50th anniversary

1973-2023

HELLO Conference & Annual Meeting

Program Agenda

June 9-10th, 2023
Embassy Suites
Greenville, SC

HEMOPHILIA OF SC FRIENDS FOR LIFE

HEMOPHILIA
of South Carolina
SERVING ALL BLEEDING DISORDERS

BDASC

In 1973, Hemophilia of South Carolina was founded by a group of parents interested in promoting awareness, providing group support, and assisting other national hemophilia organizations in an effort to support their children and other families in South Carolina who had hemophilia. We are excited you are joining us as we celebrate our 50 Year Anniversary of the organization, now known as the Bleeding Disorders Association of South Carolina, serving ALL bleeding disorders.

With our Gratitude, BDASC Presidents (1973-2023)

William Eichelberger
Betty Hammond
John Salter
Linda Robertson
George Dobbins
Pete Korn
Patty Korn
Tommy Williamson
Kim Wentzky
Darin Wentzky
Victor D. Fisher
Darin Wentzky
Rhonda Sumner
Frank Wentzky
Jim Hess
Mark Eichelberger
Lynn Warren
Phillip Lawson
Brandy Stewart
Gene Feather
Mark Eichelberger
Brandy Stewart
Victor D. Fisher
Vidalia McTeer
Suzanne (Sue) Martin
Lisa Bordelon
Mike Walden
Shelley Crisp
Aaron Smith (July 1, 2023)

Help us welcome our new Board Members

April Baird

Cristal Day

Don't forget to take our five-minute online evaluation. Go to the link below or scan the QR code to the right with your phone.
Thank you for your feedback!

https://tinyurl.com/2023HELLOEvaluation

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Friday, June 9 - 4:00PM - 10pm (Embassy Grand Ballroom)

4:00 p.m. - Registration Opens
6:30 p.m. - 50th Year Legacy Dinner & Presentations
7:00 p.m. - Chapter Awards & Scholarships
8:00 p.m. - 10:00 p.m. - Dancing and Celebrations

2023 BDASC Scholarship Recipients

Congratulate to our Scholarship Recipients!

Alba Myers Lewis Academic Memorial Scholarship:
Sarah Beth Walden
(Winthrop University)

John N Tiller Memorial Scholarship:
Regan Kayleigh Weber
(Clemson University)

BDASC Academic Scholarship:
Ava Elizabeth Newhart
(Clemson University)

Mark Asbury Eichelberger Memorial Scholarship:
Makayla Carrie Keith
(University of South Carolina)

We are excited to announce the award winners live at our Annual Meeting. Each award is meaningfully selected and presented to individuals that have contributed to the success of Bleeding Disorders Association of South Carolina over the years.

2023 Annual Meeting Chapter Award

- Board Member of the Year
- Board Member Recognitions – Shelley Crisp & Wendy Legrand, retiring.
- Legislative Advocate of the Year
- Coalition Advocate of the Year
- Coalition Ambassadors of the Year
- (NEW) Junior Advocacy Ambassador
- Appreciation and Partnership Award
- Making a Difference Award
- Volunteer of the Year "The Fisher Award"

Friday

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Saturday, June 10 - 8:30AM - 4:00PM (Palmetto Club)

We have contracted with Corporate Kids events this year to care for our children ages, 1-12 years. They provide a wealth of experience and the total care you need to enjoy the annual HELLO Conference as your children enjoy activities designed for them. All children enrolled in the "Kids Camp" will need to be registered and a consent form MUST be filled out. If you need to fill one out still, see the staff of CKE. Parent pickup is promptly at 4:00pm.

Corporate Kids Events, Inc.

The theme is Wacky Olympics!

