



Helping embrace life's learning opportunities.



HELLO Conference & Annual Meeting

June 21 – 22, 2024
Greenville, SC



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670 Verdae Blvd, Greenville, SC 29607



We appreciate you attending the 2024 HELLO Conference and Annual Meeting! We ask that you take a few moments to provide us your feedback! Take the survey by scanning the QR code with your phone or by visiting

<https://www.surveymonkey.com/r/2024HelloConference>.

Thank you!

Friday, June 21st

4:00 PM: Registration Opens (*Pre-Function Hallway*)

4:00 PM - 5:30PM: Exhibitor Hall Welcome (*Greenbriar Ballroom*)

5:30 PM: Premier Sponsor Welcomes & Chapter Opening (*Embassy Ballroom*)

6:00 PM: Connect and Celebrate: A Community Kickoff with GutMonkey

6:30PM: Buffet Dinner

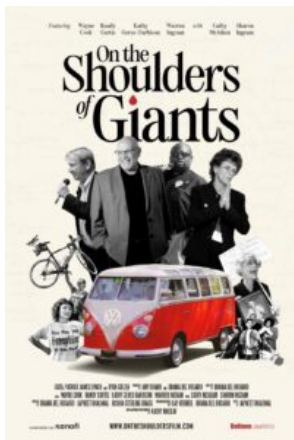
7:00 PM: Annual Chapter Awards & Scholarships

8:45 PM: Movie Viewing: On the Shoulders of Giants

Chapter Awards & Scholarships

- **Scholarship Awards**
 - **Alba Myers Lewis Academic Memorial Scholarship** - *Aiden Budde*
 - **John N Tiller Memorial Scholarship** - *Makayla Keith*
 - **BDASC Academic Scholarship** - *Regan Weber & Ava Newhart*
- **Recognizing Retiring Board Member & Welcome New Board Members** – Samantha Javorka, Shelley Crisp, Eric Townsend & Candi Mitchum
- **Recognition Board Member of the Year Awardee** – Sherlene Maloy
- **Legislative Advocate of the Year** -Representative Jason Elliot, District 22 (R), Greenville County & Representative Kevin Hardee, District 105 (R), Horry County
- **Coalition Advocate of the Year** – Whitney Galloway
- **Coalition Ambassador of the Year** – Michelle Krakowiak
- **Junior Advocacy Ambassadors of the Year** - Natalie Mitchum and Adonis Rabb
- **Appreciation and Partnership Award** – Lt. Governor Pamela Evette
- **Making a Difference Award** – Malerie Hartsel, Program Manager & Interim Director, DHEC Hemophilia Assistance Program
- **Volunteer of the Year “The Fisher Award”** – Patricia Tucker
- **Aaron Eugene Gossett Pillar of Strength Award, “On the Shoulder of Giants”** – Warren Ingram

On the Shoulders Of Giants



For the first time in history, a generation of people with hemophilia are living past 50, This heartwarming road trip around the country reunites the survivors from past generations and shares their journey.

*Supported by a contribution from Sanofi
Produced by Believe Limited in partnership with
Entertainment 2 Affect Change (E2AC)
Directed by Drama Del Rasario*

Believe LIMITED
Content. Campaigns. Advocacy. Education. Empowerment.

Saturday, June 22nd

Teen Programming

Teen Programming is provided by GutMonkey - Leading Edge Program. This program is available for teens ages 12-18 years. These sessions are facilitated by GutMonkey staff.

9:00 AM- 12:00 PM: Charleston/Columbia Ballroom & Outside Terrace

12:00 PM - 1:25 PM: Lunch with parents

1:30 PM- 4:00 PM: Charleston/Columbia Ballroom & Outside Terrace



Join GutMonkey for the Leading Edge teen program as we tackle topics like building communities, teamwork, getting clued in on bleeding disorders (trust us, it's more exciting than it sounds!), and shared decision making. It's not all serious stuff! We'll have you laughing, up on your feet, and maybe even making some new friends. We'll bring the surprises and the fun, you just bring yourself. This session is part of the Leading Edge program and is made possible through the exclusive support of Pfizer.



