

BLEEDING DISORDERS ASSOCIATION OF SOUTH CAROLINA



SUPPORT THE SOUTH CAROLINA HEMOPHILIA ASSISTANCE PLAN (HAP)

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

BDASC urges 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.

- State-funded program in the Department 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, SC 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 14 enrollees in the program.

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

Answer: \$32,200 for an individual and \$66,250 for a family of four, according to the 2021 Federal Department of Health and Human Services.

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SUPPORT FOR RARE DISEASE ADVISORY COUNCIL (RDAC)

The Importance of Having an established South Carolina Rare Disease Advisory Council (RDAC)

BDASC urges support of the South Carolina RDAC, through adequate funding and efforts to ensure that it becomes a permanent entity in the state.

- 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 U.S.
- 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.
- 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.
- 20 states have now established a Rare Disease Advisory Council (RDAC). Last year, through a *proviso* issued by Governor Henry McMaster, approval was given for the establishment of an RDAC at the Medical University of South Carolina.
- Current RDAC responsibilities:
 - Solicit comments from stakeholders, including patients and patient caregivers in South Carolina impacted by rare diseases, to assess the needs of rare-disease patients, caregivers, and providers in the State;
 - Consult with experts on rare diseases to develop recommendations to improve patient access to and quality of rare-disease specialists, affordable and comprehensive health care coverage, relevant diagnostics, timely treatment, and other needed services;
 - Research and identify priorities related to treatments and services provided to persons with rare diseases in South Carolina and develop recommendations that include safeguards against discrimination for these populations on such issues, including disaster and public health emergency-related planning;

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- Publish a list of existing, publicly accessible resources on research, diagnosis, treatment, and education relating to the rare diseases in South Carolina;
- Identify and distribute educational resources to foster recognition and optimize treatment of rare diseases in South Carolina; and
- Identify best practices to reduce health disparities and achieve health equity in the research, diagnosis, and treatment of rare diseases in South Carolina.
- Report annually (by June 30) to the Governor, the Chairman of the Senate Finance Committee, the Chairman of the Senate Medical Affairs Committee, the Chairman of the House Ways and Means Committee, and the Chairman of the House Medical, Military, Public and Municipal Affairs Committee.

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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 and other bleeding disorders, can access medications necessary for keeping them healthy and (in some cases) alive, with the help of co-pay assistance cards.

[BDASC urges support and consideration of sponsoring H4987 that would require insurers and pharmacy benefits managers to include cost-sharing amounts paid when calculating an enrollee's contribution.](#)

- 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 are marketed as having positive impacts on beneficiaries.
- At least 12 states (Arkansas, Arizona, Connecticut, Georgia, Kentucky, Illinois, Louisiana, North Carolina, Oklahoma, Tennessee, Virginia, and West Virginia) and Puerto Rico have passed bills that prohibit or limit the implementation of accumulator adjuster programs in health plans sold within the state. This year, legislation has been filed in at least another dozen states.
- National rare disease advocacy organizations, including those representing persons with bleeding disorders, are urging the Centers for Medicare and Medicaid Services (OVER)

- to issue guidance on this issue. They also are exploring the prospect of federal legislation that would prohibit such programs.
- BDASC also urges South Carolina legislators to find other solutions to accumulator programs that exist in health plans sold in the state, as they limit the ability of beneficiaries to access vital and sometimes life-saving medications.