

HBDA QUARTERLY NEWSLETTER

Fall Edition 2023
Volume 59

Van Rushton, Chairman
Vicki Jackson, Executive Director

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WORDS FROM HBDA

Happy holidays from HBDA! We cannot believe that 2023 is already coming to a close! Wasn't it just August?!

As we reflect on our year, and the difference we have made for our members, we feel a sense of pride with the programs we provided to our community. The addition of our newest event, the Women's Retreat, was definitely a highlight in 2023 and beyond! We are confident that we will continue to meet the needs of our members and grow our programs and outreach across Alabama!

As we move into this holiday season, may we all remember that the most important things are not what is under the tree, but around it. We are grateful for each and every member, sponsor, and volunteer that has been a part of HBDA this year, and pray that 2024 blesses you!





CAMP HARVEST 2023



Camp Harvest 2023 kicked off with a delightful dinner and informative exhibit booths featuring our pharmaceutical and specialty pharmacy partners. Afterwards, our families and sponsors enjoyed an evening around a campfire by the lake with delicious hot cocoa, warm apple cider, and many good friends!



Saturday sessions began with breakfast and a Hemgenix session sponsored by CSL Behring. Our lunch sponsor, Sanofi, presented information on a new product, Altuviiro. The morning was rounded out by Octapharma with a presentation about navigating Hemophilia A. Three of our specialty pharmacy partners provided us with an introduction to the services that they each have available. Thank you to CVS Health, DrugCo, and InfuCareRx for their contribution.

After a full schedule of education and learning opportunities, HBDA added a twist to the day to get everyone's brain and body moving with some fun icebreakers. A "Whisper Challenge" offered opportunities for fun, laughter, and even a chance to win prizes. Additional challenges, such as "Pictionary Charades", and "Minute to Win It", gave our families an opportunity to enjoy the beautiful outdoor weather while building friendships with their peers and learning some new skills along the way. While the adults were exercising their brains in these difficult challenges, the kids were showing off their art skills painting a pumpkin canvases in a class with Annie Bartol and having relay races and challenges of their own!



Thanks to our friends at Colburn-Keenan Foundation, our families had a wonderful carnival to enjoy on Saturday afternoon! From funnel cakes, sno cones, popcorn, and burgers, to bounce houses, Twin Spin, and a dunk tank, the carnival feel surrounded us until time to prepare for a spooktacular trick or treat night!

Haunted scenes were around every porch corner, where screams and fun were had by all! From Freddy Kreuger, to creepy Scarecrows, wicked witches and more, each scene was brought to life by our talented sponsors and volunteers!

Sunday morning, breakfast and a Hemophilia A presentation was sponsored by Bayer. Our day was rounded out with lunch sponsored by Genentech, and a presentation from Devon, their Connections Ambassador and his story with Hemlibra!

Our time at Children's Harbor at this event is always impactful for each of us and it never disappoints! We are grateful for our time together and the memories we build year after year at Camp Harvest!



CAMP HARVEST EXHIBITS 2023





WE'RE IN THIS TOGETHER.

Friday 6:26 pm

Sharing stories by the
campfire with friends

Isaac, living with
hemophilia B

Not an actual patient

Let's make today brilliant.

Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world is stronger than ever.

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HBDA GOLF TOURNAMENT 2023



Tee It Up for Hemophilia 2023 was once again a great fundraising event for HBDA. With the help of strong supporters like Dr. David Bronner, CEO of Retirement Systems of Alabama, we continue to raise awareness and funds for the bleeding disorders community in Alabama. We are thankful for the continued support of our sponsors listed below who work tirelessly to promote our tournament and help us solicit sponsorships for the continuation of our programs and our cause.

The Robert Trent Jones Golf Course at Capitol Hill is one of the most beautiful golf courses around! We are very thankful that they continue to house our tournament! Even though mother nature tried to pull out some tricks this year with the rain, nothing could stop our golfers from finishing all 18 holes!

