HBDA Bi-Annual Newsletter

Summer Edition 2025
Volume 63

Leslie Bailey, Chairman
Vicki Jackson, Executive Director

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Executive Director
Vicki Jackson
Consumer Relations Manager
Amanda Jennings

Board Members
Leslie Bailey - Chairman
Tyler Blair - Secretary
Katelyn Erben - Board Member
Van Rushton - Board Member

Rick Dinkins - Brig. Gen. USAF (Ret.)
Brian Ward - Past President
Chris Blair - Past President

Words from Leslie

In May of this year, at the Annual Meeting, I was honored and humbled to be elected as HBDA Chairman of the Board.

I realize that this role carries immense responsibility, and I will approach it with the utmost dedication and commitment.

In 2012, I was struggling with my little Catering and Event business and looking for a new direction. Vicki and I knew each other, and she reached out to me to see if I would assist with Camp Harvest that year. It was to be a one-time deal, a freelance project. Of course, like most of the world, I knew basically nothing about Hemophilia…my knowledge consisted of what I knew about English Royalty and Russian history.

At that juncture, I knew no one that had a bleeding disorder. After Camp Harvest, Vicki offered me a lifeline and a job.

I can truthfully say that the years I was blessed to work with Vicki and Amanda were some of the best years of my life.

I learned from Vicki, fairness, how to be a good steward of what I had, compassion for others and the strength of a leader. Amanda, well, let's just say without Amanda, I would probably have never learned how to make a "folder" on my computer! LOL! That young woman is the most organized, dedicated, loving person I've ever met.

As I got to know the wonderful members of the HBDA Community, and the more I learned about their day to day living with a bleeding disorder, the more I realized how brave and how strong they are, and that they are the true heroes!

I remember the first time I saw a six-year-old infuse himself, I was quite moved. I remember thinking how fearless and valiant he was, as is every member of our community.

I believe we have a very strong board who is ready to work hard for and with you. Van Rushton has brought to the board wisdom and great knowledge because of his life experiences. Tyler Blair, although young, brings to the table his real-life experience with managing Hemophilia and the challenges this disease state can cause.

New to our board is Katelyn Erben, a dynamic young woman with amazing energy, creativity and love for helping others. I often think she is my "Elphaba to my Galinda!" I hope that together, we will be unlimited!

I would like to see in the next few years more opportunities to share information on what HBDA can do for you. The Board is brainstorming new ideas to get more interest in the community. Not only inside our group, but to reach out to non-community members to tell the story of those living with a bleeding disorder.

But we can't do it alone. We want to foster an environment of collaboration and innovation where every member's voice is heard and respected. So, that means that we would like to work hand in hand with YOU!

We all have special talents in our wheelhouse that could be shared to benefit us all. Perhaps, you know of some grants that can be applied for. Or, maybe where you work you could see if the company would make a donation to the cause.

HBDA has set it up with Facebook where on your birthday and that of every member of your family, you can ask your friends and relatives to donate to HBDA in your honor.

Do you have a special gift for gardening? For building things with your hands? For baking? Let us know.

You might even know a family dealing with a bleeding disorder, who is not part of our tribe. Reach out to them and let them know there is help.

I'd like to leave you with this one thought. I am paraphrasing the late, great JFK "Ask not what HBDA can do for you, but what YOU can do for HBDA!" Until we see each other again in October…take care.

Women's Retreat 2025

HBDA Women's Retreat Celebrates Strength and Sisterhood

In February, Hemophilia and Bleeding Disorders of Alabama (HBDA) gathered a group of extraordinary women for a special retreat on the serene shores of Lake Martin. The retreat was dedicated to honoring women who are affected with bleeding disorders, as well as those who are parents, and/or serve as caregivers to loved ones within the community.

The setting was nothing short of inspiring—Lake Martin's natural beauty provided a peaceful backdrop, while the cozy and welcoming environment created space for genuine connection. Women came together not only to relax and recharge, but also to share their experiences, wisdom, and encouragement with one another.

Throughout the retreat, participants took part in uplifting sessions designed to address the daily challenges of being a patient, mother, or caregiver to someone with a bleeding disorder. These conversations offered practical guidance, but perhaps even more importantly, they reminded each participant that she is not alone in her journey.

Stories of resilience, compassion, and perseverance filled the room, as peers leaned on one another and found comfort in shared understanding. The retreat was a celebration of the powerful role women play in supporting their families and communities, and a reminder of the strength that grows when women stand together.

HBDA is proud to have created this safe and supportive space where women could honor themselves, connect with others, and return home renewed.