Kids Education (Ages 0-7)
11:15AM - 12:00 PM

Factor Man Visits with an Important Message on Staying Fit
Kids will enjoy learning the importance of staying active and incorporating exercise into their day with fun activities to promote health.

sponsored by:
CVS specialty

Tween Education (Ages 8-12)
1:30 PM - 2:30 PM

Broadway Bound
Experience theater and develop self-expression through interactive confidence-building activities and improvisation. Participants will work together to boost confidence, embrace positive responses and be creative.

sponsored by:
Optum

Saturday, June 10 - 9:00AM - 4:00PM (Check in 9:00AM) (Charleston/Columbia Ballroom & Outside Lawn Terrace)

GUT MONKEY

This year we have contracted with Gut Monkey - Leading Edge Program to provide education and entertaining sessions for our Teens (ages 13-18 years). Participants will explore "systems", or the small ways in which we live our lives, and what it says about who we are and our future goals.

12:00pm - 1:30pm Lunch with parents
1:30pm - 4:00pm: Teens return back to the teen session for the second half of the program.

LEADING EDGE
Made possible exclusively by Pfizer

We encourage all teens to attend this limited national program provided by the Leading Edge and sponsored by Pfizer.

Childcare & Teens

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Morning Keynote Educational Sessions

9:00am - 10:30am- Opening Keynote Speaker (Pinehurst Ballroom)

Our Past, Present, and the Future of Bleeding Disorders Treatment & Care
Presented by "Bobby" Duc Tran, MD, MSc, Assistant Professor, Department of Hematology and Medical Oncology Hemophilia of Georgia Center for Bleeding Disorders

Learn about the evolution of treatment care throughout the past 50 years and hear stories from our community members of what treatment care was like, and what our community looks forward to in the future. Listen to our panelist community members as they share their experiences throughout the years.

10:30am - 11:00am - Break/Exhibiting (Doral Ballroom)

Join us for the first All Inclusive Exhibit Hour as we enjoy food and drinks. Enjoy one on one conversations with our manufactures and support services. Be sure to get your sponsor bingo card stamped after visiting to enter our raffle grand prize drawing.

11:00am – 12:00pm - BDASC Advocacy Session (Pinehurst Ballroom)

BDASC's Advocacy: Past, Present, and Future
Presented by the SC Advocacy Coalition, James Romano, BDASC Legislative Coordinator & Sue Martin, Coalition Lead, and BDASC's advocates. Own Your Path presentation presented by Brendan Hayes and Heather Hicks, NHF.

Learn and celebrate our bleeding disorders community's rich history of successful advocacy throughout the past 50 years while hearing BDASC's advocacy accomplishments for the South Carolina Bleeding Disorder Community. Learn about the advocacy needs we face today, barriers with access to care, today and in the future, and learn how to become involved and have an impact on your future healthcare. Hear from community members and why they are involved in advocacy.

Learn about the newly developed "Own Your Path" of the National Hemophilia Foundation.

12:00pm – 1:30pm – Lunch (Doral Ballroom)

12:00pm: Hotel Room Check Out (for those not staying over)

Afternoon Educational Breakouts

1:30pm - 2:30pm: Session #1

Learning the Science of Kinesiology Taping (Pinehurst Ballroom)

Presented by Mike Zolotnitsky, Sponsored by Octapharma

Kinesiology taping is an interactive presentation where demonstrations of how to tape the shoulder, elbow, wrist, neck, low back, knee, and ankle will be performed while discussing the indications during acute injury. Taping will demonstrate how to reduce swelling, improve range of motion, and improve overall stability to reduce pain.

Shared Decision Making and the Shift to Person Centered Care (Kings Mill Ballroom)

Presented by Brendan Hayes, Sponsored by the National Hemophilia Foundation

You are the subject matter expert of your and/or your child's bleeding disorder. And, as the subject matter expert, you are the center of your care network and a vital member of the shared-decision making process. This workshop will explore the shift towards person-centered care and outline the concepts of shared-decision making. In addition, you will gain advocacy and communications skills as well as important resources.

Women Who Bleed – Women Carriers (Greenbrier Ballroom)

Presented by Linda Casto MSW, LISW-S Program Coordinator Hemostasis and Thrombosis Center Nationwide Childrens Hospital, Sponsored by Bayer Healthcare

This session empowers women to know the meaning of their hemophilia and bleeding disorders carrier status and understand bleeding and treatment options. It will explore issues important to women carriers whether they are symptomatic or not and includes genetics, carrier testing, the emotional impact and recognition of symptoms and treatment. The program focuses on going beyond that carrier status, getting tested, knowing that women may need to treat depending on their factor levels.

