**A** **BILL**

TO AMEND SECTION 44‑36‑10 OF THE 1976 CODE, RELATING TO THE PURPOSE AND FUNCTIONS OF THE ALZHEIMER’S DISEASE REGISTRY, TO EXPAND THE TYPES OF DATA COLLECTED BY THE ALZHEIMER’S DISEASE REGISTRY, AND TO PROVIDE FOR THE AUTHORIZATION OF STUDIES ABOUT ALZHEIMER’S DISEASE AND THE CAREGIVERS OF PERSONS WITH ALZHEIMER’S DISEASE.

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

SECTION 1. Section 44‑36‑10 of the 1976 Code is amended to read:

“Section 44‑36‑10. (A) There is established within the University of South Carolina School of Public Health the Alzheimer’s Disease Registry to provide a central information data base on individuals with Alzheimer’s disease or related disorders to assist in the development of public policy and planning.

(B) The functions of the registry include, but are not limited to:

(1) collecting data to evaluate the incidence, prevalence, and causes of Alzheimer’s disease and related disorders in South Carolina;

(2) providing information for policy planning purposes; and

(3) providing nonidentifying data to support research on Alzheimer’s disease and related disorders.

(C) In gathering data the registry shall rely upon, to the extent possible, data from existing sources; however, the registry may contact families and physicians of persons reported to the registry for the purpose of gathering additional data and providing information on available public and private resources. The registry is authorized to conduct follow‑back studies, prospective studies of the progression and treatment of Alzheimer’s disease and related disorders, and research on caregiving for individuals with Alzheimer’s disease or a related disorder, on services used by individuals with Alzheimer’s disease or a related disorder, and on causes of Alzheimer’s disease and related disorders that examines risks associated with area of residence. Patient contact following data received from the State Budget and Control Board Office of Research and Statistics must be done in accordance with regulations approved by the South Carolina Data Oversight Council and promulgated by the Office of Research and Statistics. Caregivers must provide informed consent to participate in research on caregiving.”

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

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