

HBDA QUARTERLY NEWSLETTER

Summer Edition 2023

Van Rushton, Chairman

Volume 58

Vicki Jackson, Executive Director

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Staff

Executive Director

Vicki Jackson

Consumer Relations Manager

Amanda Jennings

Board Members

Van Rushton - Chairman

Leslie Bailey - Treasurer

Tyler Blair - Secretary

Jared McLaughlin - Board Member

Rick Dinkins - Brig. Gen. USAF (Ret.)

Brian Ward - Past President

Chris Blair - Past President

Words from the Board

Greetings from **HOT and HUMID** Arkansas! And, I know it's just as HOT AND HUMID in Alabama!

It's been a few months since you've heard from me since I've stepped aside from the Chairman's role. That said, I did tell Vicki and Amanda that I'd stay in touch and I do...just to stay abreast of HBDA happenings throughout the year.

School is just around the corner and, once again, we offered gift cards for school supplies. As you recall, the funds for this comes directly from our CLOT line account and it receives its funding from the registration fees paid for our events.

Camp appeared to be a roaring success with the 35+ campers including 4 first timers! It seems that we are finally pulling away from the COVID aftermath and that is good news for the future. I was happy to see the Leadership in Training (LIT) program continue to do well and I'm sure the 4 individuals who participated this summer learned a lot.

The rest of the year's programs are on the books with a new addition this August...a Women's Retreat from August 25-27. This is a first for us and it's our attempt to bring learning opportunities and fellowship to you that is a bit outside the norm. If this is successful and brings value to you, let Vicki know and we'll take it to the next level in 2024.

Camp Harvest is set for October 20-22 and the Golf Tournament is November 10th in Prattville. So please stay tuned for more information on these events.

As for the organization's day to day operations, Vicki and Amanda continue to keep the ship moving forward at a steady pace...our finances remain good and we continue to be thankful for our industry partners for their role in HBDA.

We, its 98 degrees here with a "feel like of 110," so I'm out of here...have a great rest of the summer.

Rick Dinkins
Past Chairman



HBDA CAMP CLOT NOT 2023



The Year of the Harbor Cove Pirates



Camp Clot Not started off with a bang (and a few pesky pirates too)! We were so thankful that the weather didn't hinder our fun and we had the best time with our campers and volunteers!

From Inflatable Bull Riding in the lake and Chicken Fights in the Pool, there was an abundance of fun things to do outside. When the rain kept us in, we enjoyed Minute to Win It competitions and an infusion clinic set up by our head nurse, the one and only Juli Mason! ! We had Jack Sparrow teach us some self defense in "Sparrow's Sparring School", and our counselors put on a dance show for us during the final night ceremony.



HBDA CAMP CLOT NOT 2023



Picture 1: Friends battle each other in the pool to see who will win the Chicken fight!

Pictures 2 - 5: Getting ready for a fun filled day on beautiful Lake Martin!

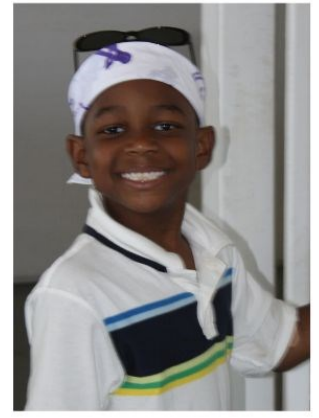
Picture 6: Lord Ramsey King of the Pirates in a heated discussion with the one and only Jack Sparrow!



VOLUNTEERS ARE THE BEST!

When campers become volunteers...

We have watched each of these boys grow up from young campers attending Camp Clot Not for the first time, to becoming one of the best groups of volunteers we could ask for! Thank you for continuing to come back and pour into the next generation! You are a blessing and we thank you!



thank
you!