2:30pm - 3:00pm: Break/Exhibiting (Doral Ballroom)

Afternoon Breakouts (Continued)

3:00pm - 4:00pm: Session #2

Advocating in the ER (Pinehurst Ballroom)
Presented by Heather Hicks, Sponsored by the National Hemophilia Foundation

Having to advocate for yourself or a loved one's care can be difficult, especially in an urgent situation! This workshop will cover how to prepare in advance for an emergency, and provide information to help you navigate difficult situations that you may encounter when you are in the emergency room.

A Challenging Bleeding Disorder: Von Willebrand Disease (vWD) (Kings Mill Ballroom)
Moderated by Sue Martin and Samantha Javorka, with Robin Jones, Midstate HTC nurse coordinator, Shonequa Smith, LMSW Midstate HTC, with Leslie Gilbert, Medical Director, HTC Prisma Health Upstate

The vWD community is unique in their experiences with their bleeding disorders. With the wide variety of von Willebrand disease categories; Type 1, 2 with subtypes, type 3, and all with different severities, including difficulties within testing accuracies, the vWD community faces many obstacles to treatment care and are sometimes left feeling frustrated, unheard, dismisses, or alone. Come together with other members of the South Carolina vWD community to share and learn how to best advocate for yourself or your loved one's needs. A variety of situational scenarios will be discussed with participants leading the discussions on how they found solutions living with this complex condition and what they feel is still lacking for the vWD community. We will engage in conversations with our healthcare providers, learn what perspectives and challenges they see in treatment care, and discuss how together we can strive to meet the needs of this community.

Newer Members Greetings: Chapter Resources, Advocacy, and More (Greenbrier Ballroom)
Learn about the Chapter's resources, support groups, financial aid, scholarships and more. Engage in round table conversations of your choice with members of the community. Enjoy sharing experiences of living with bleeding disorders. Learn how do get involved in advocacy. Meet our staff and board of directors and share your thoughts. What is on YOUR mind? What can we do to support you and your family.

4:15pm – 5:00pm: Discussing Self-Infusion and Learning How (Pinehurst Ballroom)
Presented by Robin Jones, Midstate HTC Nurse Coordinator

4:00pm – 5:00pm: Final Exhibiting (Doral Ballroom)
5:30pm – 7:30pm: Closing Dinner (Outside Hotel Terrace)

Duc "Bobby" Tran, MD, MSc, serves as Assistant Professor in the Department of Hematology and Medical Oncology at Emory University School of Medicine. Dr. Tran works at the Comprehensive Bleeding Disorders Clinic and teaches hematology and medical oncology fellows. Dr. Tran received his MD from the University of South Carolina School of Medicine. He completed his residency in Internal Medicine at the University of South Florida and Moffitt Cancer Center in Tampa, where he served as chief resident. He completed his fellowship in Hematology at Winship Cancer Institute of Emory University.

Dr. Michael Zolotnitsky is a physical therapist from NJ 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 eight years, he has spoken for countless organizations including HFA, The Coalition for Hemophilia B, and more. In his free time, he loves to travel with his wife, be a good father to his dachshund twins, watch football and exercise.

Brendan Hayes is the Senior Director of Education – Innovative Therapies at the National Hemophilia Foundation. Her focus is on developing accurate, accessible, non-biased educational content on gene and innovative therapies, strengthening collaborations with national rare disease and patient advocacy organizations, and ensuring the voices of those with lived experience help to drive content creation. Brendan serves on national committees, task forces and working groups focused on gene and innovative therapies for rare disorders. Brendan is an MPH candidate with a concentration in Public Health Leadership.