Facilitator: Bloom Davis

Bloom Davis is dedicated to fostering a compassionate world through collective action and meaningful connections. With a liberation-centered approach, Bloom harnesses the power of play, community, and nature to inspire change. An avid long-distance backpacker and wilderness guide, Bloom has hiked the Pacific Crest and John Muir Trails, and thrives on helping others build skills and align their practices with integrity. As an educator and facilitator, Bloom knows how listening and understanding help build resilient communities. Bloom is also a writer who explores themes of transformation, accessibility, and adventure.

Kids Camp Childcare & Educational Programming

Kids Camp/Childcare is provided by Corporate Kids Events, Inc. This program is available for children ages 1-11 years.

8:30 AM: Drop off Children at Kids Camp in the **Palmetto Club**

10:00 AM - 11:00 AM: Critter Keepers Show

4:00PM: Promptly - Pick up Children at Kids Camp in the Palmetto Club

This year's theme is



Corporate Kids Events provides the ultimate childcare and entertainment for events worldwide. Our time tested, age appropriate activities are always fun, enriching and we always keep safety as a priority. Combining all of this with our secure sign-in and out procedures, digital photo security system and ID tags, parents can enjoy their day knowing their little ones are safe, having fun and under the care of experienced, nurturing childcare professionals.



Saturday, June 22nd

Morning General Sessions

9:00 AM–10:20 AM: Navigating Bleeding Disorders within Transformative Times - **Doral Ballroom** *Moderated by Sue Martin with Panel Guests & Keynote Speaker, Philip Gattone, President, and CEO of The National Bleeding Disorders Foundation*

Join us for a morning plenary as we look forward to hearing from Phillip and our distinguished panel as we move forward together with our mission and visions for an era of transformational times for the bleeding disorders community. Discover and join in a robust conversation on the need for collaboration of our national organizations, national chapters, our industry partners, state agencies, insurance companies, researchers, and the bleeding disorders community with our collaborative goals on advancing health equity and access to treatment care for all individuals diagnosed with bleeding disorders.

Panel Guests

Philip Gattone, President and CEO, NBDF

Philip will share his visions and plans for the future of NBDF and the direction set by the board of directors for the national bleeding disorders community. He will share where NBDF is heading and why, and how the chapter network and their members will be important for their success. He will speak to the need for a mutual partnership between the national organizations and Chapters to advance treatments and access to care, advance important advocacy and research initiatives, and share any concerns he sees to achieving these goals within these transformational times within our national community.

Samantha Carlson, MSW, LMSW, Director of Research, NBDF

Samantha will share what is being done to advance research and how community members and the Chapter network can be involved. She will share the need for the voice of the community to be active in research and how data will drive outcomes. She will share the goals and progress of the National Research Blueprint and how patient advocacy groups will have a role in driving scientific innovation. She will share the need for community voices in research and how we all have a role to play.

Bill Robie, Director, State Government Relations, NBDF

Bill will share the advocacy work of the national Chapters; a national outlook, what successes and challenges chapters have had, how they achieved their goals or overcame the challenges, and will briefly describe the major threats in access we are still facing (CAAPs, Maximizers, Alternative Funding) as a community and will express how important our voices and stories are to drive policy change.

Malerie Hartsell, MPH, CHES, Program Manager, Blood Disorders and Contracts, S.C. Department of Health & Environmental Control, Division of CYSHCN, Bureau of Maternal and Child Health

Malerie will share information and updates on the current SC Hemophilia Assistance Program and the new inclusion to include Co-pay assistance. She will share how studies have shown patient assistance programs contribute to better healthcare outcomes by reducing out-of-pocket costs and help to keep patient's adherent on their treatment regimes.

Robin Jones, MSN, MHA, RN, CPN, CPHON – Nurse Navigator SCHTC & Leslie Gilbert, MD MSCI Upstate HTC Director

Robin and Leslie will provide any updates and information on our HTC access to treatment care for adults and children, gene therapy, and answer any audience questions related to treatment care.

————— **10:15 AM - 11:00 AM Snack Break and Exhibits - Greenbriar Ballroom** —————

Saturday, June 22nd

Morning General Sessions

11:00 AM - 12:00 PM: Panel Voices Plenary: A conversation of Health Care Access Stories: Challenges and Successes - **Doral Ballroom** Moderated by Sue Martin and Jim Romano, BDASC Legislative Coordinator

Engage in our live and robust conversations with BDASC members and Advocacy Coalition advocates who will lead sharing experiences of living with bleeding disorders today, and how they are navigating these challenging access to care transitions, barriers, and exciting times. This session will welcome audience participation as we learn together what we can do to shape the future of bleeding disorders treatment care access and how you can bring about change in South Carolina. Learn what we are planning next for our 2024-2025 advocacy legislative agenda.

