

HBDA BI-ANNUAL NEWSLETTER

Summer Edition 2026
Volume 65



Leslie Bailey, Chairman
Vicki Jackson, Executive Director

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WORDS FROM THE STAFF

As we move toward a new season—and hopefully some cooler Alabama weather—it feels like a good time to slow down for a moment, reflect on where we have been this year, and look ahead to what is still to come.

There is so much happening in the bleeding disorders community right now. Treatment options continue to grow and change, giving individuals and families more choices than ever before. New therapies and advances in care are creating opportunities that many of us could only imagine not that long ago. While every person's treatment journey is different, it is exciting to see continued progress and to think about what these advances may mean for the next generation.

At HBDA, our role has always been about more than treatment. It is about making sure our families have access to education, resources, support, and — just as importantly — one another. Looking back at the events we have already shared this year, we are reminded of just how important those connections are.

We began the year with our Women's Retreat at Children's Harbor, where women from across our community had the opportunity to step away from everyday responsibilities and spend a weekend focused on education, self-care, and each other. There were meaningful conversations, plenty of laughter, a few tears, and the kind of honest connection that happens when women are surrounded by others who understand their experiences.

In May, we returned to Children's Harbor for our Annual Meeting, bringing families together for a weekend of education and fun. From informative sessions and conversations with our industry partners to an afternoon at the pool and a very competitive Saturday night Bingo tournament, the weekend gave our families an opportunity to learn about what is happening in the bleeding disorders community while also simply enjoying time together.



WORDS FROM THE STAFF, CONT.

Summer brought one of our favorite weeks of the year—Camp Clot Not. Our campers spent the week swimming, tubing, fishing, creating, laughing, and making memories, but camp is about much more than having fun. One of the most meaningful parts of the week is watching our kids learn to take greater responsibility for their own care. Seeing a camper work toward self-infusion and earn that Big Stick Award is something that never gets old. This year, we were especially excited to include siblings in that experience as they worked toward earning their Strong Stem Award. These moments represent confidence, independence, and a future where our kids know they can take an active role in their own health.

Most recently, our Men's Retreat in Columbus, Georgia, gave the men in our community a chance to learn, reconnect, and enjoy a little adventure together—including whitewater rafting and ziplining. But beyond the activities, the weekend provided something even more valuable: time with other men who understand the realities of living with a bleeding disorder or caring for someone who does. Those friendships and peer connections often become a source of support long after the weekend is over.

When we look at all of these events together, there is a common thread running through them: connection. Treatments will continue to evolve. New products and therapies will come. The way bleeding disorders are managed may look very different in the years ahead, and that is something worth being excited about. But through all of that change, the need for community remains.

Our hope is that HBDA continues to grow right alongside the changing landscape of bleeding disorders care—creating opportunities for our members to learn about new treatment options, advocate for themselves and their families, build independence, and form relationships with others who understand their journey.

There is still much to look forward to before this year comes to a close, and we are grateful for every family, volunteer, medical professional, industry partner, sponsor, and friend who continues to be part of HBDA. As one season gives way to another, we are thankful for the memories we have already made, encouraged by the progress happening within our community, and hopeful about what lies ahead.

The future of the bleeding disorders community is changing—and we are excited to move forward together.



HBDA ANNUAL MEETING 2026:



A WEEKEND TO LEARN, LAUGH, AND RECONNECT



This year's HBDA Annual Meeting was a wonderful reminder of what makes our community so special. From May 8–10, members, families, volunteers, and industry partners gathered at Children's Harbor on beautiful Lake Martin for a weekend filled with learning, encouragement, and meaningful time together.

Throughout the weekend, attendees participated in engaging educational sessions led by knowledgeable speakers and industry partners who shared the latest information on treatments, advocacy, and the future of bleeding disorder care. While the educational sessions are always an important part of our Annual Meeting, some of the most meaningful moments happened in the conversations between sessions—families sharing experiences, offering encouragement, and reminding one another that no one has to navigate this journey alone.

