HELLO

HELPING EMBRACE LIFE'S LEARNING OPPORTUNITIES

June 12 - 13, 2020

HEMOPHILIA
of South Carolina
SERVING ALL BLEEDING DISORDERS

2020 HELLO Conference and Annual Meeting Program Agenda

Welcome to the 2020 HELLO Conference and HSC Annual Meeting. We are excited to provide this virtual event to you on behalf of our Chapter members, our staff, and the Board of Directors. Please enjoy our program agenda. We are proud to provide this educational opportunity to South Carolina and beyond.

We wish to express a sincere appreciation to all our sponsors, presenters, and support organizations for helping make this virtual meeting possible. Thank you!

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National Hemophilia Foundation *for all bleeding disorders*
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Awards and Recognition

New Board Member - Robert Butler
Leader in Training - Cedric Jordan
Board Member of the Year - Aaron Smith

College Scholarship

Felicia Alexander - *Scholarship Chair*

Every year, Hemophilia of South Carolina sets aside $1,500 annually to provide scholarships. To be considered for an HSC Scholarship, an applicant must meet the following criteria: 1. Must be a resident of South Carolina; 2. Must be enrolled or accepted at an accredited educational institution, to include accredited colleges, universities, and technical and vocational schools; 3. Must have a bleeding disorder, or be a dependent child of a person with a bleeding disorder, or be a sibling of a person with a bleeding disorder, or be a parent of a dependent child with a bleeding disorder, or be a spouse of someone with a bleeding disorder.

The 2020 scholarship awardee is Cedric Tylor Jordan
Cedric lives in Effingham, SC. His parents are Linda Jordan and Arthur Cooper, and he graduated from South Florence High School. He is attending Limestone College where his focus is Business Administration. Congratulations Cedric and best of luck in your upcoming school season!

Awards and Recognition (Cont.)

Appreciation and Partnership Award

This award is given to an individual, corporation, business, healthcare organization, state agency, or non-profit, who has shown a true partnership in service, education, or treatment care with Hemophilia of South Carolina, and shares our visions of removing barriers within bleeding disorders outreach education, and access to treatment for individual with bleeding disorders in South Carolina.
2020 Appreciation and Partnership Award - **South Carolina Department of Health and Environmental Control (DHEC): CYSHCN Director, Tammy McKenna & Anna Bleasdale, Camp Burnt Gin Director, Marie Aimone, and the Public Policy Team at DHEC.**

Legislative Advocate of the Year Award

The Legislative Advocate of the Year Award is given to a member of the South Carolina Legislature who has worked to support policies that positively impact the bleeding disorders community in our state. This individual has uniquely shown the need to advocate, through our state laws, protections for persons suffering from bleeding disorders, as well as to further cultivate an environment in our state where the everyday healthcare needs of these individuals and their families can be fairly met.
2020 Legislative Advocate of the Year – **Representative Leon Howard**

Making a Difference Award

The Making a Difference Award is giving to individual, corporation, state agency, business, healthcare organization, or non-profit whose efforts to support our Chapter's mission has made a positive impact on the bleeding disorders community.
2020 Making a Difference Award - **Ryan Griffith**

Volunteer of the Year "The Fisher Award"

For non-profit organizations, volunteers are the life-line for the success of their organizations. The Chapter named an award for volunteerism after two of the original founding fathers of the Chapter had retired. They volunteered over 40 years of consecutive service to Hemophilia of South Carolina serving on the Board of Directors. They names are Vic and Roberta Fisher. The "Fisher Award" is dedicated to individuals who make an impact on the Chapter with their volunteer services. Sometime volunteers are very apparent, perhaps they run a camp or something that is very visible to all. And sometimes their volunteer time, commitment, and sacrifices may not be so apparent to everyone.
2020 Volunteer of the Year - "The Fisher Award" - **Shannon Clearly**