2025 HBDA Women's Retreat

FACTOR UP with ALTUVIIIO®

ALTUVIIIO®
Antihemophilic Factor (Recombinant), Fc-VWF-XTEN Fusion Protein-ehtl

Higher-for-longer Factor VIII levels in the near-normal to normal range **(over 40%)** for most of the week in adults

High sustained Factor VIII activity levels
Above 40% (near-normal to normal range) for most of the week in adults and for ~3 days in kids.*

48 Hour half-life in adults
ALTUVIIIO offers the longest half-life of any Factor VIII therapy across all age groups.†

0.7 Bleeds per year‡
Mean annual bleed rate observed in 128 people previously treated with prophylaxis therapy.§

In adults and adolescents taking ALTUVIIIO in the XTEND-1 study, 20.1% experienced headache and 16.4% experienced joint pain. In children under 12 taking ALTUVIIIO in the XTEND-Kids study, 12.2% experienced fever.

*Average trough levels were 18% for adults 18 years and older, 9% for adolescents aged 12 years to under 18 years, 17% for children aged 6 years to under 12 years, and 11% for children aged 1 year to under 6 years.
†The half-life was 44.6 hours for adolescents aged 12 years to under 18 years, 42.4 hours for children aged 6 years to under 12 years, and 38 hours for children aged 1 year to under 6 years.
‡Data based on treated bleeds.
§159 adults and adolescents with severe hemophilia (aged 12 years and older) were enrolled in the XTEND-1 study; 133 people were in Group 1 and switched to ALTUVIIIO prophylaxis from prior prophylaxis therapy. Efficacy of prophylaxis was evaluated in 128 of these patients. 74 previously treated male children under 12 years who switched to ALTUVIIIO were studied over 1 year in the XTEND-Kids study. Efficacy was evaluated in 72 of these children.

CONNECT WITH YOUR CoRe TODAY

Learn more about ALTUVIIIO, living with hemophilia, and treatment options from your local CoRe.

Dennis Jones
dennis.jones@sanofi.com
334-354-4247
Serving Georgia, Alabama

INDICATION

ALTUVIIIO® [antihemophilic factor (recombinant), Fc-VWF-XTEN fusion protein-ehtl] is an injectable medicine that is used to control and reduce the number of bleeding episodes in people with hemophilia A (congenital Factor VIII deficiency).

Your healthcare provider may give you ALTUVIIIO when you have surgery.

IMPORTANT SAFETY INFORMATION

What is the most important information I need to know about ALTUVIIIO?
Do not attempt to give yourself an injection 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 injecting ALTUVIIIO so that your treatment will work best for you.

Who should not use ALTUVIIIO?
You should not use ALTUVIIIO if you have had an allergic reaction to it in the past.

What should I tell my healthcare provider before using ALTUVIIIO?
Tell your healthcare provider if you have had any medical problems, take any medications, including prescription and non-prescription medicines, supplements, or herbal medicines, are breastfeeding, or are pregnant or planning to become pregnant.

What are the possible side effects of ALTUVIIIO?
You can have an allergic reaction to ALTUVIIIO. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.

Your body can also make antibodies called "inhibitors" against ALTUVIIIO. This can stop ALTUVIIIO from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

The common side effects of ALTUVIIIO are headache and joint pain.

These are not the only possible side effects of ALTUVIIIO. Tell your healthcare provider about any side effect that bothers you or does not go away.

Please see full Prescribing Information.

sanofi

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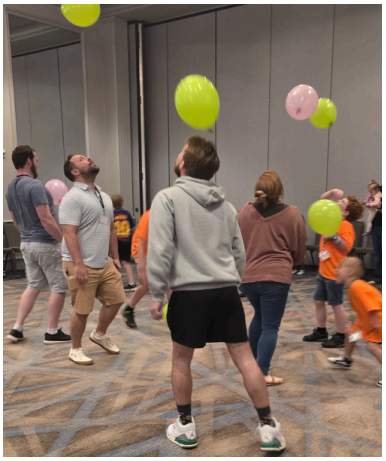
Annual Meeting 2025

Our 2025 Annual Meeting was held at the Hyatt Regency Wynfrey Hotel in Birmingham, Alabama, with a festive Cinco de Mayo theme setting the stage for a memorable event.

Members enjoyed valuable networking opportunities during the industry exhibits on our opening night. Our educational session included Jonathan James of Hope Charities, as he delivered insightful advocacy updates from Washington, D.C., and their impact on the bleeding disorders community nationwide.

The weekend offered something for everyone. Children enjoyed an exciting trip to Dave & Buster's, while families and adult participants attended a variety of educational sessions featuring top keynote speakers and patient advocates. Families also had the chance to share personal experiences and peer-to-peer challenges during our Community Connection session, which fostered meaningful dialogue and support.