Saturday afternoon gave everyone a chance to step away from the meeting rooms and simply enjoy being together. The pool was filled with laughter as children played, parents caught up with friends, and new relationships began to grow. Those relaxed moments of fellowship are often the ones that leave the biggest impression, strengthening the bonds that make our HBDA family so unique.



**Thank You to Our 2026
Annual Meeting**

Elite Presenting & Exhibit Sponsors



CSL Behring
Biotherapies for Life™

Genentech
A Member of the Roche Group

sanofi

Presenting & Corporate Sponsors



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Exhibitor Sponsors



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Simplifying Complex Care

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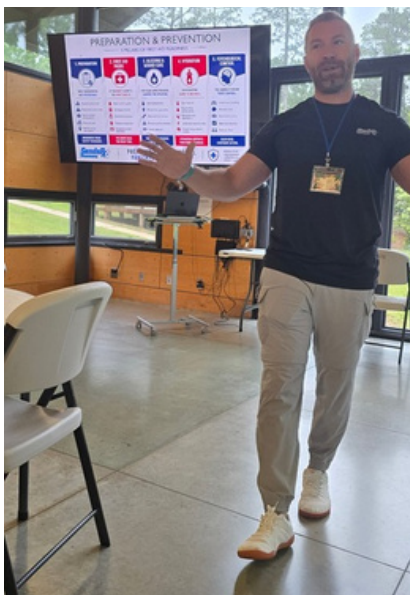


ANNUAL MEETING 2026

That evening, the excitement continued with one of the weekend's favorite events—the Bingo Tournament! The room was full of anticipation, friendly competition, and plenty of laughter as families hoped their lucky cards would earn them one of Sunday's cash prizes. Win or lose, everyone enjoyed the fun and camaraderie that made the evening such a memorable part of the weekend.

As we wrapped up the meeting on Mother's Day, many families headed home not only with new information and helpful resources, but also with renewed friendships and a stronger sense of community. Weekends like these remind us that HBDA is about so much more than education. It's about creating a place where families feel supported, understood, and connected every step of the way.

Thank you to our members, volunteers, speakers, and industry partners for making this year's Annual Meeting such a meaningful success. Your willingness to share your time, your knowledge, and your experiences continues to strengthen the HBDA family, and we can't wait to see everyone again at our next event.



CAMP CLOT NOT 2026: A WEEK OF ADVENTURE, FRIENDSHIP, AND GROWING INDEPENDENCE

There's something special about Camp Clot Not that's hard to put into words. Every summer, campers arrive at Children's Harbor on beautiful Lake Martin with excitement and maybe a few nervous butterflies.

By the end of the week, they leave with something far more meaningful—new friendships, greater confidence, and memories that will last a lifetime.

This year's Super Mario-themed Camp Clot Not was filled with adventure from beginning to end. Campers quickly settled into their cabins, created Cabin Constitutions, completed swim tests, and kicked off the week with an opening night dance party that had everyone smiling.

The days that followed were packed with unforgettable experiences. Campers paddled kayaks and canoes, tested their balance on paddleboards, bounced across the Aqua Pad, enjoyed boating and tubing on Lake Martin, and cooled off during group swims. Back at camp, they created colorful tie-dye shirts, crafted paracord bracelets, and competed in an action-packed Mario-themed relay challenge complete with obstacle courses, coin dives, Luigi's Bunker, Lakitu Lagoon, and plenty of teamwork. The week wrapped up with archery, tug-of-war, an epic water balloon battle, and one last dance party that celebrated an incredible week together.

As much fun as the activities were, the greatest accomplishment of the week wasn't found on the lake or the dance floor—it was watching campers discover just how capable they are.

One of the most meaningful traditions at Camp Clot Not is helping campers learn to self-infuse their medication. Throughout the week, our incredible medical team worked alongside each camper, offering encouragement, patience, and support as they took this important step toward independence. For many campers, learning to self-infuse is life-changing. During our final awards ceremony, those who reached this milestone proudly received the coveted Big Stick Award—a symbol of courage, perseverance, and growing independence. Watching campers walk across the stage to accept their Big Stick while surrounded by cheers from friends, counselors, medical staff, and families is always one of the most inspiring moments of camp.