"Aaron Eugene Gossett" Pillar of Strength Award

Hemophilia of South Carolina is dedicated to promoting support and awareness of bleeding disorders in our communities, our state, our country and around the world. As we continue to move into our futures, educate, and provide support, we never want to forget those heroes, those Pillars of Strength, that have brought the bleeding disorders community from a time of no treatment, through the unknown, through struggles and deep sorrow, through suffering and death, and who have allowed our community to ride on their strong and brave shoulders. We honor those brave individuals and their families, who have helped lead the way to where we are now—some, who like Mr. Gossett, have supported clinical trials and gene therapy. This award is given to our hero's, our Pillars of Strength, whom have faced hardships head on, leading the way for brighter futures for their families, and others around the world.
2020 Aaron Gossett, "Pillar of Strength Award" - **Christine Evans**

June 12 - Opening Night!

GUEST

SHARON MEYERS,
HFA CEO

SPEAKER

Which Way Do We Go?

Sharon Meyers - Guest Speaker
6:45 PM by HFA ~ Register Here

About the Program:

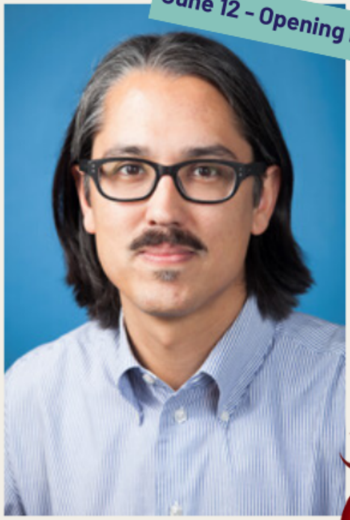
Ms. Meyers will discuss her visions for the future of HFA and the bleeding disorders community.

About Sharon:

Sharon Meyers, M.S., CFRE, is the new President and Chief Executive Officer of Hemophilia Federation of America. Appointed January 16, Ms. Meyers served as interim president during the search and as the vice president of the advancement team, overseeing fundraising, marketing and communications, and research for four years before that. Prior to joining HFA, Ms. Meyers was president and chief development officer of the St. Anthony North Health Foundation in Denver, vice president of the Penrose-St. Francis Health Foundation in Colorado Springs, foundation executive director and director of advancement of the St. Michael's Catholic Academy in Austin, and associate executive director of the University of Southern Mississippi Foundation.

Meyers is a Certified Fund-Raising Executive (CFRE) and holds a Nonprofit Management Executive Certificate from Georgetown University in Washington, D.C. She is currently working on a doctorate in education at the University of Southern California in Organizational Change and Leadership. Additionally, she holds a master's in political science from the University of Southern Mississippi. Earlier in her career, she was a public servant working on an ambulance as a nationally-certified EMT-I and answering 911 calls. She has volunteered and served as a board member for various nonprofits serving the poor and those in need.

June 12 - Opening Night!



KEYNOTE

DR.ROBERT
SIDONIO

SPEAKER

Which Way Do We Go?

Dr. Robert Sidonio - Keynote Speaker

7:00 PM by HFA ~ Register Here

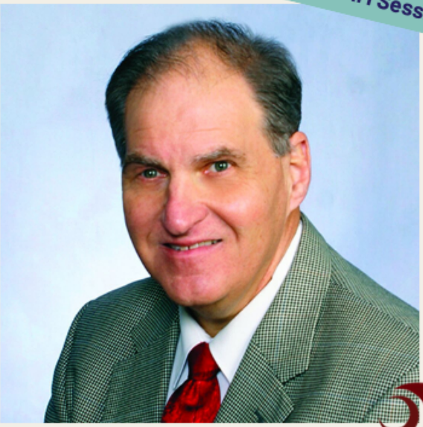
About the Program:

Dr. Sidonio will identify the current state of hemophilia treatment and the impact gene therapy could potentially have on treatment. Attendees will also have the opportunity to ask questions and engage in conversation with Dr. Sidonio about the current gene therapy trials.

