



For joining us at our State Annual Meeting and  
Educational Hello Conference

See you next year!  
June 1 & 2, 2018



44<sup>th</sup> Annual State Meeting & Conference

# HELLO

**“Helping Embrace Life’s Learning  
Opportunities”**

**June 2-3, 2017**

**Greenville, South Carolina**



## A Time For Advocacy

Become inspired by the strength, perseverance and courage within our  
bleeding disorders journeys. Join the community in learning how to  
come together as one collective voice.

## State Annual Meeting and HELLO Agenda

Friday

4:00 pm- (hotel check in)

5:00 pm -HSC Registration- *Atrium Foyer & Pinehurst Ballroom*

5:00 pm–5:30 pm Meet and Greet Social  
~HELLO~ Ice Breaker

5:45-6:00 pm – Opening Welcomes and Acknowledgements- Sue Martin,  
Executive Director  
“Our Time is Now”

6:00pm - Welcome, President Lisa Bordelon  
~ Dinner Buffet

6:30pm- Keynote: “*The Evolving Landscape of Hemophilia*” takes a look  
at how some new and emerging hemophilia therapies may work to address  
bleeds within the community. Presenter-Tanya Stephenson-Bioverativ

- HSC Mission Moments & Annual Report- Sue Martin
- Introductions -HSC Board of Directors  
New BOD- Renita Johnson, Tameelah Dawson, Wendy Legrand,  
Shelley Crisp
- Awarding of the “Board Member of the Year”
- Thank You Acknowledgements

7:45 pm-

- Awarding of the “Making a Difference Award”
- Awarding of the “Chapter Appreciation and Partnership Award”
- Awarding of the “Volunteer of the Year Award”

- ❖ Scholarship Awards Presentation- Felicia Alexander, Scholarship  
Chair

8:30pm- Wrap-up: Saturday’s Agenda Review, Childcare & Teen programs-  
free time, pools, socialize with families and friends  
Join us for our *Community Hospitality Ice Cream Social* out on the Hotel  
Terrace  
~ sponsored by **CSL Behring**

Thank you to all our distinguish guest speakers and special  
guests for their commitment to our HELLO Conference.

### Hemophilia of South Carolina 2017 Board of Directors

Thank You for your Service!

Mike Walden, President

Shawn Sperry, Vice President

Lisa Bordelon, 2<sup>nd</sup> Vice President

Patricia Tucker, Treasurer

Felicia Alexander, Secretary

Bonnie Phifer, Assistant Secretary

Cristal Day

Renita Johnson

Wendy Legrand

Shelley Crisp

Tameelah Dawson, Junior Board Member

Ex-officio Board Member  
Sue Martin, Executive Director



### Exhibit Hall Information

Meet, discuss and explore products and services with our Drug Manufacturer Representatives and Home Care Specialists while visiting the Exhibit Hall during breaks and lunch and in the afternoon. Hear about all the new treatment options, new factor products newly introduced and those coming to market soon. Discuss different treatments, services and products and become knowledgeable about your hemophilia and bleeding disorders options.

### ACKNOWLEDGEMENTS

We wish to recognize and thank our Sponsors for their support of this year's State Annual Meeting and HELLO Conference!

#### Premier Sponsors

Bayer HealthCare

Bioverativ

CSL Behring

Novo Nordisk

Pfizer Hemophilia

Shire

#### Platinum Sponsors

CVS Caremark

Grifols

Octapharma

#### Corporate Sponsors

Accredo

Aptevo

Cottrill's Pharmacy

Diplomat Infusion Specialty

InTouch Pharmacy

Matrix Health

### Saturday

7:00 am- Breakfast Buffet in the Atrium for overnight guest only

8:00-8:45 am- Exhibits Open – Premier Sponsors- Doral Ballroom

8:30-8:55 am- Check in kids: *Palmetto Club*, HSC Kids Camp Childcare

9:00 am- Teen Program check in-*Spartanburg & Florence Ballroom*

9:00 am- Conference Welcome – *Greenbrier/KingsMill/Harbor Town Ballrooms*

➤ Assistance & Company Highlight Support Services- Premier Sponsors

9:30-10:30 am- Brendan Hayes, NHF-The Evolution of Advocacy in the Bleeding Disorder Community – *Greenbrier/KingsMill/Harbor Town Ballrooms*

