event.

There are many new lawmakers in Alabama this year, so we want to be sure that our community, and its concerns, remain at the forefront of their minds.

We will be handing out **red ties** to our lawmakers so they will remember who we are!

**Make plans to join us at the State Capitol to spread the word about bleeding disorders to Alabama lawmakers on April 17th.**

**What a great opportunity for the bleeding disorders community to come together to make a difference!**



Bring  
family  
your  
ties  
April



your  
and  
red  
on  
17th!



# 2019 UPCOMING EVENTS AND DATES

April 17, 2019	Advocacy Day 2019	Alabama State Capitol
April 26 - 28, 2019	HBDA Annual Meeting	Marriott Auburn Opelika
June 15 - 20, 2019	Camp Clot Not	Children's Harbor
September 13, 2019	Golf Tournament	Robert Trent Jones
October 25 - 27, 2019	Camp Harvest	Children's Harbor
December 14, 2019	Year End Luncheon	Montgomery, Alabama



## MARK YOUR CALENDARS!

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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 150  
mg/mL  
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,  
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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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## BIRTHDAY BLESSINGS

### February

Teresa Hall  
Tyler Blair  
Heather Moore  
Paul Wood  
Kensley Moore  
Ty Pitman  
Marcus Hamilton  
Jeremy Hoggle  
Alvin Morgan  
Amber Mock  
Tyson Roberts  
Aimee Courtney  
Mallory McLaughlin  
Riley Wood  
Alicia Shipman  
Kristy Lee  
Nathan Cawley

### March

Karla Amos  
Danny Wade  
James Pashayan  
Porter McLaughlin  
Rick Vasil  
Tim Abrams  
Troy Littlejohn  
Travor Reed  
Barry Sanders  
Brian Ward  
Lawton Brooks  
Landen Powell  
Bryson Botts  
Todd Grayson  
Tarus Ottison  
Samuel Hallford  
Nathaniel Killgore  
Emili Lee  
Ivana Caro  
Mateo Caro  
LaDarrell Banks  
Traci Renfro  
Christy Patrick  
Andrew Dickinson  
Karri Botts  
Easton Mock  
Wendy Mann

### April

D'Quarius Banks  
Tucker Vasil  
Michelle Weaver  
Stacey Hall  
Jennifer Dickinson  
Camryn White  
Lesley Lemarie  
Christian Pashayan  
Ivan Caro  
Manny Forde  
Gabe Rivera  
Shannon Kelley  
Tabitha White  
Tristan Martin  
Arianna Hutchings  
Sarah Masline  
Will Dickinson