Our industry partners, including Bayer, CSL Behring, Genentech, and Sanofi, played a vital role, sponsoring meal sessions and providing excellent educational topics that enriched members' learning experiences. The atmosphere throughout the event was filled with excitement as participants gained new insights, explored innovative therapies, and learned about emerging treatment options that will shape the future of care for the bleeding disorders community.



Annual Meeting 2025

Distinguished Young Women 2025

Many of you know me as a sports-driven, country-living girl. But this year I decided to participate in a scholarship program called Distinguished Young Women. It is a program for upcoming seniors in high school to help girls become their best selves. I'll admit, when I first signed up for Distinguished Young Women, I had my doubts. I was so sure I wasn't as elegant or talented as the other girls. But as we went through countless practices, I started to see what the experience was about. It wasn't just about winning a competition; it was about becoming confident, strong, and unique individuals. What I'll remember most are the lifelong friendships I made, not just with the other participants, but with the Little Sisters, too. I might not have won the crown, but I won something better. I came in second overall and won a $1500.00 scholarship and a $300.00 Scholastic scholarship Total of $1800.00. I would encourage all upcoming seniors to participate in this program.

Be your Best self,
Madilynn Clarke

Congratulations!

We are so proud of you Madilynn!

If you or your family experience a milestone or accomplishment you would like to share with our community in the next newsletter, please reach out to Amanda Jennings with details and pictures.

Camp Clot Not 2025

I spy something…. Nuclear?!

Even when boisterous thunderstorms erupted and lightening sparked through the skies… our spy-agents-in-training were not deterred from their mission.

THE TOP-SECRET MISSION: OPERATION SNOW GLOBE

First rule of being a spy: sshhhhh! Spies must be able to communicate efficiently (and quietly) in a variety of settings to accomplish missions. Second rule: spies must learn how to work together in different settings with a variety of other agents. Third rule: spies must be able to change their look at a moment's notice. You never know who is watching ….

The evil Dr. Phinneaus Claw was on the run, disrupting the balance between peace and chaos. Our agents in training (AIT) were called to the forefront abruptly by the NSA President, Special Agent Rex Voss to secure the nuclear missile launch button before Dr. Phinneaus Claw!

To complete Operation Snow Globe, agents were randomly scrambled into new groups, assigned mission leaders, given materials to create disguises, a top-secret survival pouch and clues. PLOT TWIST: as agents listened to instructions from Special Agent Voss, the evil Dr. Phinneaus Claw's minions discovered the mission leaders' true identities and posted them all over the Agent's bunkers!! (Gasp!) Agents had to be thorough in their disguises, work quickly and quietly in order to remain undetected.

Teams went through a series of eight clues which tested their knowledge, problem solving skills, communication and agility.

The final task was to complete the ultimate spy obstacle course. Agents were required to make it through a laser room, defy gravity with a giant Jenga, Bop-It till ya drop it, and finally, cracking the code!!

All teams successfully made it back to Langley with the nuclear missile launch button. Woohoo!

Outside of training, agents enjoyed blowing off steam with ferocious games such as: King of the Mountain, Chicken, Self Portraits, legit tie dye socks, dance-offs, epic relay races and much more.

Camp is a sacred space where everyone can just be. The best parts of camp are the sweet seemingly unnoticed moments where older campers are mentoring younger campers, finding out new cool things about each other (eg. The vibe this year was Frog-centric), encouraging participation in activities, or, my personal favorite, LIT's changing up the Galley tables so everyone could sit together… and every meal, someone always sat with a new friend. Priceless!

A special thank you to our entire team who made this vision happen. None of this magic happens without you!

Tyler and Nathan, a special shout out to you both. You are the epitome of the spirit of camp and always go above and beyond.

Out of the many years I have had the honor of being a part of camp, this year takes the unicorn. Even bad weather could not stop all the fun! ♥ **Katelyn**

Camp Awards 2025

Successful Teamwork Award - Robert
Best Mentoring Award - Ayden
Most Spirited Award - Garrett
Clean Camper Award - Luke
Mission Accomplished Award - Christian
I'll Do It Award - Ruxton

Branch Award - Ayden
Big Stick Award - Maxwell
Big Stick Award - Ruxton
Big Stick Award - Luke
Big Stick Award - NyAnnah

Counselor's Choice Award
MI6 - Maxwell
CIA - Porter
Mossad - Makenzie

First approved in 2017.* Over 8,100 patients in the US treated with HEMLIBRA.†

SCAN TO HEAR STORIES FROM THE COMMUNITY

*November 2017: FDA approval for adults and children with hemophilia A with factor VIII inhibitors.

†Number of patients with hemophilia A treated with HEMLIBRA in the US as of March 2024.

INDICATION & IMPORTANT SAFETY INFORMATION

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

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. 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.