BIG STICK AWARDS



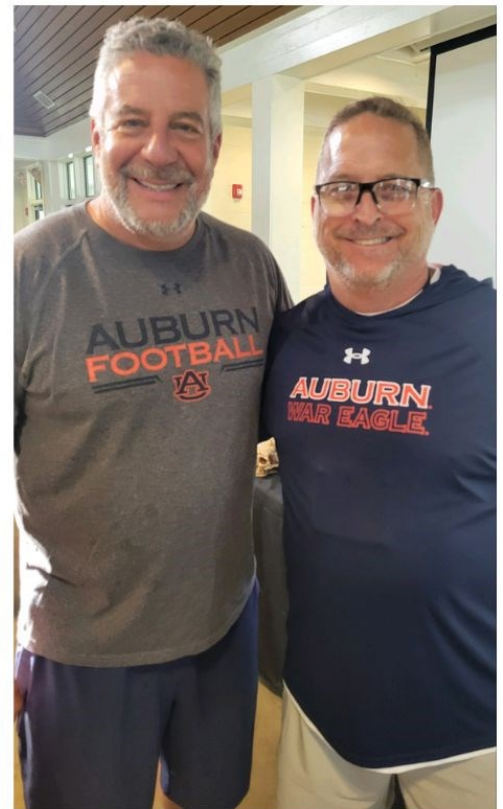
2023 Big Stick Awards:
Harmony Andrew
Levi William

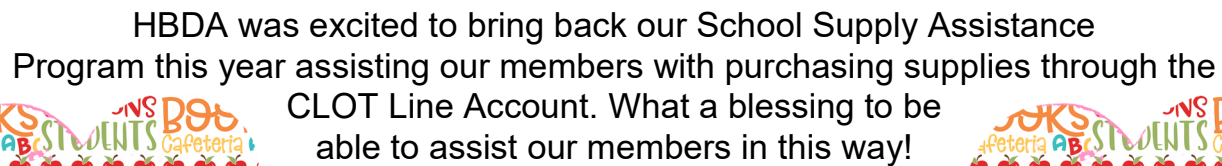


2023
Branch
Awards:
Tucker
Porter
Makenzie

THANK YOU BRUCE PEARL!

Thanks to Dennis Jones, we even had Auburn Head Basketball Coach, Bruce Pearl come visit and talk to our kids about not letting obstacles like a bleeding disorder get in the way of where they want to go in life. You may have to change the way it looks a little bit, but goals and dreams are still reachable, no matter what.





- 1 pound of breakfast sausage, browned and crumbled
- 1 egg, lightly beaten
- 1½ cups Bisquick
- 1½ cups shredded sharp cheddar cheese

1. Preheat your oven to 350 degrees.
2. Grease one mini-muffin pan. Set aside
3. In a large mixing bowl, add all four ingredients inside. Mix together until everything is combined.
4. Take a spoon and scoop out enough of the mix (patting lightly with your fingers to make sure it's not too crumbly) and begin filling your muffin tin. Repeat.
5. Place your filled mini muffin tin in the oven and bake about 10 minutes.
6. Remove and allow to cool five minutes before popping out each muffin and either enjoying or cooling completely before freezing.
7. If you're freezing your mini muffins, then whenever you're ready to enjoy, pop them out of the freezer and microwave about 30 seconds.

IN LOVING MEMORY OF MARCUS CHUNG



It is with a heavy heart we announce that on July 5th, our dear community member and friend, Marcus Chung, passed away while on vacation in the Bahamas with his family. Our hearts and prayers go out to his sweet wife, Joan and their daughters, Chanju and Grace as they face the days ahead without him. He was never seen without a smile, and was the kindest person you would ever meet. He and his family first joined our chapter in 2015, and rarely missed an event.

We had the honor of attending his funeral on July 29th in Montgomery, and it was a beautiful testament to the kind of husband and father he was. He was an adventurer, and he loved to travel and see the world. He loved Jesus! Learning the bible in English with a dear friend was his passion. He was a wonderful father and spent much of his time teaching his wife and girls to love the outdoors as much as he did. His precious wife was his soulmate, and he was her beloved. He introduced her to Jesus, and together, they built a beautiful marriage with God in the center of their life.