About Robert:

Dr. Robert F Sidonio, Jr, is an Associate Professor of Pediatrics, Emory University SOM, Clinical Director of the Hemophilia Treatment Center and the Associate Director of Hemostasis and Thrombosis, Department of Pediatrics, Children's Healthcare of Atlanta. The focus of his clinical research career has been on understanding the prevalence of congenital bleeding disorders such as low Von Willebrand Factor, qualitative platelet disorders or hemophilia carriage in adolescent girls with heavy menstrual bleeding and the diagnosis and management of females with bleeding disorders. Furthermore Dr. Sidonio is also experienced with conducting and overseeing large clinical trials (Emicizumab PUP and Nuwiq ITI study, MOTIVATE study) focused on Hemophilia A and inhibitors and various surveillance studies (ATHN 9, Mexico Inhibitor study). He is currently a board member of American Thrombosis and Hemostasis Network and Medical and Scientific Advisory Council and medical advisor to Hemophilia Federation of America.

June 13 - 9:00 AM Session



GUEST DR. LEONARD VALENTINO NHF CEO SPEAKER

Which Way Do We Go?

Dr. Leonard Valentino - Guest Speaker

9:00 AM by NHF ~ Register Here

About the Program:

Dr. Valentino will discuss his vision for the bleeding disorders future.

About Len:

Dr. Leonard A. Valentino, the new Chief Executive Officer of National Hemophilia Foundation. Dr. Valentino has more than 35 years of clinical and research experience related to bleeding disorders, a background that the board of NHF felt would work well with their strategy of a more research-focused agenda. Prior to his most recent work with Spark Therapeutics, a biotech startup, he founded and led the Hemophilia and Thrombophilia Center at Rush University Medical Center in Chicago, where he successfully balanced a $10 million budget to support research grants, research and clinical teams – keeping the patient and their families as his core focus. Additionally, he has held leadership roles with key industry groups. In these roles, Dr. Valentino was responsible for managing the global medical teams who successfully led strategic planning for multiple worldwide hemophilia product launches.

He earned his undergraduate and medical degrees from Creighton University and Creighton University School of Medicine. He then completed the University of Illinois at Chicago's Pediatric Medicine Residency before completing a fellowship in pediatric hematology-oncology at the David Geffen School of Medicine at UCLA. Dr. Valentino remains an active member of multiple professional organizations, including The American Society of Hematology; International Society of Thrombosis and Hemostasis; Medical Affairs Professional Society; and The Hemophilia and Thrombosis Research Society.

"I am truly humbled to be chosen to lead the National Hemophilia Foundation," said Dr. Valentino upon being selected for the position. "Joining an organization with such a strong, established leadership team and track record of success is a career highlight. Over the course of my career, I've always been passionate about putting the patient at the center of my work in the clinic and in the lab, striving for better outcomes for patients with bleeding disorders. I look forward to joining this community in my new role, in the hopes of finding the best treatments and cures for inheritable bleeding disorders."

Maria Santaella and Brendan Hayes –

Gene Therapy Basics for Hemophilia: What You Need to Know

9:30 AM by NHF ~ Register Here

About the Program:

Recently there has been an explosion of innovation in the treatment of hemophilia. It is becoming more important than ever to stay informed on all the advancements – what they are, how they work in the body and how safe they are.

Understanding all the options, the pros and cons and the promise and limitations of each type of therapy will enable community members to have robust conversations with their providers and to ultimately make the best decision on treatment. This presentation is designed to provide a basic overview making these complex concepts more understandable.

About Maria:

Maria Santaella is a board-certified hemostasis nurse. She currently works as a Research Nurse at NHF. Prior to her role with NHF, she was the University of Miami Hemophilia Treatment Center's pediatric bleeding disorders nurse coordinator since 2003, and the adult nurse coordinator (of the same center) from 2007 to 2014. Mrs. Santaella is a published author. She enjoys research and recognizes its importance in improving the lives of persons living with a bleeding disorder and their families. She has been an active member of MASAC's Interdisciplinary Pain Initiative Committee since 2016 and is currently involved in the development of several research protocols. She was the Chair of the Nursing Research and Evidence Based Practice Council of the University of Miami Sylvester Cancer Center.

