**A** **BILL**

TO AMEND THE CODE OF LAWS OF SOUTH CAROLINA, 1976, BY ADDING SECTION 44‑1‑320 SO AS TO ESTABLISH THE “SOUTH CAROLINA RARE DISEASE ADVISORY COUNCIL” WITHIN THE DEPARTMENT OF HEALTH AND ENVIRONMENTAL CONTROL, TO PROVIDE FOR THE PURPOSE, DUTIES, MEMBERSHIP, AND FUNDING OF THE COUNCIL, TO ESTABLISH CERTAIN REPORTING AND MEETING REQUIREMENTS, AND FOR OTHER PURPOSES.

Whereas, a rare disease, sometimes called an orphan disease, is defined as a disease that affects fewer than two hundred thousand people in the United States; and

Whereas, there are seven thousand known rare diseases affecting approximately twenty‑five to thirty million adults and children in the United States; and

Whereas, people with rare diseases face many challenges, including delays in obtaining a diagnosis, misdiagnosis, shortages of medical specialists who can provide treatment, and lack of affordable access to therapies and medication used to treat rare diseases; and

Whereas, a state‑based advisory council composed of qualified professionals and persons living with rare diseases could educate medical professionals, governmental 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 treatments for rare diseases. Now, therefore,

Be it enacted by the General Assembly of the State of South Carolina:

SECTION 1. Chapter 1, Title 44 of the 1976 Code is amended by adding:

“Section 44‑1‑320. (A) The South Carolina Rare Disease Advisory Council (council) is established within the Department of Health and Environmental Control in accordance with this section.

(B) The purpose of the council is to advise the General Assembly and other governmental agencies and departments, as appropriate, on the needs of individuals with rare diseases living in South Carolina.

(C) The council shall conduct the following activities to benefit rare disease patients in South Carolina:

(1) convene public hearings, make inquiries, and solicit comments from the general public in South Carolina to assist the council with a first‑year landscape or survey of the needs of rare‑disease patients, caregivers, and providers in the State;

(2) consult with experts on rare diseases on the council and externally, as needed, to develop policy 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 policy recommendations that include safeguards against discrimination for these populations on such issues, including in 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 on the council’s website;

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

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

(D)(1) The Governor shall appoint the chair of the council within thirty days of enactment of this section. The chair may not hold any position within the government of South Carolina.

(2) The chair shall appoint the following members:

(a) one representative from the South Carolina Department of Health and Environmental Control or Office of Minority Health in the department;

(b) one registered nurse or advanced practice registered nurse licensed and practicing in South Carolina with experience treating rare diseases;

(c) one physician practicing in South Carolina with experience treating rare diseases;

(d) at least two patients who have a rare disease;

(e) at least one caregiver of a person with a rare disease;

(f) two representatives of different rare‑disease patient organizations that operate in South Carolina;

(g) one representative of the biopharma industry;

(h) one representative of a health plan company; and

(i) one member of the scientific community who is engaged in rare‑disease research including, but not limited to, a medical researcher with experience conducting research on rare diseases.

(E)(1) The council shall submit a report to the Governor within one year of enactment of this section and annually thereafter.

(2) The annual report must:

(a) describe the activities and progress of the council as set forth in subsection (C);

(b) provide an update on the status of funding of the council including, but not limited to, grants applied for, received, used, and remaining balances; and

(c) 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.

(3) A draft of the annual report must be provided for public comment and discussed at an open public meeting and submitted to the Governor and the ranking members of the Senate Medical Affairs Committee, Senate Finance Committee, House Medical, Military, Public and Municipal Affairs Committee, and House Ways and Means Committee.

(F)(1) Members of the council may solicit funds on behalf of the council.

(2) The council shall set up a method to securely hold and distribute funds.

(3) The council shall report funding sources in its annual report.

(4) There is no limit on the amount of funds the council is authorized to accept.

(5) The council may use the funding to carry out duties set forth in subsection (C).

(G)(1) The initial meeting of the council must occur within ninety days of enactment of this section followed by in‑person or virtual monthly meetings for a period of time, as determined by the chair. Thereafter, the council shall meet on a quarterly basis in person or virtually, pursuant to a schedule determined by the chair and vice chair.

(2) The council shall provide opportunities for the public to hear updates and provide input into the work of the council, and shall create and maintain a public website on which meeting notices and minutes are posted and public comment may be submitted.

(H)(1) Initially, the Governor shall appoint a chair for an initial term of three years. At the end of the chair’s initial three‑year term, and every two years thereafter, the members of the council shall appoint, by a majority vote, a new chair to serve for a two‑year term.

(2) A council member may not serve any longer than two years.

(3) If a vacancy on the council occurs, the members, by a majority vote, shall fill the vacancy in a timely manner.

(I) Members shall serve without compensation and are ineligible for the usual mileage, subsistence, and per diem allowed by law for members of state boards, committees, and commissions.”

SECTION 2. This act takes effect upon approval by the Governor.

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