He will truly be missed as a part of our community and as a friend to HBDA. Please join us in praying for his family in the coming months as they face life without him. We plan to stay in close contact with Joan and the girls to ensure they always know how much we care for them and that Marcus will never be forgotten. We hope they will join us for many future events and remain a close part of our community.



Destin, FL
November 2 - 4th

HOPE

Conference

Join HBDA friends and family at the annual HOPE Conference in Destin, FL on November 2nd. In partnership with Hope Charities, we have secured patient travel scholarships to include free admission and hotel costs to this unforgettable hemophilia educational conference for the whole family. Space is limited so be sure to register with the link below today!

2023 Conference Topics:

- Patient Choice is Paramount!
- Getting Help with Resources:
 - Understanding Medicaid
 - Understanding the Marketplace
 - Navigating Financial Assistance Programs
- Mental Health Sessions:
 - Caring for the Caregiver
 - Understanding the Caution Signs
 - Asking the Tough Questions
- Aging with Hemophilia:
 - Improving Long-term Outcomes
 - Understanding Medicare
 - Giving Back - Elevating Lived Experience

Exciting Conference Elements:

- Leading Expert Speakers
- Engaging Patient Panel Discussions
- HOPE Night - Awards Ceremony
- HOPE's Got Talent
- Exciting Kids Program
- Teen Track

Fun for the whole family!





Just a reminder that we have moved to our new location! We are excited that we will now be 5 minutes from Children's Harbor! With 4 of our events being hosted at Children's Harbor, the location could not be better!

Our new phone number and mailing address are below!

NEW Phone Number: 334-577-0125

NEW Mailing Address:
HBDA, Inc.
PO Box 241090
Eclectic, AL 36024

NEW Physical Address:
HBDA, Inc.
8426 Kowaliga Road
Eclectic, AL 36024

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.





Add our date to your calendar now so you don't miss this amazing event!

"Camp Harvest" Family Educational Weekend is one you don't want to miss!

**Mark your calendar for October 20 -22, 2023 at
Children's Harbor on Lake Martin.**

It's a time to catch up on what is happening and what WILL be 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.

It is an opportunity to be part of some of HBDA's favorite Fall traditions: Family Portraits, hot chocolate and cider around a roaring campfire, arts and crafts, our annual Family pumpkin carving contest for bragging rights and so much more!



2023 EVENT DATES AND LOCATIONS

<u>Event</u>	<u>Date</u>	<u>Location</u>
Women's Retreat	August 25 - 27, 2023	Children's Harbor
Camp Harvest	October 20 - 22, 2023	Children's Harbor
Golf Tournament	November 10, 2023	Robert Trent Jones Prattville
Year End Luncheon	December 9, 2023	Children's Harbor

We are still hosting Educational Dinners with presentations throughout the year in 2023.
Please keep an eye on your email for more details on all of our upcoming events.



CHILDREN'S HARBOR FAMILY CENTER

"THE HARBOR"

Anchored in Hope. Strength in the Storm.



Children's Harbor provides respite and resources to families with children who have experienced a life-altering medical diagnosis. The families we serve seek a safe refuge when faced with unexpected life circumstances. The Family Center at the Children's Hospital, "The Harbor," meets the families where they are by providing care services to inpatient and outpatient children, caregivers and siblings.

The Harbor is designed to help strengthen families with children facing a life-altering medical diagnosis through refuge, respite and resources anchored in hope. Children can connect with others with similar diagnoses for a sense of community and camaraderie, while parents can escape to The Harbor and leave the noise and activity of the hospital rooms behind to find solace.