About Brendan:

Brendan Hayes, Director of External Affairs for the National Hemophilia Foundation leads NHF's Gene Therapy Initiative. The goal of the initiative is to position NHF as the trusted source of accurate, non-biased educational information on gene therapy. Prior to working for NHF, Brendan spent four years as the Executive Director for the Texas Central Hemophilia Association in Dallas, TX.

She has held leadership positions in the private, corporate and non-profit sectors. She graduated from the University of Texas at Austin with a Business degree in Finance and Risk Management / Insurance and attended the University of Texas at Dallas with a concentration in Organizational Dynamics in the MBA program. In 2015, Brendan received NHF's Advocate of the Year award.

Betsy Kovel - Von Willebrand's Disease 101

11:00 AM by Takeda ~ Register Here

About the Program:

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 virtual 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.

About Betsy:

Betsy Koval is a Senior Clinical Specialist with Takeda. Prior to her role at Takeda, she was the Lead Nurse Coordinator at the Hemophilia of Georgia Center for Bleeding and Clotting Disorders at Emory University and Children's Healthcare of Atlanta for about 10 years. During that time, she had articles published on transition to independence for those living with bleeding disorders. Betsy has spoken and presented research at multiple regional and national conferences for the hemophilia community and provided education for practitioners as well as patients and their families. Betsy has been in nursing for many years and worked in clinical research as a Certified Clinical Research Coordinator in a multispecialty clinic participating in many types of research. She also worked in surgical and transplant ICUs and was an educator for those new to those areas.

Empowering patients, families as well as providers with knowledge for improving health is Betsy's favorite part of her role and she is honored to work within the bleeding disorders community.

June 13 - 11:00 AM Session

HELLO

LET'S TALK ABOUT WHAT ISN'T TALKED ABOUT

SANDRA VALDOVINOS-HEREDIA

SPEAKER

National Hemophilia Foundation
for all bleeding disorders

Which Way Do We Go?

Sandra Valdovinos-Heredia - Let's Talk About What Isn't Talked About

11:00 AM by NHF ~ Register Here

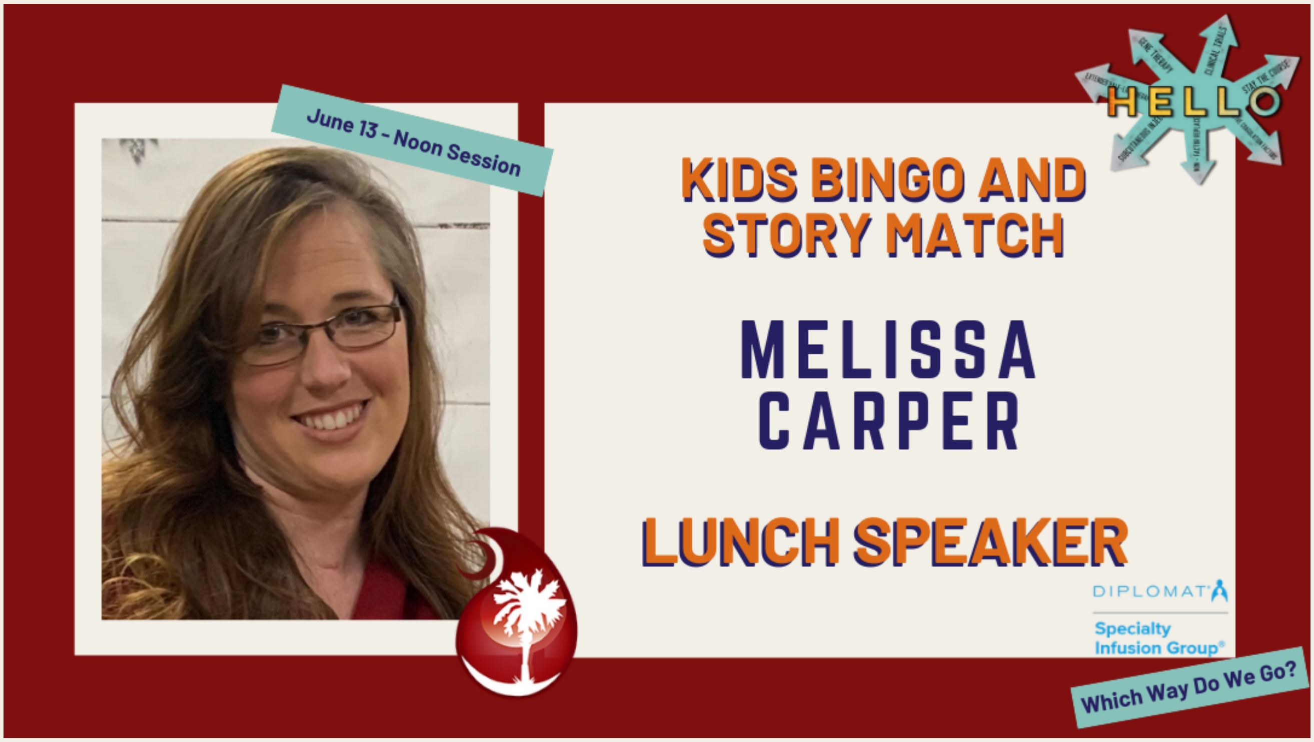
About the Program:

Creating discussions on mental health can be very difficult and uncomfortable for a variety reasons. This workshop will begin to help community members to build a dialogue and create talking points by understanding the stigmas related to mental health. Participants will also understand the foundation for mental wellness in addition to learning coping skills and resources.

About Sandra:

Sandra is a Clinical Social Worker at Children's Hospital Los Angeles HTC.
Sandra decided to become a Guía Cultural to extend the clinical knowledge, raise awareness on related resources, and to advocate for the needs of Latino population that are primarily Spanish-speaking in the bleeding disorders community and any other individual/family from this community. According to Sandra, it is a privilege and an honor to have the opportunity to be in a position at the national level, to be able to raise awareness on some of the related issues within this sub-population of the bleeding disorders, advocate, bring up ideas/suggestions on how to improve overall wellbeing, and connect with other professionals and individuals within the bleeding disorders community on this mutual goal.

Her favorite word is “Vacation”, and her beautiful children and Nana are her greatest inspiration. Sandra can’t live without coffee, especially in the morning!! if someone wrote a book about her the title would be "The Life and Inspiration of Sandra Valdovinos-Heredia".



June 13 - Noon Session

KIDS BINGO AND STORY MATCH

MELISSA CARPER

LUNCH SPEAKER

DIPLOMAT
Specialty Infusion Group®

Melissa Carper - Kids Bingo and Story Match 12:00 PM by Diplomat ~ Register Here

About the Program:

Ready for some fun interactive games with your friends? Melissa will provide some activities to get you engaged. This workshop will include "I Am Nate" book reading and bingo along with a scavenger hunt. We will discuss safety equipment, school environments, and family encouragement. Please have a pencil or crayon available and your smile. Win a prize!

About Melissa:

My name is Melissa Carper, National Workshop Director, with Diplomat Specialty Infusion Group. I currently live in Greensboro, North Carolina with my husband, 13 year old son with Severe Hemophilia A, and my 11 year old daughter. I have a B.S. degree in Education and I love that I have the opportunity to provide such valuable resources to the bleeding disorders community that allows everyone to be inspired, gain independence and build relationships. I enjoy playing soccer and doing anything craft related. Can't wait to meet you!

Note: If you need another bingo card, chose one from the links below.

BINGO CARD 1

BINGO CARD 2

BINGO CARD 3

Jeff McFall - Adversity, Strength, and Resilience

1:00 PM by Pfizer ~ Register Here

About the Program:

An overview of coping with chronic illness, communicating with the health care team and others regarding hemophilia, financial considerations of health care through life stages, and the importance of staying physically active with appropriate activities.