10:30-11:00 am- Coffee Break: All Exhibits Open- *Doral Ballroom*

11:00-12:00 pm- Katie Verb, HFA-Healthcare Policy Updates *Greenbrier/KingsMill, Harbor Town Ballrooms*

12:00 pm-Hotel Check Out

12:00-1:30 pm ~Lunch on the Run ~ *Doral Ballroom and hotel atrium courtyard*

Enjoy a Caddy Bag, Embassy Box, Bristro Box or Veggie Box as the Exhibits open for visiting one-on-one with Industry Drug Manufacturers and Home Care Specialists.  
(Additional seating in the atrium)



**1:30-4:00 pm- Afternoon Breakout Sessions-** we ask that you please attend at least one per session

➤ **Session 1 ~ 1:30-2:30 pm**

- Understanding Von Willebrand Disease: *Charleston Room*
- Social Media in the Bleeding Disorders Community: *Columbia Room*
- Persistent Pain, Considerations for the Hemophilia Community: *Greenbrier/KingsMill/Harbor Town Ballrooms*

➤ **Session 2 ~ 3:00-4:00 pm**

- Encouraging Champions with Choices: *Charleston Room*
- Advocacy Coalition Panel: *Columbia Room*
- Infusion Workshop: *Greenbrier/KingsMill/Harbor Town Ballrooms*

**4:00 - ALL CHILDREN IN KIDS CAMP NEED TO BE PICKED UP ON TIME PLEASE!!!**

**Exhibit Hall Return: 4:00-5:00pm-** All attendees are encouraged to return to exhibit hall for additional conversations and consumer needs, discovery & inquiries.

**5:15-6:30 HSC Dinner Conference Wrap-up will be out on the Outside Terrace**

**Good-byes,** turn in evaluations, exhibit cards drop-off in box for drawings, NHF raffle drawing, corn hole toss, games.

**May we suggest the following for those staying on the weekend:**

Depart on your own to Downtown Greenville: Cleveland Park, Swamp Rabbit Trail, (Walking, Biking, Running) Greenville downtown shopping, music, Falls Park and the Liberty Bridge.

**UNDERSTANDING VON WILLEBRAND DISEASE: Developed for those with VWD or interested in learning more about VWD**

Did you know that von Willebrand disease is the most common inherited bleeding disorder? This program provides an educational format to introduce the symptoms and types of von Willebrand disease, recognize potential treatment options, and learn how emotional and community support systems can help those living with this bleeding disorder. Join your VWD community in this special session just for you! Learn and share your experiences in this interactive educational session. Get to know your fellow VWD community in South Carolina and empower each other with knowledge.

***Featured Guest Speaker: Ms. Nancy Roy, MSN, FNP***

**Ms. Nancy Roy** has been an active member of the hemophilia community, serving as nurse coordinator and Family Nurse Practitioner, providing care to community members of all ages at HTC's in Maine and South Carolina for the past 28 years. She has served on local, state, regional and national committees for hemophilia, bleeding disorders and HIV care. Ms. Roy has been active as an author and speaker on hemophilia and bleeding disorders care on local, regional, national and international levels. She enjoys sharing experience and clinical knowledge with all members of the community. Ms. Roy now serves as the Senior Clinical Specialist for Shire in the south east area. Ms. Roy earned her degrees from Hartford Hospital, New Hampshire College and Simmons College, with post graduate work at Simmons College, Boston. Many years and broad range of clinical experience and community history. Enjoys meeting/educating providers, families and any interested individual. Excited about advances in research, clinical practice and opportunities to improve care.

**Infusion Clinic Workshop**

Join us for an Infusion Workshop available for parents, grandparents, spouses and patients. It is important to understand the process of self-infusion and independence. Learn and share in this class designed just for our community!

***Featured Guest Speakers: Jennifer Harris, RN, BSN***

Jennifer is a Hematology Clinical Support Specialist with Bayer Healthcare. Prior to her career with Bayer, she was the Adult Clinical Nurse Coordinator at the Hemophilia Treatment Center at Emory University in Atlanta.”

***Featured Guest Speaker: Robin Jones, RN, MSN, MHA, CPN, CPHON  
The South Carolina Hemophilia Treatment Center Nurse Coordinator***

### **Social Media in the Bleeding Disorders Community: Benefits and Risks**

Have you ever posted a photo of your child on social media? Have you ever mentioned your child's bleeding disorder on social media or a website for fundraising or advocacy purposes? Have you ever joined an online discussion group to give or receive advice? Have you ever thought about the digital footprint you are leaving for your child before your child is even old enough to give consent? Have you avoided social media out of concern? Please join the discussion!

