

SUPPORT THE HEMOPHILIA ASSISTANCE PROGRAM (HAP)



SUPPORT THE HEMOPHILIA ASSISTANCE PROGRAM (HAP)

The purpose of this state-funded program is the purchase of blood products for persons with hemophilia or other congenital blood clotting disorders.

- State-funded program in the Dept. of Health & Environmental Control (DHEC)
- 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).
- DHEC uses state funds to help eligible persons become enrolled in a marketplace insurance plan. The HAP program covers comprehensive as well as preventative healthcare services relevant to bleeding disorders.
- Must have income at or below 250% of the federal poverty level (FPL), ineligible for Medicaid or Medicare, non-insured, U.S. citizen or lawful permanent resident, and not eligible for insurance under any other plan.
- Is vital to the health and livelihood of people with bleeding disorders, ensuring they continue to have access to life-saving clotting factor medications. Currently, there are 16 enrollees in the program.
- HSC encourages continued funding and support for the HAP program, to help patients who have no other place to turn for assistance, in order that consistent, uninterrupted healthcare access is guaranteed. 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.

○ *What is the annual revenue for an individual at 250% (FPL)?*

Answer: \$31,900.00- according to 2020 Federal Department of Health and Human Services

ESTABLISH A RARE DISEASE ADVISORY COUNCIL (RDAC)



ESTABLISH A RARE DISEASE ADVISORY COUNCIL - H3956

The Importance of Creating a South Carolina Rare Disease Advisory Council (RDAC)

- According to the National Organization for Rare Disorders (NORD), there are 7,000 known rare diseases impacting the lives of 1 in 10 Americans, the majority of whom are children. Based on that ratio, more than 500,000 South Carolinians are living with a rare disease. A rare disease is a disease that affects fewer than 200,000 individuals living in the US.
- For many of these diseases it can take years to receive an accurate diagnosis and effective treatment.
- While 95 percent of rare diseases do not have treatment options, for those that do, the cost of medications has risen 54% in the last four years.
- Hemophilia of South Carolina (HSC) has been working with the National Organization of Rare Diseases and a number of rare disease patient advocacy groups in South Carolina to develop legislation to create a Rare Disease Advisory Council (RDAC) in South Carolina.
 - An RDAC 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 professionals and persons living with rare diseases, the RDAC could educate medical professionals, government agencies, legislators, and the public about rare diseases as an important public health issue.
 - Would serve as a forum for information on the provider-patient relationship and identify “best practices” throughout the nation.
 - Would work with legislators and other government leaders to improve public policy throughout the entire state.
 - Would also serve as an educational resource to all stakeholders about the ways in which rare disease patients interact with the healthcare system.
 - People with rare diseases face many challenges, including delays in obtaining a diagnosis, misdiagnosis, shortages of medical specialists who can provide treatment, and a lack of access to therapies and medication for treatment.
- 16 states have now established a Rare Disease Advisory Council
- [Please support H3956 to establish a Rare Disease Advisory Council for South Carolina](#)

SUPPORT ANTI- ACCUMULATOR ADJUSTMENT PROGRAM LEGISLATION



SUPPORT ANTI - ACCUMULATOR ADJUSTMENT PROGRAM LEGISLATION

The importance of anti-accumulator adjustment legislation is to help ensure that individuals and families with chronic health conditions, like hemophilia, can access medications necessary for keeping them healthy and (in some cases) alive, with the help of co-pay assistance cards.

- Many pharmaceutical companies offer co-pay assistance cards to help cover the patient's portion of medication costs. Until recently, pharmacy benefits managers have allowed these payments to count towards a patient's out-of-pocket costs.
- Accumulator adjustment programs prevent any co-payment assistance for high-cost specialty drugs from counting towards a patient's deductible or annual out-of-pocket maximums.
- The monthly cost of many patients' medications, such as those for bleeding disorders, can easily exceed the deductible. This means that many patients are faced with the choice of either paying thousands of dollars (if they are able to) for their medications, or going without.
- Ostensibly, these programs are intended to incentivize patients to select cheaper generic medications. However, with many serious chronic diseases, like hemophilia, no such generic alternatives are available.
- Patients are often unaware that these new parameters are implemented in their plans. These programs often have deceptive names, like "Benefit Protection Program," and marketed as having positive impacts on beneficiaries.
- At least five states (Arizona, Georgia, Illinois, Virginia, and West Virginia) have passed bills that prohibit or limit the implementation of accumulator adjuster programs in health plans sold within the state.