



SCHABDC & Ambassadors

2021 Advocacy Days Training

9:00 - 10:00 a.m. | Saturday, June 19

Agenda

ZOOM MEETING REGISTRATION LINK – tinyurl.com/2021hellojune19

- 9:00 a.m. **Welcome & Introductions**
Sue Martin, Executive Director, Hemophilia of South Carolina (HSC)
- 9:10 - 9:30 a.m. **Hemophilia of South Carolina’s 2021 Advocacy Accomplishments**
This session will provide an overview of HSC’s legislative and other policy accomplishments during the first half of 2021. These include legislative Advocacy Days, proclamations, and other initiatives that have furthered our mission. We will also review the Ambassador Program and why is it important to our advocacy mission.
- Sue Martin*, Executive Director, HSC
Cristal Day, Advocacy Coalition Chair, HSC
Jeremy Williams, Advocacy and Policy Consultant, HSC
Greg Witul, Chapter Development and Communications Coordinator, HSC
Member Voices of the of South Carolina Coalition and Ambassador Program
- 9:30 - 9:40 a.m. **National Policy Briefing**
This session will provide insight into recent and ongoing healthcare developments at the federal level, including an update on Congressional developments; the status of the Supreme Court’s hearing challenges to the Affordable Care Act; and relevant changes at the executive level that impact healthcare policy implementation.
- Nathan Shaefer*, Vice President of Public Policy, National Hemophilia Foundation
- 9:40 - 9:50 a.m. **Rare Disease Advisory Councils**
This portion of the program will look specifically at the benefits of rare disease councils and what they have accomplished in other states. It is an opportunity for members to get a better understanding of what impacts an RDAC can have in South Carolina for the bleeding disorders community and others.
- Annis Reed*, Regional State Policy Manager, East Coast, National Organization for Rare Diseases
- 9:50 - 10:00 a.m. **Juneteenth Recognition**
Juneteenth, which celebrates the abolition of slavery while remembering and honoring those held in bondage in the early years of our country, is the longest-running African-American holiday in the nation. It is typically celebrated on the third Saturday in June. As a sign of HSC’s continued dedication to inclusion and diversity within our community, we will end the training with a short video and recognition of this important day. We will include the opportunity to end the meeting with “Courageous Conversations”.
- 10:00 a.m. **Closing**
Advocacy members have the opportunity to share their advocacy experiences with meeting participants and close the training session with Q and A.