

SUPPORTING THOSE LIVING WITH BLEEDING DISORDERS FEBRUARY 28TH - APRIL 17TH

### **Annual Giving and Awareness Campaign**

The Bleeding Disorders Association of South Carolina's Annual Giving drive is held every year during the month of March as part of the Bleeding Disorders Awareness Month. Funds raised during the campaign help us support research, global initiatives, provide community advocacy and education, and help us secure access to quality treatment care. All donations to our Campaign stay within South Carolina to serve our community. BDASC's Bleeding Disorders Awareness Campaign runs from Rare Disease Day, February 28th through World Hemophilia Day on April 17th. For more information and to help us reach our \$2,500 goal, please visit our campaign website from **www.bda-sc. org** or <u>https://tinyurl.com/2025BDAM.</u>

### **Bleeding Disorders Awareness Events**

February 25th - 26th - State Advocacy Days February 28th - Rare Disease Day March 1st - von Willebrand Disease Awareness Day (Virtual Event) March 5th - 7th - NBDF's Washington Days March 15th - Ultra Rare/Platelet Disorders Awareness Day (Virtual Event) March 17th - Go Red for March - wear Red in support of Bleeding Disorders March 31st - Women Who Bleed Awareness Day (Virtual Event) April 17th - World Hemophilia Day

Visit our website for more information on these events at <u>www.bda-sc. org</u>





## **Securing Proclamations**

Help us raise awareness about Bleeding Disorders by asking your local Towns and Counties for a Proclamation! All you need to do is take one of the forms from our campaign website page and provide it to your Town or City council representative with a note saying , "I would like our (town/ city) to recognize March as Bleeding Disorders Awareness Month". That's all. You can do the same thing at the county level using the County form. Visit <u>tinyurl.com/2025BDAM</u> for more information and contact the Chapter for additional assistance.

#### **Men and Women's Retreat**

We are excited to provide this weekend symposium to our membership adults, ages 21 and over, who are living with bleeding disorders themselves, are carriers of a genetic bleeding disorder, or are caretakers for someone in their immediate family who is affected. Visit <u>https://bdasc.org/events/educational-programs/adult-workshops/</u> for more information.

#### **Go Red for March**

During Bleeding Disorders Awareness Month, have some fun and start a conversation as you wear some red on **March 17th**! Take a picture and tag us on Social Media in support of your efforts!

#### Our advocacy efforts continue on the back page!

# **BDASC State Advocacy Days February 25- February 26, 2025**

BDASC will be holding it's 16th Annual Advocacy and State Legislative Days during March as part of the National Bleeding Disorder Awareness Month. BDASC, along with our national partners, will be hosting advocacy training sessions leading up to the event. This important advocacy event fosters educational awareness with state legislators on the effects living with bleeding disorders can have on families. Health care access continues to be a threat to accessing high cost medications. We need **YOU** to help us share the impact this may have on the quality of life for those with bleeding disorders. You will have the opportunity to have important discussions and to ask for support on key areas of concern for access to affordable treatment care. Since its inception, our State Capitol Advocacy Days have provided for over 500 individual meetings with the South Carolina House of Representatives and our State Senators from districts throughout the state. These meetings are of key importance in helping our elected officials understand our communities unique needs while asking for support of our state programs that provide a safety net to those in need.

Advocacy training is provided in partnership with our national organizations; The National Bleeding Disorders Foundation, Hemophilia Federation of America, PhRMA, and our stakeholders, and other local and national advocacy partners. Additional information about our State Advocacy Days can be found at <u>bda-sc.org/state-</u> <u>capitol-days/</u>. Registration deadline for hotel rooms and legislative meetings is February 10, 2025.

# **NBDF Washington Days March 5th - 7th**

As a member of NBDF's State Based Advocacy Coalition, our commitment to access to care has never been stronger. We encourage all our advocates to sign up for Washington Days this year. By now, many of you have heard about Accumulator Adjustment programs and the devastating effects the can have on our community. In the next years, these programs will only get worse! Be sure to join us for NBDF's Washington Days so we can head off these barriers and ensure your access to quality care and treatment. Washington Days will take place on March 5-7, 2025. For South Carolina to have the most impact, we need members from each Congressional District to register so we can meet with every Congressmember representing South Carolina. The more members we meet with, the greater the impact we will have. If you are unsure what Congressional District you live in, contact the Chapter. Last year, volunteer advocates met with legislators and staff to discuss federal funding for bleeding disorder programs and the Accumulator Adjustment Programs. The issues and priorities for 2025 Washington Days will be announced soon. Join BDASC and community members throughout the nation on the hill and make your voice heard! Contact the chapter office for more information.