Your body may make antibodies against HEMLIBRA, which may stop HEMLIBRA from working properly. Contact your healthcare provider immediately if you notice that HEMLIBRA has stopped working for you (eg, increase in bleeds).

Please see Brief Summary of Medication Guide on following page for Important Safety Information, **including Serious Side Effects**.

HEMLIBRA®
emicizumab-kxwh
injection for subcutaneous use
150 mg/mL

Medication Guide
HEMLIBRA® (hem-lee-bruh)
(emicizumab-kxwh)
injection, for subcutaneous use

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
  - confusion
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - stomach (abdomen) or back pain
  - nausea or vomiting
  - feeling sick
  - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - swelling in arms or legs
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - trouble seeing

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

Your body may make antibodies against HEMLIBRA, which may stop HEMLIBRA from working properly. Contact your healthcare provider immediately if you notice that HEMLIBRA has stopped working for you (e.g. increase in bleeds).

See "**What are the possible side effects of HEMLIBRA?**" for more information about side effects.

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I use HEMLIBRA?

See the detailed "Instructions for Use" that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.
- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. **Do not** give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

What are the possible side effects of HEMLIBRA?

- See "**What is the most important information I should know about HEMLIBRA?**"

The most common side effects of HEMLIBRA include:

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 86°F (30°C).
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

Keep HEMLIBRA and all medicines out of the reach of children.

General information about the safe and effective use of HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048

For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised: 03/2023

HEMLIBRA®
emicizumab-kxwh
injection for subcutaneous use
150 mg/mL

Genentech
A Member of the Roche Group

Hope on the Hill 2025

My name is Justin Clarke and my wife, Mary Beth, and I were honored to be invited to attend Hope on the Hill 2025. This event is facilitated by Hope Charities and focuses on advocacy for the rare disorders community with a focus on hemophilia and other bleeding disorders. We arrived in Washington D.C. on June 3 and were welcomed at the hotel along with all of the other attendees with a dinner and briefing on the plans for our day on "the hill" the next day. At dinner, we sat at tables with the team we would be working with while on the hill. Our team included the Alabama and South Carolina residents. We left the hotel early the next morning and walked to the offices of the Health and Medicine Council to meet with staffers for training on the topics we were to discuss with the Senate and House offices. We also received our schedule for the day. After training was complete, we headed to Capitol Hill to start our meetings.

Our first meeting was with Senator Tommy Tuberville's office. We met with his medical legislative aide Caleb. He was very knowledgeable in his understanding of the issues we discussed. We focused our discussions on PBM reform to allow patient choice, blood safety, insurance alternative funding and requested that Senator Tuberville consider co-sponsoring the HELP Copays Act (to ensure third party assistance counts towards a patient's out of pocket costs). Caleb informed us that they had just met with representatives for some of the major insurance companies the week before our meetings. We also discussed the need to establish a true HTC for patients in Alabama and about some of the challenges that this community faces in Alabama. Caleb told us that Senator Tuberville has plans to tour the state of Alabama this summer to meet with constituents and would love for our community to have an opportunity to meet with him to continue our discussions.

Our next stop was with Senator Katie Britt's office. Senator Britt hosts "Coffee with Katie" sessions on Wednesdays and our group was scheduled to meet with her. Unfortunately, she was called into a congressional meeting before the session was able to begin so we did not have an opportunity to meet with her, but we did stop by her office and speak with her legislative correspondent Emily Grace. We left a packet of information for the Senator that outlined our talking points and asks for this community.

The third stop on our agenda was the office of South Carolina Senator Ted Budd. We met with one of his aides and our South Carolina resident, Amanda, lead the conversation. Her primary focus was the need to diagnosis and treat women with inherited bleeding disorders.

Hope on the Hill 2025

Hope Charities hosted a Lunch and Learn in the House of Representatives building conference room for the aides and staffers to come and enjoy. While eating a taco bar lunch, they were able to hear personal stories shared by members of our community that have struggled with some of the issues we were discussing during our meetings. It was very impactful and hard to hear some of these struggles that we as Americans should not have today. As we were talking with some of those that attended the Lunch and Learn, they shared that they enjoyed the program and learned many things they could take back to their respective Senator or Representative.

Our final meeting of the day was in the office of Representative Terri Sewell. Our team was a little nervous about this meeting due to a previous experience one of our team had shared with us. We met with Representative Sewell's health policy advisor Dr. Cameryn Blackmore. Dr. Blackmore seemed genuinely interested in the topics we presented and stated that Representative Sewell frequently hosts round table discussion back home in Alabama. She asked if we would be interested in participating in one of those discussions in the future. We left that meeting with high expectations and a sense of accomplishment on a productive day.