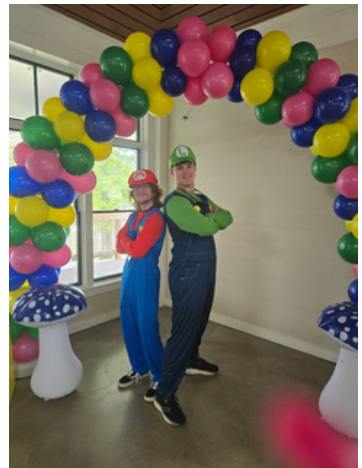


This year also brought an exciting new addition to Camp Clot Not as we welcomed siblings ages 9–15 to share in the experience. Siblings are often the quiet heroes of the bleeding disorders community, offering support, encouragement, and understanding every day. By including them in camp, we strengthened not only their connection with their brother or sister but also their connection to other families who share similar experiences. We were especially proud to introduce the Strong Stem Award, recognizing siblings who learned to self-infuse alongside their camper sibling. Like the strong stem of a tree that supports every branch, this award celebrates the unique bond between siblings and reminds us that strengthening one family member strengthens the entire community.

The week concluded with our awards celebration, where campers were recognized not only for what they accomplished but for who they became throughout the week. We celebrated leadership, kindness, perseverance, courage, and friendship. There were cheers, laughter, hugs, and even a few happy tears as we reflected on everything the week had meant.

While the games, crafts, and adventures make Camp Clot Not unforgettable, it's the relationships that leave the greatest impact. Camp gives children living with bleeding disorders—and now their siblings—a place where they are understood, encouraged, and empowered to grow. They leave knowing they are never alone, and that the confidence they found at camp can carry with them long after they leave Children's Harbor.

None of this would be possible without our dedicated volunteer counselors, medical team, Children's Harbor staff, industry partners, generous sponsors, and families. Their commitment makes Camp Clot Not more than just a summer camp—it creates a place where lives are changed, independence is celebrated, and lifelong friendships are formed.



As we said our goodbyes, there were promises to keep in touch, plans to reunite next summer, and countless memories to carry home. Camp Clot Not 2026 may be over, but the confidence gained, the friendships formed, and the lives touched will continue long after the final level was completed.

Camp Clot Not 2026 Awards:

Strong Stem Awards (Sibling Big Stick):

Liam Hall
Beck Reynolds
Elisha Rios
Jenson Mooring
Joseph Clarke
Caroline Buffington
Braylin Mooring

Individual Awards:

Power Up Achievement Award - Porter McLaughlin
Luigi's Team Player Award - Robert Masline
Best First Time Camper - Beck Reynolds
Yoshi's Helpful Friend Award - Braylin Mooring
Superstar Player Award - Christian Gillespie
Best Overall Camper - Elisha Rios
Counselor's Choice - Blue Shell Bandits - Maxwell McLaughlin
Counselor's Choice - Mushroom Militia - Chance Wright
Counselor's Choice - Luma Legends - Fallon Howard

Big Stick Awards:

Harrison Hall
Robert Masline
Chance Wright
Clay Buffington
Erynn Mitchell



FACTOR UP with ALTUVIII[®]

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

ALTUVIII[®]
Antihemophilic Factor (Recombinant),
Fc-VWF-XTEN Fusion Protein-eht1



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

ALTUVIII[®] 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 ALTUVIII[®] in the XTEND-1 study, 20.1% experienced headache and 16.4% experienced joint pain. In children under 12 taking ALTUVIII[®] 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 446 hours for adolescents aged 12 years to under 18 years, 424 hours for children aged 6 years to under 12 years, and 39 hours for children aged 1 year to under 6 years.

†Data based on treated bleeds.