Heather Hicks is an enthusiastic and dedicated Manager of Education at the National Hemophilia Foundation, where she has been making a significant impact on the lives of those with bleeding disorders. She manages the NYLI program for young adults, fostering the development of leadership and advocacy skills among the next generation. Additionally, she oversees the Own Your Path program. Heather holds a B.S. in Molecular and Microbiology and a Master of Public Health. With a rich 17-year career in the field of education, Heather leverages her extensive experiencecreate meaningful, engaging, and empowering learning experiences for those affected by bleeding disorders.

Linda Casto is the Program Coordinator for Nationwide Children's Hospital and is responsible for the overall coordination and implementation of the Hemostasis and Thrombosis Program. She also includes clinical social work services to hemophilia patients and their families.

Speakers

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1973	**Hemophilia of South Carolina is established by a small group of families living with Hemophilia.**
	The Hemophilia Act of 1973 allows federally funded comprehensive hemophilia treatment centers to be established.
1976	**The first camp for kids with Bleeding Disorders in South Carolina is hosted by HSC at the Clemson Outdoor Laboratory and was called, Camp Running Brave. It was the only camp for kids with bleeding disorders on the east coast and served S.C., N.C., G.A., F.L., V.A., El Salvador and K.Y.**
1977	DDAVP is developed to help boost levels of both factor VIII and von Willebrand factor.
1982	The CDC reports the first cases of people with hemophilia through the use of tainted blood products to treat bleeding disorders.
1983	HIV is identified. Blood products are recalled after two identified blood donors die of AIDS.By October of 1983 manufacturers begin issuing clotting factor recalls.
1984	A research team has successfully cloned the human gene for the production of Factor VIII.
1986	President Ronald Reagan proclaims March “Hemophilia Awareness Month.”
	The first product for the treatment of von Willebrand Disease is approved.
1988	The first World AIDS day is noted as a global health day.
1989	The structure of the VWF Gene is successfully cloned for the first time.
1990	Congress passes the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act.
	Genome Mapping Begins.
1992	The first recombinant factor VIII product is approved by the FDA.
1994	MASAC issues recommendations for prophylaxis treatment for individuals with r factor VIII or r factor IX.
1996	The first Washington Days advocacy event is held by NHF.
1999	The first factor IX recombinant product is approved by the FDA.
2003	The CDC’s Universal Data Collection system publishes a report demonstrating that since 1998, no new infections of hepatitis A, B and C or HIV has been linked to blood products used to treat hemophilia.
2007	Prophylactic treatment becomes standard of care in the United States for people living with hemophilia.
2009	The first Rare Disease Day is celebrated in the United States.
2010	The movie Bad Blood debuts, chronologizing the HIV crisis in the hemophilia community.
	Hemophilia of South Carolina hosts its first Legislative Advocacy Days.
2013	Gene Therapy for Hemophilia begins.
2015	First recombinant therapy for von Willebrand Disease is FDA approved for adults.
2016	March officially becomes known as the national Bleeding Disorders Awareness Month.
2017	My Life, Our Future: Development of the World’s Largest Genetic Research Repository for Hemophilia.
	Chris Bombardier is the first hemophiliac to summit Mount Everest.
	FDA approves the first subcutaneous treatment for hemophilia A.
2018	The FDA gives Priority Review to the first gene therapy for Hemophilia A.
2021	**Hemophilia of South Carolina becomes *Bleeding Disorders Association of South Carolina* to reflect a more inclusive organizational name as serving all bleeding disorders.**
	NHF in collaboration with ASH, ISTH and WFH publishes guidelines on the diagnosis and treatment of von Willebrand Disease.
2022	The FDA approves the first Gene Therapy treatment for adults with Hemophilia B.
2023	**BDASC, in partnership with other rare and chronic patient advocacy organizations, creates a statewide collaborative known as the *Palmetto Health Collective* to be a voice for the rare and chronic disease patients in South Carolina.**
	The first Research National Blueprint for Inherited Bleeding Disorders was published in the Expert Review of Hematology. **BDASC participated in its development.**

