

# HSC Advocacy Days 2021!

## Virtually March 9 - 11

Please join us as we raise awareness of bleeding disorders with our state legislators during the "National Bleeding Disorders Awareness Month". Be part of this unique virtual opportunity to educate your elected state representatives. Advocacy is within all of us and it is up to our community to make our needs known to those who can affect change. We need your voice to help us enact a Rare Disease Advisory Council in the state, support state programs that assist in access to care and treatment and prevent insurance programs that cause financial hardships and barriers to treatments.

### **Support adding a Rare Disease Council to the Newborn Screening Advisory Committee - Bill H 3233**

A Rare Disease Advisory Council in SC would provide a unified voice for rare disease patients, and a forum to make recommendations to elected officials and other state leaders about pressing healthcare issues. Composed of qualified professions and persons living with rare diseases, they could educate medical professionals, government agencies, legislators, and the public, about rare diseases as an important public health issue and encourage and secure funding for research for the development of new treatment for rare disease. They would also work with legislators and other government leaders to improve public policy throughout the entire state.

### **Support the South Carolina Hemophilia Assistance Program (HAP)**

The State-funded program in the Dept. of Health & Environmental Control (DHEC) was established to assist state residents with bleeding disorders by offering insurance case management and financial assistance for private health insurance premiums and co-pay assistance (for plans purchased through the South Carolina marketplace). *The HAP program saves money for the state and diminishes the threat of future costs by keeping people healthier, more likely to gain and maintain employment, and less reliant on other government safety nets.*

### **Accumulator Adjuster Programs Awareness**

Raise awareness of the financial damage Accumulator Adjuster Programs do to families when their Co-pay cards don't count towards their out-of-pocket totals.

**[Register NOW: tinyurl.com/HSC3921](https://tinyurl.com/HSC3921)**

