



January 1, 2018

Dear HSC Members and Friends:

Hemophilia of South Carolina would like to invite you and your family to participate in our *9th Annual State Advocacy Days* at the state capitol in Columbia. This is your chance to meet with your elected state officials and educate them about bleeding disorders and the many unique challenges and needs of our community. We will begin with an Advocacy Day training the evening of Tuesday, February 27, which will take place at the *Marriott Courtyard Columbia Downtown at USC Columbia*, 630 Assembly St. Columbia, SC 29201; (803) 799-7800. We will continue with meetings with lawmakers throughout most of the morning of Wednesday, February 28. Also, this year, we will have a booth in the first floor lobby of the State House. We will need several members to help present educational materials at that stand. This event is free to our members, but please register as soon as possible, so that we can begin to plan our activities.

Tuesday night's dinner session will offer informational presentations and discussions on our talking points, bills we are supporting or opposing, and any concerns we are addressing as a community. You also will receive any other necessary Advocacy Day training, so that you will be well prepared to meet with your elected officials. Let us come together with this common bond and special purpose as we enjoy dinner, presentations, and meeting fellow attendees. Your attendance is so very much needed and appreciated!

We will regroup on the morning of Wednesday, February 28, to visit the General Assembly buildings to meet with members of the House of Representatives and the Senate, as well as their staff. Now is the time to be thinking about what you want your representative or senator to know about hemophilia, bleeding disorders, yourself and your family. You are the experts, and your stories can have monumental impacts on the people making critical healthcare decisions for everyone South Carolina. Education opens many closed doors. This is a unique opportunity to make your voices heard and advocate for support for bleeding disorders resources in South Carolina. The chapter is very excited to have this time afforded to us and hope that you will come out and be a voice for Hemophilia of South Carolina!

We are grateful to our participating advocacy partners and sponsors for their continued leadership and assistance; including the National Hemophilia Foundation and the Hemophilia Federation of America for their partnership, public policy expertise, and advocacy leadership.

For more information about how to register for the event and lodging, please see the enclosed form. Upon request, the chapter can provide documentation for your place of business or for your child's school to explain any absences. Lodging and meals are included, and travel assistance will be offered as needed to attend.

You may also register online on our website at www.hemophiliasc.org. Click on the Advocacy banner and go directly to our State Advocacy Days Page for the registration link.

If you have any special needs concerning this event, such as mobility, attendance, etc., please communicate them when registering. We look forward to seeing you and your family at this important event.

Thank you for your partnership in advocacy!

Quick Schedule View

Tuesday, February 27, 2018

4:00pm: Hotel Check-in

5:30pm: Registration with HSC

6:00pm: Welcome Remarks

6:10pm-8:30pm: Working dinner, presentations, and advocacy training workshop.

Wednesday, February 28, 2018

6:30-8:00am: Breakfast in the Hotel (overnight participants only), Group Photo

9:00-1:00pm: Meetings with Legislators (all members meeting times vary)

12:00-2:00pm: Lunch at the Hotel and wrap-up discussions, evaluations



YES, YOU CAN!

YOU CAN... be a leader at Statehouse Days 2018!

Youth and young adults from across South Carolina will be spending time together learning how to **RAISE THEIR VOICE** and educate South Carolina lawmakers about their bleeding disorders.

You will learn how to bring your unique insights, perspective and experiences into public policy discussions. You will learn methods for reaching out to legislators to tell **YOUR STORY**. You will learn the skills to become a partner with your legislators in the decision-making process so they pass legislation that benefits your life and the life of your family.

Please join your peers and HSC in this advocacy project. Together with your family join us for Advocacy Days. We would like to encourage our youth and young adults to attend this special and exciting event. This is such a great opportunity to let your voice be heard by the lawmakers of South Carolina and as an added bonus, your resume and scholarship applications will get a boost for your Community Service for Hemophilia of South Carolina.

2018 HSC Advocacy Days Registration Form

Please register me/us in the Advocacy Day activities:

Dinner Tuesday and Meetings on Wednesday: Yes_____

A hotel room will be provided to members attending legislative meetings on Wednesday living outside the Columbia area. Travel grant assistance may also be available upon request for distance travelers.

Please use the following address in order to identify my appropriate Legislative Representative:

Head of Household Name:

Street Address_____

City _____ State _____ Zip_____

Phone contact_____

E-mail contact_____

***Your information will be kept confidential.

Participant Name:_____ Bleeding Disorder: Y /N

Participant Name:_____ Bleeding Disorder: Y /N

Participant Name:_____ Bleeding Disorder: Y /N

Child's Name: _____ age: _____ Bleeding Disorder: Y/N

Child's Name: _____ age: _____ Bleeding Disorder: Y/N

Accommodations

I / We will need hotel accommodations for the night of February 27, 2018 Yes _____ No_____

1. Room Type: _____ 2 Queen Beds _____ 1 King Bed

Please return completed registration form by February 11, 2018- you will receive a confirmation notice of your registration with any added agenda information.

Mail, fax or e-mail to our Office Address below at:

Hemophilia of South Carolina
439 Congaree Road, Box #5
Greenville, SC 29607

E-mail: Sue.martin@hemophiliasc.org
Fax: 864.244.8287

Register online on our website at <http://hemophiliasc.org/advocacy/advocacy-day-state-capitol-day/>
The online link is under the REGISTRATION Information.