

HBDA QUARTERLY NEWSLETTER

Spring Edition 2022

Rick Dinkins, Chairman

Volume 53

Vicki Jackson, Executive Director

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Hemophilia and Bleeding
Disorders of Alabama, Inc.

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Words from the Chair

Spring has Sprung!

Old Man Winter has come and gone and I, for one, am happy for the change! Winter 2022 seemed a bit damper and colder than normal; but, the warmer days and cool nights of Spring are most welcomed.

Since the last time I wrote, the 2022 Annual meeting has come and gone and what a wildly successful event it was. Unfortunately, I was out of town that weekend and missed it and seeing you. Rave reviews continue to pour in and our "after the event" review continues as we look for ways to make it even better next year. I think it's safe to say that Auburn/Opelika will be our Annual Meeting destination for the next few years!

As Spring changes to Summer, Camp Clot Not is just around the corner. If you attended the annual meeting, you got a sneak peek at the theme for Camp Clot Not 2022...I won't spill the beans for those who could not attend; but, let me say, YOU DON'T WANT TO MISS CAMP CLOT NOT '22! Check out the HBDA homepage for the latest details.

One change that will be occurring this summer is very personal for me. Debby and I have relocated to Central Arkansas to be closer to our son, grandkids, and great grandkids. After 38+ years in the USAF and 19 moves, Alabama was our "final home." But, things change over time, and we decided that a move was in our best interest and that of our family. It has been physically and, more importantly, emotionally difficult; but the good Lord always has a plan and we're doing our best to follow His lead.

My plan is to continue to be the Board Chair for the duration of 2022 and will revisit board positions in 2023. That said, the organization will continue to do well, and I look forward to seeing many of you at future events...take care, be safe.

Rick Dinkins

HBDA ANNUAL MEETING 2022

The results are in...and the 2022 Annual Meeting has been voted BEST ONE EVER! The venue was incredible, the hotel staff was very accommodating, the food was delicious, and the presentations were engaging and informative. Having the opportunity to see, hug, and fellowship with our members and industry partners was a welcomed part of our educational weekend!



We started the day off with wonderful food and engaging educational presentations. Some of the top experts in the field of bleeding disorders presented to our members and were sponsored by CSL Behring, Takeda, Bayer, Genentech, and Octapharma! Our friends at BioMarin presented an interactive game of Gene Therapy Jeopardy, which was educational and enlightening for our members. In the afternoon, we took a bit of a break for some Shark Tank competitions which engaged our members in a creative and challenging marketing experience. Saturday evening offered additional educational presentations with top keynote speakers as well as informative breakout sessions from other industry partners, such as Pfizer and Sanofi.

Our weekend concluded with not only educational sessions, but a great summer camp discussion as well. Some of our Leaders in Training (LITs) shared their experiences at camp and encouraged everyone to get involved by volunteering or sending their affected kids to camp so that they too can experience all that Camp Clot Not has to offer.

This was the best Annual Meeting to date! A huge thank you goes out to each and every member who attended and every sponsor who provided education, meals, and fellowship. The exhibits this year were second to none and shared important up to date information and resources.

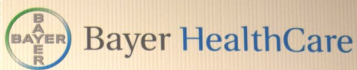


HBDA ANNUAL MEETING 2022

Lets Talk About Camp!



2022 Elite Presenting Sponsors



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HBDA ANNUAL MEETING 2022 - EXHIBIT BOOTHS





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SANOFI GENZYME 

CAMP CLOT NOT GOES GALACTIC!



Get out your capes and dust off your shield.....
we are heading out into the Multiverse for this years
Camp Clot Not! Put the date on your calendar! I can
guarantee you will have a MARVEL-ous time!

Applications have been sent out. If you are interested in
attending, please contact HBDA!



WHEN: JUNE 18 - 23, 2022

WHERE: CHILDREN'S HARBOR ON LAKE MARTIN

APPLICATION DEADLINE: MAY 13, 2022



Campers beware.....the Cosmic Super Villian is coming to camp....and it is our mission to defeat him once and for all! With Dr. Strange in the house....anything is possible!



HFA JOB ASSISTANCE

Job Readiness Grants are now available to bleeding disorders community members ages 18 to 64 to help pay for technical training and certification. Whether they want to secure a better paying position, find a new job that's easier on joints or transition to the career they've dreamed of, gaining a technical skill or certification may set them apart from other applicants.

Physically and financially sustainable work is critical for adults with bleeding disorders. This grant application sets up applicants for success through completion of the Career Planning module in **HFA Learning Central**, a resume, reference letter and a brief essay.

Click the link below:

[Hemophilia Federation of America Offers \\$1000 Grants to Learn New Skills and Help Land Your Dream Job! - Hemophilia Federation of America](#)

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therapy trial
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therapy in hem B
underway

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WHAT OLDER PEOPLE WITH BLEEDING DISORDERS NEED TO KNOW ABOUT OSTEOPOROSIS

Author: Kathryn Anne Stewart
Posted: May 2, 2022

Osteoporosis, a disease of low bone mass and strength, is a common concern in aging individuals. People with hemophilia have a higher risk of the disease, compared with other groups. (Other bleeding disorders, while less studied, also seem to affect bone health.)