Pro baseball player, Pete Dyson, joined us for the afternoon on the Legislator course. He shared with us at the luncheon, sponsored by CSL Behring, that hemophilia does not have to define what you are, it's just what you have. He is such an inspiration to everyone and we can all take something away from his life lesson!

Our participating teams had a blast! Spirits were high, food was great, and mulligans were used! Raffles included a TV, a high end putter, and a range finder!

HBDA does not put on an event of this caliber without help from our amazing sponsors and volunteers! We are immensely grateful for our industry partners, volunteers, and friends who make this exciting fundraiser a huge success each year!

We hope you have a great rest of your 2023 and we look forward to seeing you again in 2024!



**WELCOME 2023 SPONSORS**
"TEE IT UP FOR HEMOPHILIA"


GOLD SPONSOR
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 **Bayer HealthCare**

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THANK YOU PAT MORGAN!

"In the end, it's not the years in your life that count, but the life in your years."

-Abraham Lincoln



On October 3rd, after 20 plus years working at CVS Health, Pat Morgan retired. Her passion and dedication to her patients exceeded all expectations. Her love for the community and her commitment to excellence was exactly what her clients needed. There was never a time someone couldn't get a hold of Pat to talk about struggles, announcements of joy, or just to have a friend. She truly cares for each of you and while she is now retired from work her love for all of you will never end! I personally want to thank Pat for everything she has taught me and blessed me with in my life! I'm proud to have been her manager! Enjoy your retirement Pat!

Love you!

Robb



Ms. Pat,

It has truly been an honor having you as part of the HBDA family for all of these years. Your heartfelt contributions to the bleeding disorders community have touched countless lives, and your handprint will remain on the hearts of those you have touched for decades to come! Your love and commitment to the families and the children in this community became a beacon of hope for many. Thank you for what you have meant to our community and to HBDA. We pray your retirement is everything you hoped it would be and more!

Your HBDA Family!



THIS GAL'S RETIRED





To say it was rejuvenating is an understatement. From the welcome goodies in our room to the specialty coffees we were treated to, we couldn't have asked for anything more. We were spoiled and pampered. Shared many stories with each other. Made many new friends and strengthened bonds with others. I am looking forward to attending more of these in the future and if you have the opportunity please make sure you don't miss the next one. - Maralee Clarke

Our Inaugural Women's Retreat was a resounding success! It was very important for us to introduce not only a new event, but one that has been requested for many years. We wanted to make sure when we added this event, that we could truly do it justice for what we wanted to provide the ladies in our community. We feel that we accomplished that and so much more!

From the moment they entered, you could see them take a deep breath, their shoulders relax, and peace wash over them. We truly wanted to make a lasting impression on their hearts that they could carry home with them at the close of this special weekend.

Beginning with the opening session on Friday night to lunch on Sunday; food, coffee, and tears were freely flowing! Each special lady was welcomed with a "Women's Retreat" shirt, a box filled with self-care items to pamper herself, and a personalized journal to document feelings, thoughts, and goals that were realized throughout the weekend. Inspirational quotes throughout the venue reminded us of our beauty, power, and worth.

We sipped mimosas while painting a picture with instruction from our sweet new friend Annie Bartol, a local artist who was beyond excited to play a part in such an important weekend for our ladies. We had deep discussions during sessions on Emotional Wellness, Women Who Bleed, Harnessing the Power of Joy, and Resilience and Change presented by our sponsors. We were gifted by volunteer boaters, with a sunset cruise on Lake Martin, and even attended a yoga session Sunday morning.

We are honored to have been able to make this dream a reality in 2023 and look forward to expanding this event in 2024 to house many more women in our community. As women, we tend to overlook ourselves and our needs because we are always caring for our loved ones. This is a time and place where we can let it all go and remember to look in the mirror every now and then and remember who we are outside the roles of wife, mother, caregiver, etc. and to remember...

You Are Beautiful. You Are Worthy. Breathe in the calm!

The date for our next Women's Retreat will be **February 23 - 25, 2024**. Keep an eye out after the first of the year to receive all of the details for this next event!