BDASC Member Panelists Representing the Following:

- Access to care and treatment barriers: Accumulators and more - Whitney and Cole Galloway
- von Willebrand Disease: The lack of a proper diagnosis and treatment education - Candi Mitchum
- Advocating for women carriers and girls to have treatment protocols with access to quality treatment, and the concerns on testing and factor levels - Kristen Shelton
- Having a positive outlook throughout the journey of living with hemophilia - Eric Townsend
- How far we have traveled in the community, what we have learned & the needs for our future; an advocates perspective - BDASC Award Winning - Warren Ingram

12:00 PM – 1:30PM: Lunch and Exhibits - **Hotel Atrium**

12:00 PM - Hotel Checkout

Afternoon Sessions **1:30 PM - 2:30PM:** Breakout Sessions

Health and Fitness with Improved Mobility and Stability, including Kinesiology Taping - Doral Ballroom

Presented by Dr. Michael Zolotnitsky - Sponsored by Octapharma

Learn safe home exercises that will be presented to target the upper and lower body to prevent bleeds, improve overall mobility, and stability. This will be an interactive presentation where participants can join in exercise, learn the usefulness of therabands, and the value of Kinesiology taping. You will learn how taping will demonstrate how to reduce swelling, improve range of motion, and improve overall stability to reduce pain.

Share Decision Making - Homestead Ballroom

Presented by Rachel Cooper-Leal - Sponsored by Pfizer

In this session, we will take a look at what shared decision making is and how to integrate it into medical appointments. This interactive overview covers how to participate in the care team, discuss therapy changes, and find quality sources of information.

Mental Health: A Deeper Dive - Port Royal Ballroom

Presented by Cathy Tiggs, MSSA, LISW Sponsored by The National Bleeding Disorders Foundation

Millions of people in the U.S. are affected by mental health issues. While we have started to have more open conversations about our mental health, it is time to dig deeper and move beyond the basics. This workshop will investigate mental health issues seen in the blood and bleeding disorders community and provide innovative skills and resources to you.

2:30 PM - 3:00 PM: Exhibits Break - Greenbriar Ballroom

Saturday, June 22nd

3:00 PM - 4:00 PM: *Breakout Sessions: Support Groups*

Moving Forward from the Women and Girls with the Potential to Menstruate Summit - Doral Ballroom

Presented by Natalia Winberry, MNLM - Sponsored by National Bleeding Disorders Foundation

The Women, Girls, and People who have or had the Potential to Menstruate (WGPPM) Summit took place in May 2023 bringing together people with bleeding disorders, health care professionals, chapter representatives, and national organizations to map out a coordinated plan for progress. This interactive workshop will highlight the outcomes of the summit and invite everyone to become part of the movement. You will walk away feeling empowered with the advocacy tools and knowledge to create change for this community.

Being Prepared for Hemophilia & Bleeding Disorders Emergency Rooms (provided in English or Spanish) - Port Royal Ballroom

Presented by Barbara Castano Arrebola- Sponsored by Bayer

The session will prepare patients and caregivers living with hemophilia and bleeding disorders with the communication and advocacy skills needed in emergency care and travel situations. This session will be provided in Spanish.

von Willebrand Disease: A to Z- Homestead Ballroom

Presented by Morgan Cook - Sponsored by Takeda

Join the VWD community for an educational session on living with VWD. You will get to know the inheritance patterns and types of VWD, and its various symptoms, including those that are specific to women. Treatment approaches available to people living with VWD will be also be discussed. This session will be conversational and informative.

“It’s Bro Time” The Blood Brotherhood - Bay Hill Ballroom

Facilitated by James Romano and national Blood Brothers members

Discover and learn about the comfort of knowing there is a brotherhood of support for men affected by bleeding disorders, young and old (seasoned), in a group wrap session with blood brothers with a long history of advocacy and support within the community.