The reason is not entirely understood. Likely, there are multiple factors at play at different times, according to Christine L. Kempton, MD, MSc, professor in the Department of Hematology and Medical Oncology at Emory University School of Medicine and director of the [Hemophilia of Georgia Center for Bleeding & Clotting Disorders](#) of Emory.

“In male mice, factor VIII deficiency alone leads to abnormal bone formation,” Kempton explains. “At later ages, joint bleeding contributes to increased bone resorption, or breakdown. Defects in bone metabolism have also been seen in hemophilia B mice.”

Possible Causes

In people with hemophilia, the risk factors strongly associated with osteoporosis include:

- Advanced joint disease
- HIV
- Low body mass index
- Tobacco use

As for how factor VIII or factor IX deficiency impacts bone, much of the existing research is conflicting. Studies are ongoing.

One factor commonly thought to cause osteoporosis is lack of physical activity. According to Kempton, many people assume that people with hemophilia develop osteoporosis because they aren't as physically active as others.

“One can't say that it doesn't play any role, but it's not as big a contributor as many think,” she says. “Being active is good, but [being inactive is] not why people get osteoporosis.”

How Osteoporosis Is Managed

Kempton's HTC performs routine screening in patients over age 50. Osteoporosis by itself doesn't cause pain or disability, but it can lead to dangerous fractures from relatively minor trauma or falls. That's why screening is key—to identify osteoporosis early and begin treatment that can lessen fracture risk.

If a bone mineral density test indicates a patient has osteoporosis, Kempton will coordinate treatment with an endocrinologist. Commonly, treatment includes medications that prevent bone breakdown or encourage bone formation. She also recommends assessments of vitamin D, calcium, testosterone and parathyroid hormone levels—and replacement with supplements if necessary.

Staying Active with Osteoporosis

Physical activity is good for everyone, and people with osteoporosis are no exception. Experts recommend 150 minutes of moderate physical activity per week. However, joint disease can make it difficult to find exercises that aren't painful.

To lessen the risk of falls (and bone fractures), Kempton suggests focusing on activities that improve balance, strength and flexibility.

Yes:

- Stretching
- Walking
- Swimming
- Dancing
- Stair climbing
- Weightlifting (free weights, weight machines or floor exercises using your body weight)
- Gardening
- Tai chi
- Standing on one leg

No:

- High-impact exercises (jumping, running, jogging)
- Activities that involve bending or twisting, which is how most fractures occur (situps, golf, tennis, bowling, some yoga and Pilates poses)

Learn More: Visit NHF's website to download the Playing It Safe: Bleeding Disorders, Sports and Exercise booklet: [hemophilia.org/community-resources/request-information/read-our-publications](#). For more information on osteoporosis, visit the Bone Health & Osteoporosis Foundation at [bonehealthandosteoporosis.org](#).

**** 2022 EVENTS ****

Date of Event:

June 18 - 23, 2022
October 21 - 23, 2022
November 11, 2022
December 10, 2022

Event:

Camp Clot Not
Camp Harvest
Golf Tournament
Year End Luncheon

Event Location:

Children's Harbor
Children's Harbor
RTJ Prattville
Location TBD

More information will be coming out soon!



**** UPCOMING **** **EDUCATIONAL DINNERS**

May 12	Sanofi	The Noble South	Mobile
June 2	Genentech	Bonefish Grill	Birmingham

Additional dates and locations coming soon! Please check our website for updates at www.hbda.us



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H-Fit

with Dolvett Quince

Regular exercise is important. But moods vary. No two days are exactly the same. So we asked celebrity trainer Dolvett Quince to create a series of exercise videos called H-Fit. Each video features a different **hemophilia-friendly workout**. And each workout is built around a different mood. How are you feeling today? H-Fit has got you covered.

Always talk to your health care provider before starting any new exercise routine.



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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 have been affected by COVID-19, or if you need assistance purchasing school supplies for your kids, please reach out to us.



HBDA INFORMATION

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Facebook: www.facebook.com/hbda4u



BIRTHDAY BLESSINGS

May

Cayden White
Maxwell McLaughlin
Samuel Wilson
Rexanne Johnson
Davie Wood
Bonnie Utterback
Tayla Cooper
Amy Croushorn
Libby Hall
Evan Ward
Jack Mason
Tytus Stracener

June

Jeremy Donahoo
Taylor Renfroe
Chandler Ward
Jhonathan Davis
Carla Vickery
Carver Bailey
Christian Hall
Aiven Miller
Hunter Abrams
Jackson Sanders
Alex Leonard
Harmony Pressley
Isabella Sandow
Cole Croushorn
Kim Speer
Anthony Zucco
Tavien Casey
Macey Kelley
Keshawndra Cooper
Haley Jones
Maddie Sanders
Keondre Cooper
Micaela Caro

July

Ron Dickerson
Natarra Waters
Edward Masline
Sarah Blyden
Connie Grammer
Pat Morgan
Christine Chung
Dana Abrams
Nelson Davis
Tera Bradshaw
Andrew Walls
Matthew Watts
Amy Barton
Ann Mitchell
Caitlin Zucco
Britnee Vasil
Mackenna Sorrells
Noah Guadalupe
Terrontheon Crayton