The overall numbers from Hope on the Hill 2025: 51 attendees from all over the U.S. We had 3 representing Alabama. 20 total states were represented. We had 50 congressional meetings: 28 in the Senate and 22 in the House. We had 106 attendees for the Lunch and Learn.

The trip was not all meetings and lunch and learns for us. Mary Beth and I requested a later flight home so that we could enjoy some of the sights of Washington D.C. We enjoyed a tour of the Capitol courtesy of Senator Tuberville's office and visited the galleries of both the Senate and the House. It was interesting to see the business of our nation being conducted. We saw many Senators enter and have conversations and vote while in the Senate gallery. The House gallery was less exciting as a hearing was in progress during our visit, but it was still interesting to observe. We even caught a glimpse of Steve Scalise as he emerged from the Speaker of the House's office. Unfortunately, Mary Beth was not quick enough with her camera to get a photo of him, only his escorts.

We are extremely grateful to HBDA and Hope Charities for this opportunity. We are truly blessed and excited to see how we can continue this important work back home in our own state. We look forward to continuing this with HBDA and our community to make positive changes for those in the State of Alabama that have been diagnosed, or who have yet to be diagnosed, with an inherited bleeding disorder.

Thank you,

Justin and Mary Beth Clarke

In Loving Memory: Amy Blair

Amelia "Amy" Yvonne Blair

Amelia Yvonne Blair, age 87, of Northport, Ala., passed away on Sunday, April 20, 2025, at DCH Regional Medical Center surrounded by loved ones. Services will be held Saturday, April 26, 2025, at 2:00 p.m. at Magnolia Chapel Funeral Home located at 4905 Hwy 69 N. with Dr. Ken Cheek officiating. Burial will follow in Tuscaloosa Memorial Park with Magnolia North Chapel directing. Visitation will be one hour prior to the service.

She was preceded in death by her husband, James Robert Blair Jr.; parents, Herman Krause and Clara Westbrook Bond; brother, Sonny Bond.

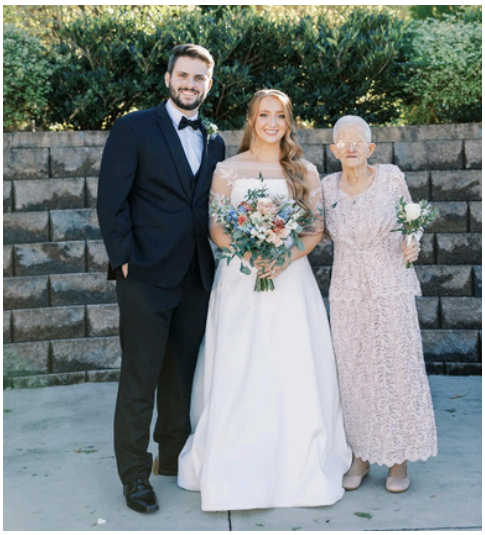
She is survived by her sons, Chris Blair (Robin), James Blair III; grandson Tyler Blair (Madison); granddaughter Kristen Blair; sister, Emily Kahaneck; brothers-in-law Carl Blair (Suzie), Fred Blair, John Blair (Kay); sister-in-law Cindy Bond; a host of nieces and nephews.

Amelia "Amy" was born on August 1, 1937, in Gonzalez, Texas to Herman and Clara. She graduated from Ball High School in Galveston, Texas in 1956. She faithfully supported her husband, Jim Blair, through his long service with the United States Coast Guard. They were happily married for over 57 years. After Jim's retirement from the Coast Guard, they moved back to Shiner, Texas, where Amy was the director of Shiner's senior citizen center and also helped Jim run their electronics store. She was an active member of Chapel Hill Baptist Church for many years. Her devotion for Christ always drove her to serve others, especially through her numerous recipes which were all cooked with love. God saw fit to call her to her Heavenly home on Easter, which serves as a great reminder that she is now spending eternity with Him.

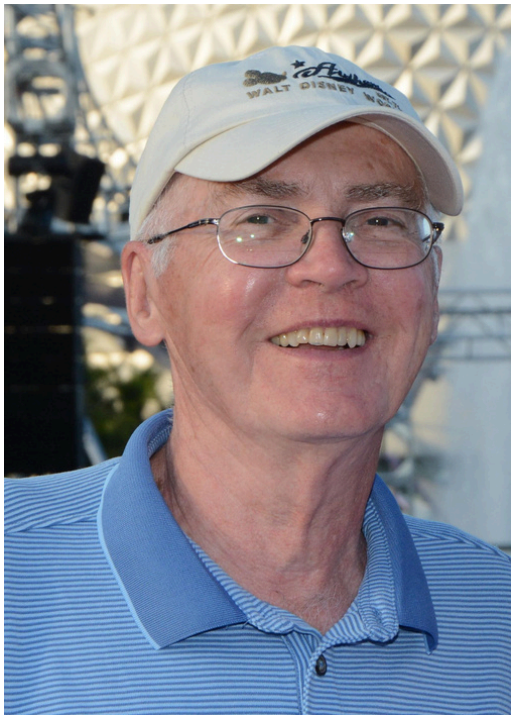
Throughout her life, she was passionate about sports-especially when her grandkids played-as well as cheering on the Alabama Crimson Tide. She enjoyed bowling, playing dominos, and spending time with her family. She was a loving and devoted daughter, sister, wife, mother, "Grandmommy," aunt, and friend.