‡129 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 ALTUVIII[®] prophylaxis from prior prophylaxis therapy. Effect of prophylaxis was evaluated in 129 of these patients. 74 previously treated male children under 12 years also switched to ALTUVIII[®] were studied over 1 year in the XTEND-Kids study. Effect was evaluated in 72 of these children.

CONNECT WITH YOUR CoRe TODAY

Learn more about ALTUVIII[®], living with hemophilia, and treatment options from your local CoRe.



Dennis Jones
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Serving Georgia, Alabama

INDICATION

ALTUVIII[®] (antihemophilic factor (recombinant), Fc-VWF-XTEN fusion protein-eht1) 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 ALTUVIII[®] when you have surgery.

IMPORTANT SAFETY INFORMATION

What is the most important information I need to know about ALTUVIII[®]?

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 ALTUVIII[®] so that your treatment will work best for you.

Who should not use ALTUVIII[®]?

You should not use ALTUVIII[®] if you have had an allergic reaction to it in the past.

What should I tell my healthcare provider before using ALTUVIII[®]?

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 ALTUVIII[®]?

You can have an allergic reaction to ALTUVIII[®]. 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 ALTUVIII[®]. This can stop ALTUVIII[®] from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

The common side effects of ALTUVIII[®] are headache and joint pain.

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

Please see full [Prescribing Information](#).

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ANNUAL MEN'S RETREAT 2026

The 2026 HBDA Men's Retreat brought together men from across Alabama's bleeding disorders community for a great weekend in Columbus, Georgia, filled with education, adventure, fellowship, and connection.

One of the most important parts of Men's Retreat is simply giving men the opportunity to spend time with others who understand the bleeding disorders journey. Living with a bleeding disorder—or caring for someone who does—comes with experiences and challenges that can be hard to explain to someone outside the community. Having a group of peers who can relate, share their own experiences, and offer encouragement is incredibly valuable.

Throughout the weekend, those connections happened naturally—over meals, between sessions, during activities, and in the downtime in between. Longtime friends had a chance to catch up, while new friendships were formed. These conversations and shared experiences are a big part of what makes weekends like this so meaningful. The relationships built at HBDA events often continue long after everyone heads home.

Education was also an important part of the weekend. We are grateful to our industry partners for providing informative and engaging sessions, including Genentech's Caregiver Burnout, Sanofi's ALTUVIII CoRe Program – Peer Meet-Up, CSL Behring's Staying Active Through Every Stage, Bayer's Journey to Jivi, and an interactive educational presentation from Novo Nordisk.



And, of course, there was plenty of adventure! The men took on whitewater rafting on the Chattahoochee River and ziplining in Columbus. There were plenty of laughs, a little adrenaline, and lots of opportunities to encourage one another and enjoy the experience together.

Men's Retreat is about more than a weekend away. It gives men in our community a chance to learn, have fun, talk openly, and build friendships with people who understand where they are coming from. Those peer connections are an important part of the support HBDA works to provide throughout the year. We sincerely thank all of our sponsors for supporting the 2026 HBDA Men's Retreat and helping us provide these educational and peer-support opportunities.

Most of all, thank you to the men who joined us in Columbus. We hope you came home with useful information, some great memories and stories, and—most importantly—stronger connections with others in the bleeding disorders community. We're already looking forward to the next time we can all be together!



**Women with hemophilia have been
unheard for too long**

That is why we advocate.



Real women and girls
with hemophilia and
a treating clinician.

It is a myth that only men get hemophilia. About 50% of females who carry the hemophilia gene may have mild hemophilia A. But for too long, women have been dismissed, misdiagnosed, and undertreated. They can no longer be ignored. Novo Nordisk is honored to present **Because She Matters,**

a platform created to bring together healthcare professionals and patients to shatter the silence with powerful, unspoken stories of women with hemophilia.



SCAN ME

**WATCH THE VIDEO EVERYONE
IS TALKING ABOUT:**

www.WomenWithHemophilia.com



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*Because She
Matters*

Save the Date!



OCTOBER

23 - 25

Children's Harbor



"Camp Harvest" Family educational weekend
is one you don't want to miss!