***Featured Guest Speaker: Brendan Hayes, Government Relations Specialist with the NHF (See Bio, Evolution of Advocacy)***

### **Persistent Pain: Considerations for the Hemophilia Community**

This session will provide an overview of persistent pain in the general population as well as how it may impact those with bleeding disorders and what you may consider.

***Featured Guest Speaker: Linda L. Pollhammer BSN, RN***

Linda has worked as a Nurse Educator Specialist, serving the hemophilia community, since January of 2010. She then moved into the Patient Affairs Liaison position with Pfizer in April, 2016. Linda received her Bachelor of Science degree in nursing from the University Of Maryland Medical System School Of Nursing, and brings with her over thirty-five years of experience in clinical nursing, and nursing management. Ms. Pollhammer has worked extensively in the home infusion and specialty pharmacy industry in every capacity. Linda is committed to keeping herself informed, and her knowledge of issues that can affect the hemophilia community current, in order to best serve the patients and their families.

### **Encouraging Champions with Choices**

Raising a son with severe Hemophilia B has afforded me the opportunity to gain first-hand experience as well as a vast amount of knowledge of the condition. Speaking to audiences of social organizations, athletics, academia, as well as healthcare professionals gives me an appreciation for the advancements available to this community. It has been my privilege to serve the bleeding disorders community for more than ten years in various capacities (Board Member for local chapter, Consumer Advocate for Specialty Pharmacy, as well as US Congress and Louisiana Legislative Advocate) My son continues to accomplish both academic and athletic goals, including lettering in varsity swimming as a freshman. He also enjoys weightlifting, basketball, golf, horseback riding and martial arts. Although hemophilia can create limits and "Setbacks," we have accepted this diagnosis as a "Set Up" to a fulfilling life with privileges and opportunities that sometimes only those with a bleeding disorder can receive. Her message- *Everyday is a gift. Enjoy the present.*"

***Featured Guest Speaker: Shonda Joshua***

## **Childcare and Teen Programming**

### **Kids Camp 2017/ HSC Childcare Services 8:45-4:00pm**

Corporate Kids Events, INC. will facilitate "***Super Spectacular Hero Day***" as your children enjoy the day at Kids Camp. Corporate Kids Events provides the ultimate childcare and entertainment for events worldwide. Their time tested, age appropriate activities are always fun, enriching and they always keep safety as a priority. Your kids will have a fun time as you enjoy a day of restful learning among friends.

HSC's childcare liaison and HSC member, special needs teacher Miss Ashley Bordelon will help to assure your children are having a good time and keep you informed if your child requests your assistance during the day.

**Childcare Staff: Corporate Kids- Sarah Aikens** will be the lead coordinator.

### **Teen Program 9:00-10:15 (Break-Snacks) 10:45am-12:00pm (12:00-1:30)**

#### **Lunch with parents, 1:30-3:30pm Art Painting Team Building**

#### **9:00-10:15am: Advocacy is All Around Us:** (Teen Program)

An interactive activity intended to get teens talking to one another about the basics of advocacy and awareness. Teens get to know each other by answering a series of fun introductory questions in pairs. Gradually, participants will answer questions related to advocacy and leadership. For example, how do you stand up for others at school and what issues are important to teens and why? The activity concludes with a discussion about how to apply ways we are already advocating for ourselves and others to the bleeding disorders community and life beyond high school.

#### ***Facilitator: Sarah Shinkman, HFA***

**Sarah Shinkman** is the Advocacy & Outreach Manager for HFA. She joined HFA in the spring of 2016, after volunteering at Symposium in Las Vegas. Sarah was inspired to get involved with HFA because of her brother-in-law, who has moderate hemophilia A. Prior to HFA, Sarah was the Volunteer Manager for Make-A-Wish Mid-Atlantic. She began her career in non-profit work as an AmeriCorps Volunteer, serving in Washington, D.C. for two years with an organization that coordinates service-learning programs for students. Sarah is passionate about engaging people in service and advocacy work. In 2011, she was named a national Champion of Change by the White House for her work in community. Sarah lives in D.C. with her husband, and loves to spend time outside, and making pottery.

#### **10:45-12:00pm: You've Got This, The Art of Speaking Up:** (Teen Program)

***The Art of Speaking Up:*** This session exclusively designed for our teens will offer insight and sample scenarios on how to ask for support in areas of social life, dating, sports, self-care, pain management and more.