Pallbearers will be Joe Fendley, Greg Rubio, Chuck Pittman, Tyler Blair, and Brady Giles. Honorary pallbearers are Amy's Sunday School class, members of the WINGS ministry at Chapel Hill, and George and Melissa Hassell.

In lieu of flowers, donations can be made to Hemophilia and Bleeding Disorders of Alabama (www.hbda.us), Chapel Hill Baptist Church, or a charity of your choice.



In Loving Memory: Franklin Ward



SCARBOROUGH – Franklin James Ward, 82, of Scarborough, passed away on June 18, 2025.

Frank was born on Aug. 15, 1942, in Portland, son of the late Irene Virginia (Collins) Ward and Philip James Ward. Frank and his younger sister, Marianne (passed on Nov. 23, 2017), grew up in South Portland, spending most of his time in a small home just outside the Willard Square neighborhood of South Portland. As a young child he was introduced to the world of arts- dance, piano, acting and elocution. Later in life Frank would tell stories to his children of how he abhorred these lessons and didn't have an ounce of creative blood in him, though the elocution lessons paid off as he was an outstanding public speaker.

Frank graduated from South Portland High School in 1960 and went to The University of Maine in Orono to ultimately earn his master's degree in chemistry in 1966. During those years, he spent endless nights at the library studying and courting his soon to be wife, June. Date nights tended to take place in the halls of Fogler Library. Frank and June Norton married in the summer of 1964 at Holy Cross Church in South Portland.

After graduating, Frank and June, with two young children, Michael and Erin, moved to Rochester, N.Y., where he began his career as a chemist at Kodak. Missing his family in Maine, Frank, June, and their young family, now including a third child, Brian, moved back to South Portland.

Frank began a new career at S.D. Warren (now SAPPI Westbrook) as a chemist working in the specialty release paper division, tasked with working on developing new types of coatings for specialty paper. This career spanned the rest of his working life. His work with specialty release papers would eventually lead to new innovations in electron beam coating methods and the invention of Ultracast, the main source of revenue for SAPPI Westbrook to this day.

Frank and June had two more children, Kevin and Stephen, and raised their family in Cape Elizabeth.

Frank enjoyed travel, going on many vacations to Disney World, visiting National Parks and going to Europe. Frank enjoyed family gatherings and cookouts. He also had a sweet tooth with a love of Cookie Jar jelly donuts, homemade blueberry pie with extra sugar and black licorice. Frank had a passion for running and participating in numerous 5Ks including the Beach to Beacon in Cape Elizabeth.

Frank retired from SAPPI in 2008 but was quickly brought back on as a consultant until he ultimately left in 2019.

Frank is survived by his wife, June; his five children, Michael of Deatsville, Ala., Erin of Rancho Mirage, Calif., Brian and his wife Tisha of Wetumpka, Ala., Kevin and his wife Heather of Kennebunkport, Stephen and his wife Becky of Auburn; two nieces, Amber McGrath-Guterman of Marietta, Ga. and Holly Menchaca of Naples, Fla.; 12 grandchildren; and two great-grandchildren.

The family's deepest gratitude goes out to all of the staff at Gosnell Memorial Hospice House in Scarborough for their wonderful and dignified care. A private family gathering will be held in Frank's honor.

In Loving Memory: Reggie McNamee

John Reginald McNamee, Sr.

To family and friends he was known as Reggie. He was born on September 8, 1948 to Milton McNamee, Sr. and Thelma Kelly McNamee in Jackson, Mississippi. He went to be with his Lord on July 17, 2025, at the age of 76, after an extended illness. He was in the care of Southern Care Hospice and received excellent care from his home care staff.

Reggie graduated from Forest Hill High School and then attended Hinds Junior College briefly. He enlisted in the United States Marine Corps in April of 1968 and served until April of 1974. He again served his country in the Army National Guard from September 1991 to November of 1992.