4:00 PM - 5:00 PM: **Discussing Self-Infusion and Learning How - Homestead Ballroom**

Presented by Robin Jones, Midstate HTC Nurse Coordinator

Infusion Session

- Included: “Tips & Tricks” and Trouble Shooting
- What are the ways to increase visibility of veins? Are there exercises that help – ones that young kids or adults could safely do? Do vein finders really work (there is an app now)?
- Take-away documents filled with tips and tricks.
- Port information, and injections. Pros and cons of port vs. peripheral. Understanding the challenges of each. Opting for ports in adulthood.

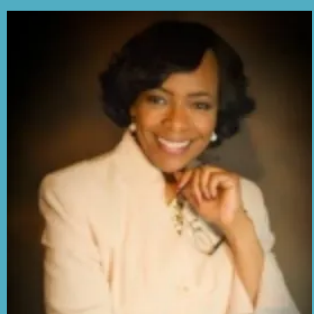
5:30 PM - 7:30 PM: Closing Dinner; Raffles, Evaluations & Good - Byes - **Hotel Outside Terrace**

Speaker Bios



Philip Gattone
*President and CEO of
The National Bleeding
Disorders Foundation*

Philip is an organizational leader and communicator who understands the dynamic of a national organization and a chapter network, and he recognizes the importance of a strong collaboration between the two. He's skilled at long-term strategy but also knows the importance of adapting and shifting throughout challenging times. Phillip joined NBDF in February and is passionate about building capabilities with an open, empathetic leadership style that can help advance NBDF's focus of innovative, inclusive research, education, and advocacy. Gattone was president and CEO of the Epilepsy Foundation of America (EFA) from 2012-2019.



Cathy Tiggs, MSSA, LISW
*HTC Social Worker,
Sponsored by the
National Bleeding
Disorders Foundation*

Cathy Tiggs is the social worker for the HTC at UH Cleveland Medical Center in

Cleveland, Ohio. Cathy has worked in the bleeding disorder community for more than 15 years. She serves on several committees within the BDO community and works to create and expedite educational programs. She also provides competency training for social workers and social work managers in the areas of leadership, conflict mediation, empowerment of vulnerable populations and all other areas of influence that prepares them to effectively impact communities and families.



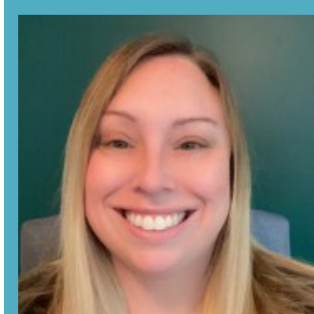
Rachel Cooper-Leal
*Patient Affairs Liaison
for Pfizer Rare Disease*

Rachel is a Patient Affairs Liaison (PAL) with Pfizer Rare Disease. The PAL is a field-based, non-sales community-facing colleague who serves as the regional point of contact for local advocacy groups, patients, and caregivers. Rachel earned her Bachelor of Science degrees from Auburn University in Alabama. She has over 15 years of pharmaceutical experience, most recently in rare disease.



Barbie Castano Arrebola
*Bayer Hemophilia
Community Executive*

Barbie is a Hemophilia Community Executive with Bayer, covering the Southeast region since 2018. Barbie comes to Bayer with over 20 years of hemophilia experience. Barbie is an active member of the bleeding disorders community and has a special place in her heart for all of those living with hemophilia. Prior to joining Bayer, Barbie was the Client Relations Executive of a specialty pharmacy during which she participated in a mentor program and served on a marketing advisory board. Barbie is a graduate of Nova Southeastern University where she obtained her bachelor's degree in Education. Barbie's passion is to empower persons to live beyond their bleeding disorders through education.



Morgan Cook
*Community Education
Specialist for Takeda*

Morgan joined the Takeda team in 2022. Being a part of Takeda's Community Education Specialist (CES) team allows her to continue to give back to the bleeding disorders community, by playing an integral part in educating and supporting patients on their journey and living their best, healthy life. As a person with VWD, as well as marrying into a family of bleeders, Morgan believes this is just as much of a personal journey as it is for her to help others. Outside of work Morgan enjoys spending time with her husband and their fur baby, Cooper. Together they collect vinyl records and can often be found listening to their vastly dynamic collection. Morgan is also an avid reader and loves to repurpose and refinish furniture in her garage workshop!

