

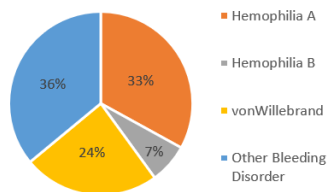
Facts about Bleeding Disorders in South Carolina

- 1 A bleeding disorder is a rare and complicated disorder in which the blood does not clot properly. This can lead to spontaneous bleeding as well as bleeding following injuries or surgery.
- 2 The most common types are hemophilia and von Willebrand Disease (vWD). Blood contains many proteins called clotting factors that can help to stop bleeding. People with hemophilia have low levels of either factor VIII (8) or factor IX (9). The lower the amount of the factor, the more likely it is that bleeding will occur which can lead to serious health problems. Currently, there is no cure.
- 3 There are nearly 4,000 known genetic variants in hemophilia, making identifying which mutation that affects a family extremely important for coordinating proper treatment.
- 4 Hemophilia and vWD affect all racial and ethnic groups equally.
- 5 The CDC estimates that vWD affects approximately 1 percent of the population, which would mean that some 50,000 individuals in South Carolina have the disease, perhaps have not been diagnosed with it, and therefore are at risk of not receiving the proper medical treatment needed to prevent and/or treat bleeds.
- 6 Hemophilia and vWD are two of about 7,000 "rare diseases" that exist today. Collectively, rare diseases affect one in every 10 Americans, or some 30 million people nationwide, and more than half of these are children. Overall, hemophilia occurs in approximately one in every 5,000 births. There are about 20,000 people living with hemophilia in the United States today.

Treatment

Treatment varies by diagnosis, but most patients with hemophilia require an intravenous injection of clotting factor. This can be quite expensive; according to the National Hemophilia Foundation, the average annual cost to treat hemophilia per patient is **\$250,000**. Patients can receive comprehensive care from medical experts at the federally funded treatment center, at Palmetto Health Richland Hospital, in Columbia. For information contact, 803-434-1028.

Identified Bleeding Disorders in South Carolina



HSC has currently identified 521 patients with bleeding disorders being treated at the Palmetto Health Hemophilia Treatment Center, as well as two other major medical facilities that specialize in the treatment of bleeding disorders, Greenville Health Systems and the Medical University of South Carolina.

Hemophilia of South Carolina

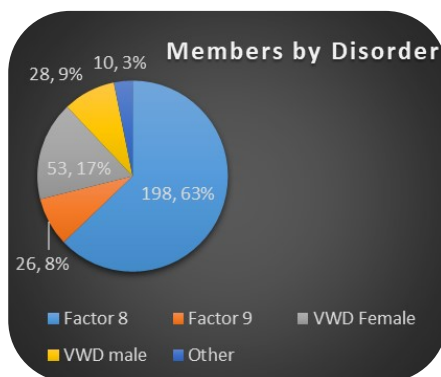
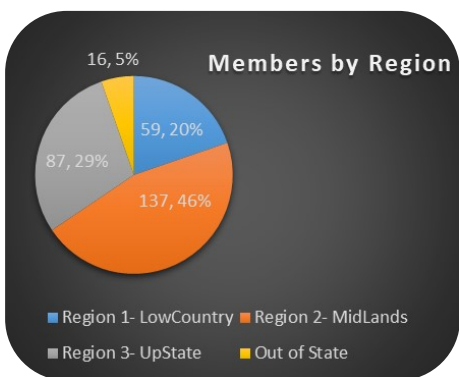
Bleeding Disorders



Advocacy

HSC maintains a strong coalition, made up of partnerships with national hemophilia foundations, other health-related advocacy organizations, hospitals, doctors, and of course individuals who contribute a great deal of their time and resources to furthering HSC's mission of furthering awareness and education about bleeding disorders. **The mission of the coalition is to Empower the Hemophilia and Bleeding Disorders Community in South Carolina to speak to public and private decision-makers about improving Access to Quality and Affordable Health Care and Treatment.**

Our Stories Matter!



We host an official awareness day at the state capitol every year. Nearly 100 participants join us each year to raise awareness and provide a voice for those affected in South Carolina. We have had over 250 meetings with our State Representatives and Senators. Find out more through our website, <http://hemophiliasc.org/advocacy/advocacy-coalition/>



HEMOPHILIA
of South Carolina
SERVING ALL BLEEDING DISORDERS

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Hemophilia of South Carolina is the only advocacy agency in South Carolina that provides education, advocacy, and supportive services for those affected by bleeding disorders, including family members and caregivers, well over 900 individuals combined.



www.hemophilia.org



www.hemophiliafed.org