



# South Carolina Hemophilia & Bleeding Disorders Advocacy Coalition

Ambassadors, Coalition Members, and HSC Members  
Education, Training, and Advocacy Team Building Workshop

Virtual Meeting via Zoom  
September 26, 2020 10am – 2:00 pm  
Register here to join the meeting

<https://us02web.zoom.us/meeting/register/tZMtcuiqpi4jHtMUNV3gU-MCvv4Y1FT4dE4I>

## *Agenda*

- 10:00 - 10:15 a.m. Welcome and Introductions, Review Agenda  
HSC's New Advocacy Video Preview
- Sue Martin, Executive Director*  
*Jeremy Williams, HSC Advocacy Coordinator*  
*Cristal Day, Advocacy Coalition Chair*
- 10:30 - 11:00 a.m. **General Assembly Updates with SC House Rep. Jason Elliott**  
This session will feature discussions with Rep. Jason Elliott on the fall special session, State COVID response efforts, and what to look for in the upcoming 2021 legislative session. It is also a chance for our members to ask questions of their local elected official. We will present our concerns for access to care barriers in the State and what we would like to accomplish this upcoming 2021 session and how best that can be achieved. We will also learn and share our knowledge about the Co-Pay Accumulator Adjustment programs and how these programs negatively affect those with bleeding disorders.
- 11:00 – 11:30am. We will hear from chapters advocates who have held a virtual advocacy day this year with best practices and advice in the event we need to hold our advocacy days virtually in 2021 due to the pandemic.
- Representative Jason Elliott, South Carolina House District 22 (Greenville)*  
*Kollet Koulianos, Senior Director Payer Relations, National Hemophilia Foundation*  
*Charlene Cowell, Hemophilia of North Carolina*
- 11:30 - 12:30 p.m. Lunch Break
- 12:30 – 1:30 p.m. **National Policy Updates, Health Insurance 101, South Carolina Programs**  
In this session, we will hear general updates about the climate in Washington, including the status of Congress's coronavirus response initiatives, and the policy proposals national bleeding disorders advocacy organizations are working on. We will also hear about the status of the Affordable Care Act.
- We will have a discussion on general health insurance policies, State Medicaid updates, SC HAP Program, and disability qualification. Where can you turn for assistance if you are uninsured in SC and need help. It will cover medical healthcare policies acronyms like premiums, co-pays, deductibles, and max out-of-pocket costs, to more complex issues like the Accumulator Adjuster programs. Leave this session with a better understanding of

healthcare policy language and where to turn if you find yourself in need of additional information and assistance.

*Nathan Shaefer*, Vice President of Public Policy, National Hemophilia Foundation

*Kimberly Ramseur*, Senior Manager for Policy and Advocacy,  
Hemophilia Foundation of America

*Marla Feinstein*, Senior Policy and Healthcare Analyst

*Tammy McKenna*, Director, CYSHCN, DHEC

*Sue Martin*, Executive Director, Hemophilia of South Carolina

1:30 - 2:00 p.m.

Time for Questions and Final Remarks