About Jeff:

Jeff holds a Bachelor of Science degrees in Human Ecology and Industrial Education from The University of Tennessee. His legacy in health care and health management dates more than 30 years, with the past 15 years in the hemophilia/bleeding disorders and rare disease space. Jeff's passion for community is evident by his overarching commitment to patients, caregiver, and advocacy groups. *"I have over 32 years of health care experience coupled with a true passion for community advocacy." - Jeff McFall*

June 13 - 1:00 PM Session

JEOPARDY AND KAHOOT

MARLEE
WHETTEN

TEEN PROGRAM

Which Way Do We Go?

Marlee Whetten - Jeopardy and KAHOOT
1:00 PM by NHF ~ Register Here

About the Program:

Who says virtual can't be fun? This competitive game-based workshop will test community member's knowledge on various bleeding disorders, our community history, and fun trivia. Each participant will need access to two screens (smartphone, tablet, or laptop) in order to participate.

About Marlee:

Marlee joined the Bleeding Disorder community after being diagnosed with vWD in her teens. She joined the Education Team at NHF in 2016 managing the National Youth Leadership Institute (NYLI). She loves working with teens and young adults to help them find their best selves and their independence – all while having as much fun as possible.

Julie Johnson and Sarah Mills

Art and Team Building / Creative Coping with COVID-19

2:00 PM by HTC Psychology Department~ Register Here

About the Program:

A 45-minute session about coping with COVID-19! During this session, you will complete an art activity while reviewing your coping efforts and learning new coping strategies. Connect with your peers!

About Julia and Sarah:

Julia and Sarah are psychology doctoral students at the University of South Carolina. They specialize in working with children and teens with chronic health conditions on issues related to stress and coping, school, and managing a medical condition. Sarah and Julia work alongside Dr. Jeff Schatz as part of Prisma Health's Psychosocial Team. They are involved in research and programming related to supporting youth and their families.

Note: This is the first part of a two part series. The series will continuously run with a 15 min intermission.

June 13 - 3:00 PM Session

PRISMA HEALTH

DOES YOUR PERSONALITY MATCH YOUR CAREER?

JULIA JOHNSTON - SARAH MILLS

SPEAKERS

Which Way Do We Go?

Julie Johnson and Sarah Mills

Does Your Personality Match Your Career?

3:00 PM by HTC Psychology Department~ Register Here

About the Program:

What is your dream career? Does your personality match it? During this session, Sarah and Julia will have you complete an individual personality quiz. You will learn about your personality characteristics and what careers best match your strengths! Also, play a fun ‘get to know you’ game and career Jeopardy.

About Julia and Sarah:

Julia and Sarah are psychology doctoral students at the University of South Carolina. They specialize in working with children and teens with chronic health conditions on issues related to stress and coping, school, and managing a medical condition. Sarah and Julia work alongside Dr. Jeff Schatz as part of Prisma Health’s Psychosocial Team. They are involved in research and programming related to supporting youth and their families.

Note: This is the second part of a two part series. The series will continuously run with a 15 min intermission.

Tanya Stephenson - Getting Ready for What's Next

2:30 PM by Sanofi Genzyme ~ Register Here

About the Program:

Discuss ways to help move smoothly from life stage to life stage; including tips for creating a support network, managing health needs, and staying informed about what resources are available.

About Tanya

Tanya Stephenson is a CoRe Manager at Sanofi Genzyme. Her role is to connect patients and their families with others in the community, introduce Sanofi Genzyme educational programs, and support you on your journey. Tanya is here so you can take action together! She is also a carrier of hemophilia and has a son with severe hemophilia A.

Thank You!

CHAPTER OF EXCELLENCE

To all our sponsors, speakers, presenters, staff members, the tech support team, and you our members, we thank you for attending our virtual conference. We also want the thank all who give of their time, treasures, and talents, our advocates, volunteers, and supporters, who make us who we are today. See you in 2021!

Thank You Again,

The Board and Staff of Hemophilia of South Carolina.