He is survived by his wife of 49 years Shirley Oakes McNamee; son John “Jay” R. McNamee, Jr. of Lowndesboro, AL; daughter Mary Beth (Justin) Clarke, of Lowndesboro, AL. He leaves behind two granddaughters Madilynn and Makenzie Clarke and one grandson Joseph Clarke all of Lowndesboro, AL. He is also survived by three sisters Beth McNamee Gordon and Melinda McNamee of Jackson, MS and Connie (Robert) Schapp of Cary, NC as well as his brother Joe (Jean) McNamee of Brandon, MS and numerous nieces and nephews.

He was preceded in death by his parents Milton McNamee Sr. and Thelma Kelly McNamee, his grandparents Calvin Kelly Sr. and Lillie Berry Kelly of Jackson, MS and Joseph McNamee and Corrine Elizabeth Jolly McNamee of Gulfport, MS. His infant daughters Stephanie and Lisa McNamee, his brother Milton “Mac” McNamee, Jr. one niece and various aunts and uncles also preceded him in death.

He was an active member and served as a deacon at Hayneville Baptist Church. He was also a Mason. He worked at GE Plastics and later Sabic Plastics. He was an avid hunter and fisherman. He was a supporter of Lowndes Academy where his children attended and his grandchildren now attend. He was also a supporter of Ole Miss, where his wife graduated from nursing school.

A Celebration of Life will be held on September 6, 2025 at 2:00 p.m. at Hayneville Baptist Church in Hayneville, AL. In lieu of flowers, donations can be made to The Parkinson’s Foundation or to the American Cancer Society.

HBDA Inaugural Men's Retreat 2025

As many of you know and heard at the Annual Meeting, we announced a new event for HBDA, a Men's Retreat.

We officially held our first Men's Retreat at De Soto State Park in Fort Payne, AL August 2 - 3. What a great facility with hiking trails, to waterfalls, Zip lining, canoeing, and much more! The weather was not ideal, as we were unable to kayak the last day due to the rain, but the company and programs were great!

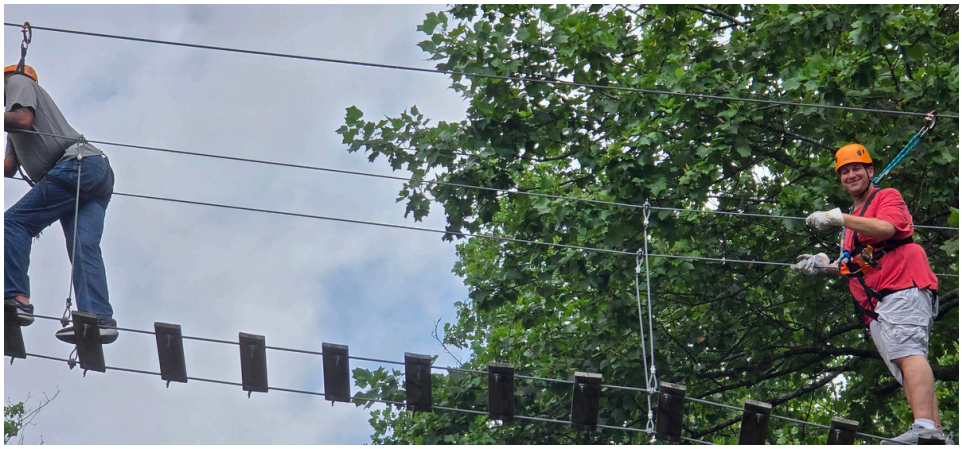
We started on Saturday afternoon with lunch and then off we went to zipline. To say that we were in close quarters at all times on the zipline is a understatement. We had to wait on a treetop on a platform with 10 others, and all I can say is it was bonding at its finest. After ziplining we had dinner and a speaker. To my surprise, the speaker was a gentleman I met when I was a counselor at the camp in Georgia!

