**A** **BILL**

TO AMEND SECTIONS 44‑37‑30, AS AMENDED, AND 44‑37‑35, CODE OF LAWS OF SOUTH CAROLINA, 1976, RELATING IN PART TO THE “NEWBORN SCREENING ADVISORY COMMITTEE”, SO AS TO RENAME THE COMMITTEE THE “NEWBORN SCREENING AND RARE DISEASE COUNCIL” AND TO ESTABLISH CERTAIN REQUIREMENTS FOR MEMBERS OF THE COUNCIL.

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

SECTION 1. Section 44‑37‑30(H) of the 1976 Code, as added by Act 55 of 2019, is amended to read:

“(H) The department shall establish the Newborn Screening ~~Advisory Committee~~ and Rare Disease Council to review the feasibility and advisability of including additional metabolic, genetic, and congenital disorders in the neonatal testing conducted pursuant to this section and to advise the Governor, the General Assembly, and the department on research, diagnosis, treatment, and education relating to rare diseases. The ~~committee~~ council must be multidisciplinary and composed of members deemed appropriate by the department including, but not limited to:

(1) an emergency room physician licensed and practicing in the State;

(2) a medical researcher with experience conducting research concerning rare diseases;

(3) at least two persons age eighteen or older who have a rare disease;

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

(5) at least three representatives of a rare disease patient organization that operates in the State.”

SECTION 2. Section 44‑37‑35(B) of the 1976 Code, as added by Act 55 of 2019, is amended to read:

“(B) The department shall require additional lysosomal storage disorders to be tested upon the recommendations of the Newborn Screening ~~Advisory Committee~~ and Rare Disease Council and in accordance with Section 44‑37‑30 pursuant to a duly promulgated regulation as testing for such disorders becomes available.”

SECTION 3. This act takes effect upon approval by the Governor.

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