**Facilitators: Edward Kuebler, LCSW** is employed at the University of Texas Gulf States Hemophilia and Thrombophilia Treatment Center, Houston, Texas USA as the Senior Social Worker for 17 years. He has worked in the bleeding disorders community for 23 years. Ed is a graduate of the University of Houston, Masters of Social Work Graduate Program. Ed is currently the Director of Development and Training for the working on regulatory issues involving consumer product safety and international trade. Ed has presented at World Federation Hemophilia from 2006 through 2014. He has presented at National Hemophilia Foundation Annual Meetings for the last 16 years.

**Dana Francis, MSW** is a social worker who specializes in working with adults with bleeding disorders, their spouses, partners and family members. He has had the privilege of working with the hemophilia community since 1988. After twelve years as a health educator with the Hemophilia Council of California, he joined the UCSF- HTC team as their adult social worker in September, 2000. Dana provides resources and supportive counseling to patients and their families. His passion has been to address the issue of men's emotional isolation, and to that end he has worked to create forums, retreats and ongoing groups for men and couples to gather and share strategies for coping with the challenges of living with a bleeding disorder. He currently represents several western states on the National Hemophilia Foundation's Social Work Working Group and has written articles about hemophilia issues for the NHF publication "HemAware". In his spare time, Dana enjoys photography, playing music with friends, riding his bike, traveling and spending time with his wife and two college age sons.

**1:30-3:30pm: Teen Painting ~ Team Building:** Burlap and Bows- Teen Room

## **Presentations and Sessions Overview**

### **The Evolving Landscape of Hemophilia**

**Featured Guest Speaker: Tanya Stephenson** has the privilege to work for Bioerativ as the Community Relations Manager for the Carolinas to serve the hemophilia community. Tanya is the mother of two boys, Dylan and Alex. Dylan has severe hemophilia A. This influenced Tanya's decision to dedicate her personal and professional life to serving the community. Tanya resides in Fort Mill, SC and is always available to serve the hemophilia community that she loves so dearly.

### **The Evolution of Advocacy in the Bleeding Disorders Community**

NHF will present on advocacy from a historical perspective, discuss the policy issue NHF is currently working on and explain why it is important for ALL of us to be involved in advocacy work now to insure access to care for future generations.

### ***Featured Guest Speaker: Brendan Hayes***

**Brendan Hayes**, Government Relations Specialist for the National Hemophilia Foundation's Public Policy team works with chapters across the country providing both policy and advocacy expertise. Brendan also helps chapters view advocacy work from a strategic perspective and enjoys helping advocates find their voice. Prior to working for NHF, Brendan spent five years as the Executive Director for the Texas Central Hemophilia Association in Dallas, TX. While at TexCen she created the Texas Bleeding Disorders Coalition and is proud of the work that both Texas chapters have done to get important legislation passed. Brendan graduated from the University of Texas at Austin with a Business degree in Finance and held leadership positions in the private and corporate sectors. In 2015, Brendan received NHF's Advocate of the Year award. She is Mom to two sons with Severe Hemophilia ages 18 and 21 who are both in college. She lives with her husband and two Westies in Plano, TX.

### **Healthcare Policy Updates**

An up-to-date look of where we are now, what's happening, and what you need to know.

### ***Featured Guest Speaker: Katie Verb***

Katie Verb is the Director of Policy & Government Relations at the Hemophilia Federation of America (HFA) where for the past 3 years she has driven the policy agenda, served as a federal advocate, and assisted states in advocating for those with bleeding disorders. Prior to joining HFA, Katie was a member of the government affairs team at the Toy Industry Association working on regulatory issues involving consumer product safety and international trade. Before turning her interest to policy and advocacy work and moving to Washington, D.C., Katie worked in Chicago for a nonprofit that took a grassroots approach to educating and preparing women to run for office. She also helped found a nonprofit that provided educational and mentoring opportunities for women in the business world. Katie earned her law degree from Michigan State University in 2008, and has a B.A. in Political Science from Loyola University Chicago.

### **Advocacy Coalition Panel Discussion**

Join us for this interactive breakout and learn what policy issues NHF is focused on at the national level, what is happening at our state level and why you should care! Meet HSC's Advocacy Coalition Members and learn how they are working closely with the NHF Public Policy Team. Learn how to become an ambassador in advocacy for HSC with year-round advocacy!

***Presented by the SCHBDAC***