The HBDA Women's Retreat was a wonderful experience. I thoroughly enjoyed getting to know the women that are part of this unique community. I learned so much from the time we spent sharing our stories with one another. We were truly spoiled by Vicki and Amanda and the team they recruited for the event. The food was delicious, the coffee bar was phenomenal, the sunset cruise on Lake Martin was amazing and the paint party was so fun. The sessions provided by Industry members were so informative and motivating. Most importantly, we had time to connect with fellow patients and caregivers. We had time to reflect on where we have been and where we are headed, both individually and as a community. This event is one I am looking forward to attending again in the future. It is a much needed opportunity to relax, reflect and network. Thank you Vicki and Amanda!

Mary Beth Clarke



CHILDREN'S HARBOR ON LAKE MARTIN

Mary Hunter



ANDREW "ANDY" LOUIS HALL

OCTOBER 27, 1965 ~ NOVEMBER 11, 2023 (AGE 58)



Andrew "Andy" Hall Obituary

On Saturday, Nov. 11, 2023, Andrew Louis Hall triumphed over this life and gained his ultimate reward. He is survived by his wife, Elizabeth "Libby" Hall. Two sons, William Henry Hall (Jessica) and Christian Blaine Hall (Rena). The daughter of his heart, Alanna Leigh Blount (Tamma) and two grandchildren, Rowan William Hall and Ridge Layne Hall. His mother, Jamie Hall, two sisters, Charleen Tomberlin (Bub) and Rosalind Hall (Al Atchison). Numerous nieces, nephews and extended family.

He was predeceased by his father, Howard Henry Hall and his brother, Stanley Howard Hall.

Andy spent his life defying the odds and soaking up every moment. His professional life was spent as an Automotive Technician and was renowned for his diagnostic expertise. For many years, he was passionate about all motor sports. From building street rods in his backyard to working on the latest makes and models, he was doing what he loved.

After retirement, his passion shifted to empowering youth. Whether he was leading the RA's at East Pointe Baptist Church or developing youth leaders with Hemophilia and Bleeding Disorders of Alabama, he thrived on being able to exemplify determination and strength while showing tenderness and care. He led by example. He considered his greatest accomplishment outside of his family to be granted the opportunity to watch the young people he mentored begin mentoring the next generation.

Funeral services will be held Thursday, November 16, 2023 at 2:00 p.m. at the chape of Norris Funeral Home with Reverend Jonathan Maddox officiating. Burial will follow at Magnolia Methodist Cemetery in Old Brady.

The family will accept flowers but requests that memorial contributions be made to: Hemophilia and Bleeding Disorders of Alabama, P O Box 241090 Eclectic, AL 36024, 334-577-0125. Checks can be mailed or donations will be accepted by phone if you wish to use a credit card. Please mention that the donation is in honor of Andy Hall.

Pallbearers will be Howard Byrd, Matt Dickman, David Hill, Mark Osborne, Gary Robinson and Curtiss Sickafoose. Honorary Pallbearers will be Jimmy Franklin, Bub Tomberlin, Al Atchison and the Bay Minette Fire Department.



ANDREW "ANDY" LOUIS HALL

OCTOBER 27, 1965 ~ NOVEMBER 11, 2023 (AGE 58)



Andy was a fixture in the hemophilia community and a role model for so many young boys growing up in Alabama. He dedicated his time and shared his experiences openly to mentor the next generation at HBDA and Camp Clot Not. His passion was always in the Leader in Training (LIT) program and his impact through that program lives on as his legacy today. Andy volunteered tirelessly at almost every HBDA event for many years. He strived to prove to the younger generation that Hemophilia does not have to limit or define you.

Andy's legacy and memory will live on for years to come at HBDA and the hemophilia community in Alabama. Rest in peace our dear friend. You will never be forgotten. We love you!



CSL BEHRING'S JUNIOR NATIONAL CHAMPIONSHIP 2023!