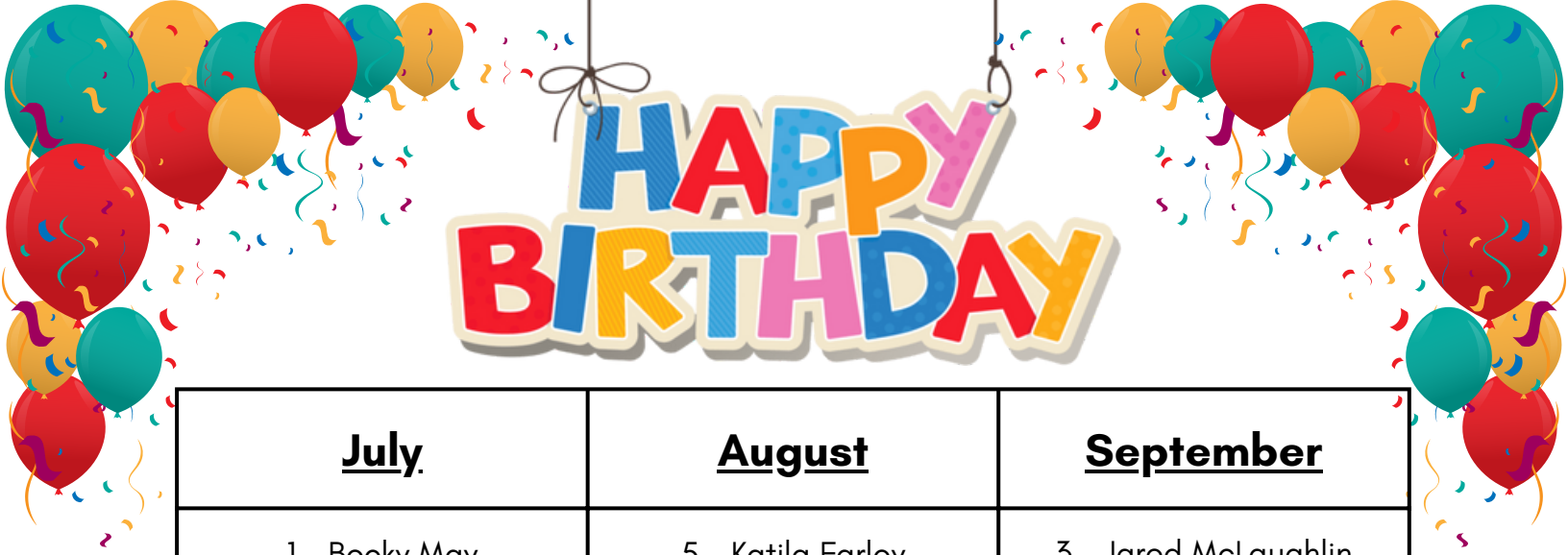
After the presentation and industry exhibit time, we played poker and other card games. We all learned new games and spent time connecting with each other. They say men don't talk, well we laughed, talked, and some even cried. What a great way to end the evening! We did get kicked out of the lodge at 10:00 pm. I think we could have stayed and continued fellowshipping for many more hours.

Sunday morning, we had breakfast and enjoyed another presentation. Since we were rained out of our morning activity of kayaking, we talked and played cards again. We wrapped up the weekend with a delicious lunch!

Thank you to HBDA and all the Men's Retreat sponsors: Bayer, CSL Behring, DrugCo, Genentech, Novo Nordisk, SandsRx, Sanofi, Soleo Health . We all agreed that we need to continue this program and extend the time to a full weekend for 2026.

HBDA Inaugural Men's Retreat 2025





July	August	September
1 - Becky May 6 - Trey Hall 7 - Connie Grammer 8 - Ava Shifflett 8 - Pat Morgan 10 - Dana Pauley 12 - Ashley Hall 12 - William Shifflett 13 - Anthony Martin 18 - Tera Bradshaw 20 - Chris Baughman 20 - Matthew Watts 29 - Liam Hall 30 - Noah Guadalupe	5 - Katila Farley 6 - Kristopher Lewis 6 - Linda Smith 9 - Rick Dinkins 13 - Jeannie McLaughlin 14 - Maralee Clarke 14 - Tim Mason 17 - Joan Chung 22 - Bethalyn Bailey 23 - Mackenzie Clarke 30 - Erin Buffington 30 - Garrett May	3 - Jared McLaughlin 4 - Nicole Haigler 11 - Larry Grammer 12 - Brayden Cooper 12 - Rachel Shifflett 13 - Mary Hunter 13 - NyAnnah Davis 17 - Brittany Gillespie 21 - Cooper Guadalupe 21 - Vicki Jackson 23 - Chesca Barnett 24 - Stephen Pauley 26 - Jace McLaughlin 28 - Amber May
October	**November**	**December**
3 - Nicole Lloyd 7 - Levi McLaughlin 8 - Chad Mitchell 15 - Katelyn Erben 19 - Brian May 19 - Justin Clarke 20 - Jonathan Hall 22 - Fallon Howard 25 - Royal Smith 27 - Tisha Ward 28 - Molli Cunningham 31 - Brandee Cookston	6 - Cameron Jones 9 - Laura Pitman 10 - Chelynn Pargo 13 - Ruxton Reynolds 16 - Myra Cooper 16 - Patsy Lewis 23 - Ellie Shifflett 27 - Rusty Chapman 28 - Sonya Bross	5 - Joseph Clarke 9 - Tricia Watts 10 - Harrison Hall 14 - Cosette Reynolds 14 - Kimberly Wood 23 - Juliette Reynolds 25 - Amanda Jennings 29 - Leslie Bailey 30 - Gavin Chapman 31 - Jonathan Vermillion

HBDA Bi-Annual Newsletter

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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 need assistance due to an unexpected circumstance, please reach out to us.