

## Amendment: 20

**Representative HERBKERSMAN proposes the following amendment:**

### GENERAL PROVISIONS

New

117.rdac (GP: Rare Disease Advisory Council) (A) For the current fiscal year, there shall be established the South Carolina Rare Disease Council, to be housed within the Medical University of South Carolina. The council shall advise the Governor, the General Assembly, and other stakeholders on research, diagnosis, treatment, and education related to rare diseases as defined by 21 U.S.C. Section 360bb.

(B) The council shall be composed of fifteen members and shall be appointed as follows:

(1) one member appointed by the Director of the Department of Health and Environmental Control;

(2) one member appointed by the Director of the Department of Health and Human Services;

(3) one member from the Medical University of South Carolina as appointed by the President;

(4) one member from the University of South Carolina School of Medicine as appointed by the Dean;

(5) one member appointed by the Executive Director of the South Carolina Hospital Association;

(6) one member appointed by the Executive Director of the South Carolina Primary Healthcare Association;

(7) one member representing the biopharma industry as appointed by the President of the Medical University of South Carolina;

(8) three members with experience in the research and treatment of rare disease, one of whom must specialize in pediatrics, as appointed by the President of the Medical University of South Carolina;

(9) two members who are patients diagnosed with a rare disease as appointed by the President of the Medical University of South Carolina;

(10) one member from a rare disease organization operating in the state as appointed by the President of the Medical University of South Carolina;

(11) one caregiver of a person with a rare disease as appointed by the President of the Medical University of South Carolina; and

(12) one member representing the state health plan as appointed by the Executive Director of the State Public Benefit Authority.

(C) The council shall convene its first meeting by October 31 and hold public meetings at least quarterly throughout the year. The council shall, at a minimum, conduct the following activities to benefit rare disease patients in South Carolina:

(1) 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;

(2) 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;

(3) 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;

(4) publish a list of existing, publicly accessible resources on research, diagnosis, treatment, and education relating to the rare diseases in South Carolina;

(5) identify and distribute educational resources to foster recognition and optimize treatment of rare diseases in South Carolina; and

(6) identify best practices to reduce health disparities and achieve health equity in the research, diagnosis, and treatment of rare diseases in South Carolina.

(D) The council shall provide an annual report no later than 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. The annual report shall describe the activities and progress of the council and provide recommendations to the Governor and

General Assembly on ways to address the needs of people living with rare diseases in the state of South Carolina.

(E) The Medical University of South Carolina shall provide staff support to the council and set up a public website that shall include the annual reports, meeting notices and minutes, and the resources developed as part of section (C). Members of the council shall serve without compensation or per diem.