50 Years of History

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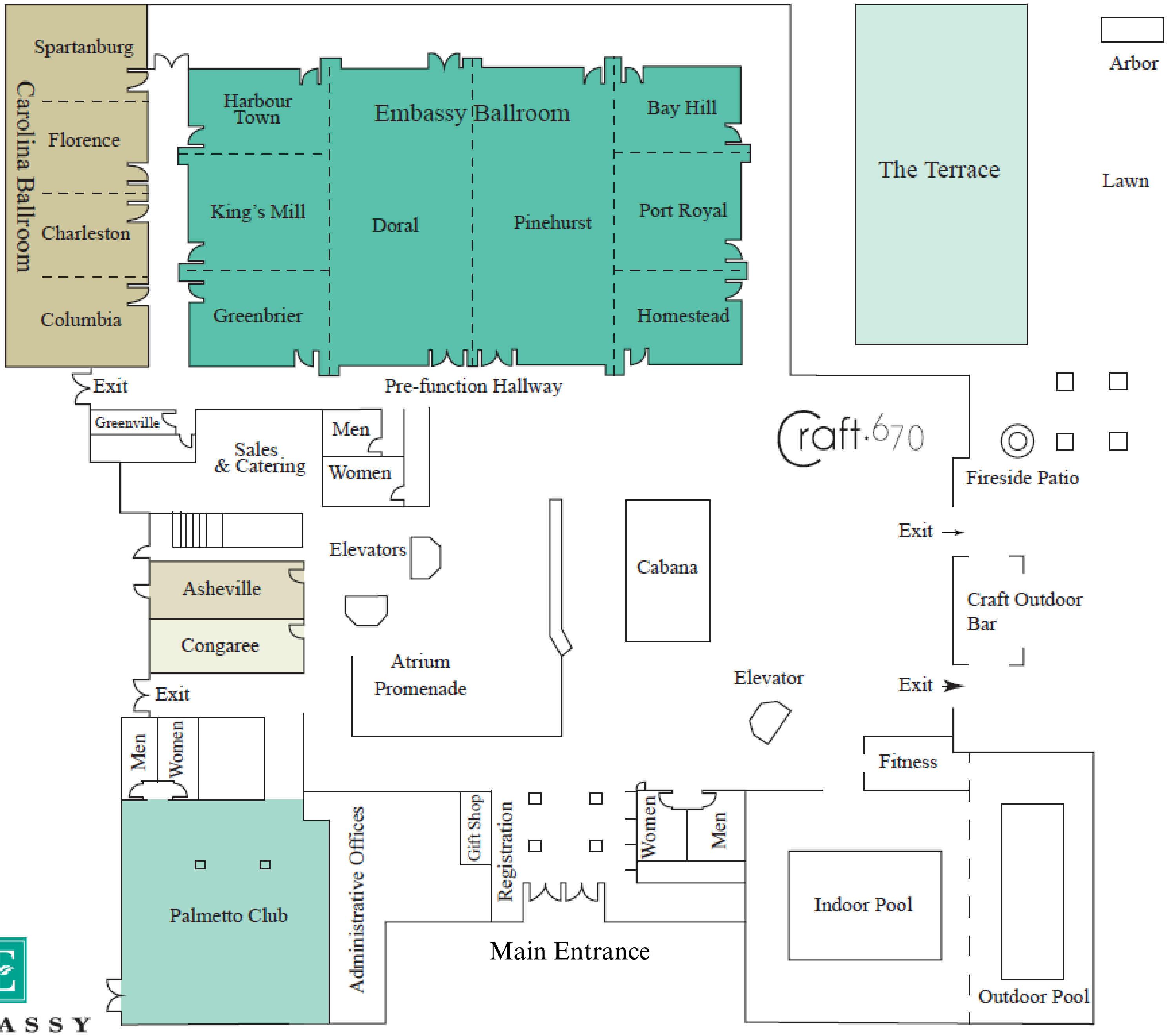

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EMBASSY SUITES
by HILTON
Greenville Golf Resort & Conference Center

Embassy Map

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for all bleeding disorders

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Visit each of our sponsor booths, get all their LOGO boxes stamped, then tear off this sheet and place it in our raffle box at the closing dinner to win our annual meeting grand prize. You must be present when we announce the winners to claim the prize. And don't forget to include your name!

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