SERVICES PROVIDED AT NO CHARGE

FOR THE FAMILY



- Kitchen
- Lounge
- Nap Rooms
- Salon
- Library

FOR THE KIDS



- Basketball Court
- Game Room
- Toddler Play Area
- Arts & Crafts
- Story Time

FOR THE PARENTS



- Business Center
- Fitness Center
- Laundry Unit
- Shower

WHERE WE ARE

Second floor of Children's of
Alabama hospital

1600 6th Avenue South, Suite 200

Open Monday through Friday
8:30 a.m. to 5:00 p.m.

Closed everyday from
noon to 1:00 p.m. for lunch

LEARN MORE

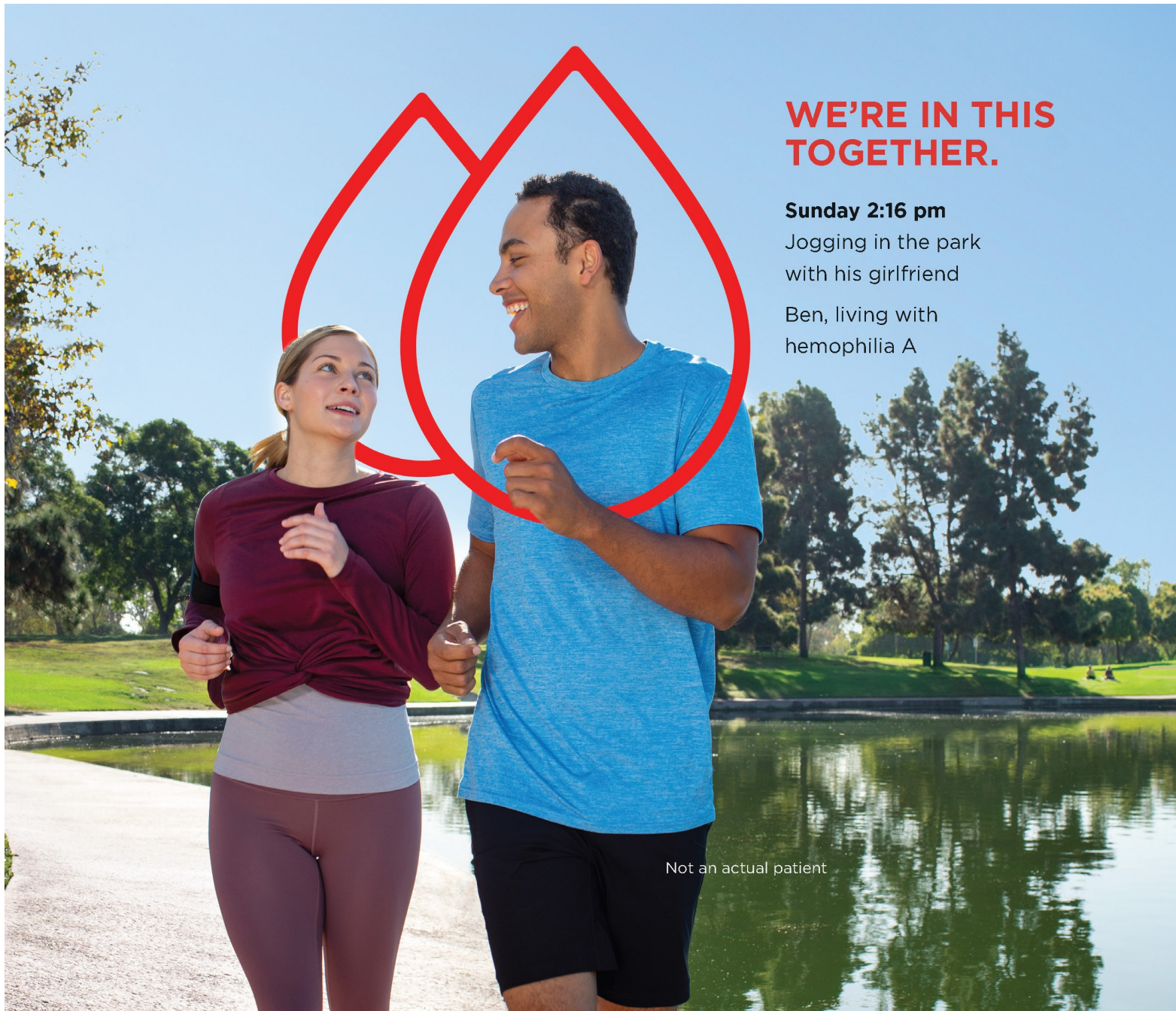


COME VISIT FOR A TOUR

205-638-6123
www.childrensharbor.com



@childrensharbor



WE'RE IN THIS TOGETHER.

Sunday 2:16 pm

Jogging in the park
with his girlfriend

Ben, living with
hemophilia A

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.

bleedingdisorders.com



FACTOR **UP** with ALTUVIII[®]

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

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



HIGHER FACTOR LEVELS FOR LONGER

Above 40% for most of the week (near-normal to normal range).^{*†}

48

HOUR HALF-LIFE IN ADULTS

In a Phase 3 study,[†] ALTUVIII[®] offered adults the longest half-life of any Factor VIII therapy.

0.7

BLEEDS PER YEAR[‡]

Mean annual bleed rate observed in 128 people previously treated with prophylaxis therapy.[‡]

In people taking ALTUVIII[®] in the XTEND-1 study, 21% of people had headache, 16% had joint pain, and 6% had back pain

^{*}Average trough levels were 18% for adults 18 years and older, 9% for adolescents aged 12 years to under 18 years, 10% for children aged 6 years to under 12 years, and 7% for children aged 1 year to under 6 years.

[†]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 ALTUVIII[®] prophylaxis from prior prophylaxis therapy. Efficacy of prophylaxis was evaluated in 128 of these patients.