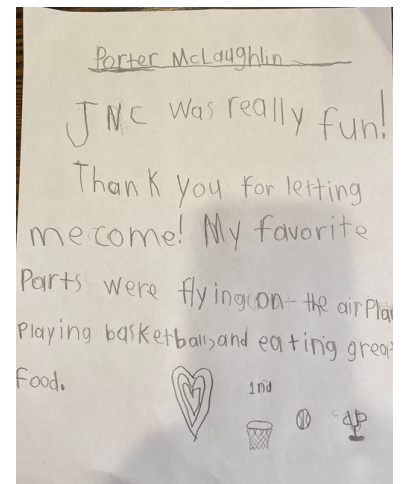
Adam Bradshaw reflects on the experience with CSL Behring's Junior National Championship 2023:

In a life full of first experiences, our weekend in Las Vegas was packed full. From logistics, to travel, to arriving in an unfamiliar destination that looks like a whole different world to an 8 year old boy, these "firsts" will always be with him. Luke can often be reserved, but the gracious group of volunteers quickly helped him flourish. Luke doesn't often reveal his excitement, but he couldn't hide his favorite part. When he got to participate in a game with the "big kids", he was engaged, determined, and thrilled! This was a first for me. I got to see firsthand, a glimpse of the positive impact this community and their generosity has on my cautious and reserved son. These "firsts" will shape and mold the person he becomes and how he navigates his life. We're all so grateful for those who ensure these experiences are positive.



Jared McLaughlin reflects on the experience with CSL Behring's Junior National Championship 2023:

JNC was such a great experience! It helped build Porter's confidence and let him experience new things that he had not tried before. It was something we will never forget. The JNC team expanded the kids' horizons with what they offered throughout the weekend. Porter loved getting to know other kids with hemophilia and learning that he can still be active, have fun and dream big! Porter said his favorite parts were flying on the airplane, playing basketball and eating great food. We are so grateful to HBDA and CSL Behring for giving us this opportunity.



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On behalf of the Staff and Board of HBDAl, we hope you have a very Merry Christmas and a Happy New Year! We have enjoyed serving each and every one of our members, old and new, and look forward to a fresh and bright new year with each of you! We pray for peace, warmth, and happiness for you this holiday season!



2024 EVENT DATES AND LOCATIONS

<u>EVENT</u>	<u>DATE</u>	<u>LOCATION</u>
Women’s Retreat	February 23 - 25, 2024	Children’s Harbor
Annual Meeting	April 2024 - TBD	Location TBD
Camp Clot Not	June 15 - 20, 2024	Children’s Harbor
Camp Harvest	October 18 - 20, 2024	Children’s Harbor
Golf Tournament	November 2024 - TBD	Robert Trent Jones Prattville
Year End Luncheon	December 14, 2024	Children’s Harbor



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BIRTHDAY BLESSINGS

<u>November</u>	<u>December</u>	<u>January</u>
Clayton Findley Cameron Jones Casey Sanders Laura Pitman Chelynn Pargo Jessica Blankenship Robin Blair Brayden Botts Quintez Renfroe Larry Doggette Myra Cooper Patsy Lewis Grace Chung Ciara Pargo Stephen McClellan Alexandra Hall Fantine Martin Michael King Rusty Chapman	Joseph Clarke Mary Cathrine Noa Tricia Watts Debby Dinkins Guilaya Goldsby Camdyn Pressley Kimberly Wood Daniel Botts Cheyenne Warren Derek Blankenship Nichole Goldsby Dawson Findley Joseph King Ben King Amanda Jennings Michael McElhaney Leslie Bailey Gavin Chapman	Madilynn Clarke Nathan Sanders Mary Beth Clarke David Hall Lois Thomas Robert Masline Jayla Johnson Amare Banks Takiya Wells Eyleighn Goldsby Jamie Rivera Elizabeth Chapman Bentley Golden Erin Hassan Donna Bate Bryan Utterback Carolann Sorrells Josh Blankenship Jeremy Jones