Speaker Bios



Natalia Winberry, MNL
*Manager of Education
for NBDF*

Natalia Winberry started her career as an AmeriCorps VISTA working on community outreach and continued to work in refugee resettlement

for eight years by helping refugees and immigrants thrive in their new communities. She earned her graduate degree in Nonprofit Leadership and Management from Arizona State University and focused on supporting nonprofit organizations to improve accountability to the populations they serve. Throughout her nonprofit career, Natalia has worked on community development, advocacy, and social service efforts in collaboration with a wide variety of community partners. Natalia is currently a Manager of Education for the National Bleeding Disorders Foundation.



Bill Robbie
*Director of State
Government Relations
at NBDF*

Bill Robie is the Director of State Government Relations for the National Hemophilia Foundation, where he is in

his tenth year serving the bleeding disorders community. He works from his home in Bend, Oregon and covers health care policy issues in sixteen states in addition to managing two other government relations staff persons. Bill has worked in government relations for more than twenty years and has experience at the local, state, and national levels.



Malerie Hartsell MPH, CHES
*Program Manager, Blood
Disorders and Contracts, S.C. Department of Health & Environmental
Control, Division of CYSHCN, Bureau of Maternal and Child Health*

Malerie Hartsell currently serves as the Interim Director for the Children and Youth with Special Health Care Needs program at the SC Department of Health & Environmental Control. She is a Certified Health Education Specialist who has worked in both the public and private sector, with over 11 years of state government service, and has a passion for public health!

She has been with the CYSHCN program for over 8 years overseeing several different programs to include the Bleeding Disorders Program.



Dr. Michael Zolotnitsky
*Physical Therapist,
Patient Educator for
Octapharma*

Dr. Z is a physical therapist from NJ living with severe hemophilia. He has worked with countless individuals

living with bleeding disorders assisting in exercise prescription, kinesiology taping, aquatic physical therapy, and more. For the past ten years, he has spoken for countless organizations including HFA, Coalition for Hemophilia B, Hope for Hemophilia, and others. He currently speaks as a patient educator for Octapharma where his goals are to educate as many people as possible therefore created a YouTube channel HemoDoc to assist those he cannot meet in person.



Samantha Carlson
*Director of Research at
NBDF*

Samantha Carlson is a licensed Master of Social Work who has been practicing in southwest Michigan since 1998. She is

the Director of Research at the National Bleeding Disorders Foundation (NBDF). Samantha oversees advisory board programming, as well as partnerships and collaborations across the community focused on person centered care; making research relatable to all. She is the co-chair of the Mental Health Priority Action Team, served as the co-chair for the National Research Blueprint Health Equity, Diversity, and Inclusion Working Group, is an NBDF mentor, and HEDI Champion. She has been part of the inheritable blood disorder community since 2009; serving as a clinical social worker through an HTC for ten years.