[‡]Data based on treated bleeds.

CONNECT WITH YOUR CoRe TODAY

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



Shawana Darnell
shawana.darnell@sanofi.com
404-796-0084
Serving AL and GA

INDICATION

ALTUVIII[®] [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 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, joint pain, and back 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](#).

sanofi

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MAT-US-2301368-v1.0-03/2023

HBDA INFORMATION

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PO Box 241090, Eclectic, AL 36024

Phone: (334) 577-0125

Fax: (334) 577-0127

Website: www.hbda.us

Facebook: www.facebook.com/hbda4u



BIRTHDAY BLESSINGS

August

Amy Blair
Jacob Weaver
Kaitlyn Weaver
Rachel Cooper-Leal
Dylan Ward
Rocisa Banks
Rick Dinkins
Kristopher Lewis
Barbara Sokol
Cannan Dickinson
Mackenzie Jones
Bella Dickinson
Jeannie McLaughlin
Tim Mason
Ajie Attawia
Joan Chung
Christian Blyden
Bethalyn Bailey
Makenzie Clarke
Jeannie Dickerson
Robert Bate
Ericka Caro
VaShette Davis
Garrett May
Chris Blair
Odin Walls

September

Ayden Hoggle
Jared McLaughlin
Lyric Donahoo
Jessica Ward
Zachary Pressley
Mark Osborne
Jasmine Hoggle
Larry Grammer
Brayden Cooper
Nyannah Davis
Mary Hunter
John Lawrence Masline
Janet Rivera
Jaymee Vowell
Cooper Guadalupe
Vicki Jackson
Kristen Blair
Chesca Barnett
Abi Dickinson
Lee Hall
Jace McLaughlin
Raley Hoggle
Jennifer Mason

October

Scott Weaver
Pat White
Caelum Walls
Nicole Lloyd
Isaiah Montgomery
Levi McLaughlin
Luke Bradshaw
Chance Abrams
Blake Morgan
Christian Pressley
Sophie Johnson
Justin Clarke
Brian May
Harper Walls
Jonathan Hall
Fallon Howard
Adam Bradshaw
Cation Rivera
Royal Smith, Jr.
Andy Hall
Tisha Ward