Mark your calendar for the date listed above!



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



Plus, you will have time to re-connect and bond with your HBDA family and industry representatives.

**MORE DETAILS
COMING SOON!**

*We can't wait
to see you!* ❤️

Save the DATE

HBDA's

TEE IT UP for

HEMOPHILIA

Annual Golf Tournament

FRIDAY

NOVEMBER 13TH



ROBERT TRENT JONES GOLF TRAIL
PRATTVILLE, AL



REGISTRATION
10:00 AM



LUNCH
11:00 AM



TEE OFF
12:00 PM

For more information,

please contact us at hbdaeevents@gmail.com

or call us at 334-577-0125

Save THE Date

Women's Retreat

FEBRUARY 2027 

A weekend to refresh, recharge, and reconnect. 



EDUCATION



SELF-CARE

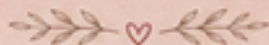


FRIENDSHIP

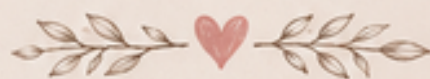


ENCOURAGEMENT


OFFICIAL DATE
WILL BE ANNOUNCED
AT A LATER DATE



 Children's Harbor



MORE DETAILS *coming soon!* 

HBDA 

Hemophilia & Bleeding Disorders
of Alabama



HAPPY BIRTHDAY

<u>July</u>	<u>August</u>	<u>September</u>
1 - Becky May 6 - Trey Hall 8 - Pat Morgan 8 - Ava Shifflett 9 - Marjorie Kyles 10 - Dana Pauley 12 - Ashley Hall 12 - William Shifflett 16 - Nelton Davis 16 - Jeff Tissier 18 - Tera Bradshaw 18 - Michael Fedoroff 20 - Chris Baughman 20 - Matthew Watts 29 - Liam Hall	1 - Tobias Threatt 5 - Katila Farley 9 - Rick Dinkins 13 - Jeannie McLaughlin 14 - Maralee Clarke 14 - Tim Mason 16 - Rory Fedoroff 17 - Lauren Clark 21 - Liam Hogan 23 - Makenzie Clarke 30 - Garrett May	3 - Jared McLaughlin 4 - Nicole Haigler 6 - Audrea Smith 7 - Cooper Cummings 7 - Shannon Phelps 9 - Cory Allen 12 - Brayden Cooper 12 - Rachel Shifflett 13 - NyAnnah Davis 13 - Mary Hunter 17 - Brittany Gillespie 21 - Vicki Jackson 23 - Chesca Barnett 24 - Stephen Pauley 26 - Jace McLaughlin 28 - Amber May 29 - Samuel Smith
<u>October</u>	<u>November</u>	<u>December</u>
3 - Nicole Lloyd 7 - Levi McLaughlin 8 - Lara Green 8 - Chad Mitchell 9 - Tori Threatt 10 - Rylie Cummings 12 - Blake Morgan 15 - Katelyn Erben 19 - Justin Clarke 19 - Brian May 22 - Chelsy Caldwell 22 - Fallon Howard 25 - Royal Smith 27 - Tisha Ward 28 - Molli Cunningham 31 - Brandee Cookston	3 - Duvani Tejiram 6 - Cameron Jones 7 - Casey Sanders 9 - Laura Pitman 10 - Isabella Hallmark 10 - Chelynn Pargo 11 - Malijah Threatt 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 12 - Ledger Threatt 14 - Cosette Reynolds 14 - Kimberly Wood 20 - Zoe Ridley 21 - Dawson Findley 23 - Juliette Reynolds 29 - Leslie Bailey 30 - Gavin Chapman 31 - Jonathan Vermillion

HBDA BI-ANNUAL NEWSLETTER

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PO Box 241090

Eclectic, AL 36024

Phone: (334) 577-0125

Website: www.hbda.us

Facebook: www.facebook.com/hbda4u



CLOT Line Assistance Program

Members:

If you are an active member of HBDA and 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.