Notes



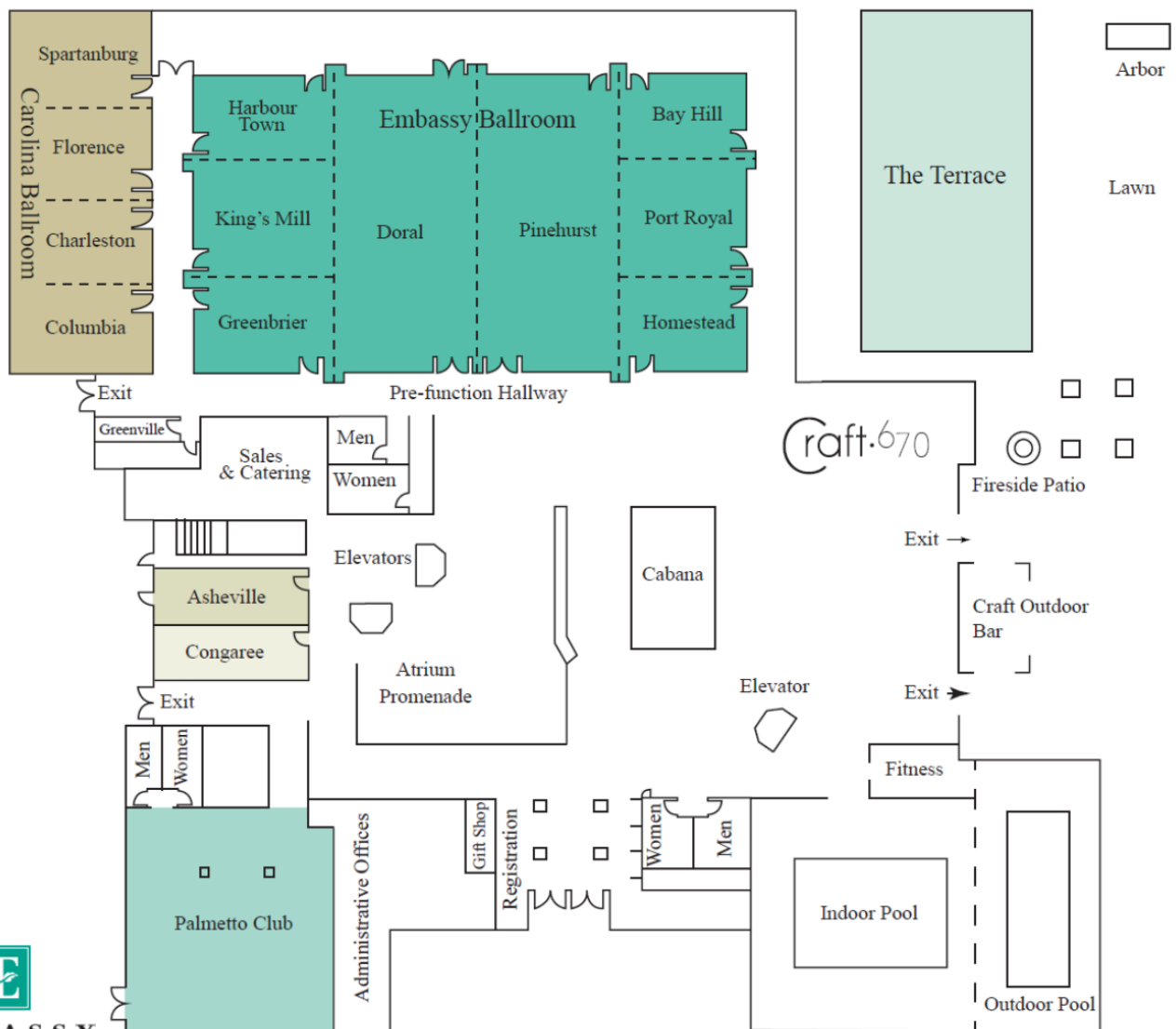
“THE VOICES OF 46”
COMMUNITY RESOURCES &
ENGAGEMENT PROGRAM - RURAL
COMMUNITIES
HEALTH EQUITY OUTREACH

In an effort to meet our community members where they live, we are now traveling to local and rural counties where our members reside. As part of our discovery in our 2022 Health Equity Summit in Charleston, community members shared challenges of attending meetings and events where they have to travel far distances and asked for smaller meetings closer to some of the small counties outside the larger cities. These meetings will be casual events at local restaurants or facilities to engage in conversations between BDASC and the community. The gatherings, similarly to all BDASC events, will be offered free of charge to all community members in the designated targeted area. We will also provide community members the opportunity to provide anonymous information with access to quality healthcare barriers and challenges through our outreach survey. Please take this time to take the survey now by scanning the QR code with your phone. Please only take the survey once.



Hotel Map

EMBASSY SUITES HOTEL & CONFERENCE CENTER MAP



670 Verdae Blvd, Greenville, SC 29607
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Sponsor Bingo



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Phone Number: _____

Visit each of our sponsors have have them mark your Exhibit Board!
Each completed card will be entered into a drawing during our final
dinner. You must be present to win!

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Thank You Sponsors

Exhibitor Hall Hours: Come learn about the current and future treatment therapies in the pipeline and supportive services available to our community as you explore and speak one - to -one with our sponsors in healthcare treatment therapies and service.

8:00 AM- 8:45 AM: Premier Sponsors Exhibiting Only

10:20 AM - 11:00 AM: All Sponsors Exhibiting

12:00 PM - 1:30 PM: All Sponsors Exhibiting (Lunch)

2:30 PM - 3:00 PM: All Sponsors Exhibiting

4:00 PM - 5:00 PM: All Sponsors Exhibiting

Premier Sponsors



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NATIONAL
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Save the Date!

Next Year's HELLO Conference & Annual Meeting will be June 6th-7th, 2025 in Greenville, SC