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CHAPTER 36.

 ALZHEIMER’S DISEASE AND RELATED DISORDERS

ARTICLE 1.

 ALZHEIMER’S DISEASE REGISTRY

**SECTION 44‑36‑10.** Establishment of Registry; purpose and functions; sources of data.

(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 examine 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 44‑36‑20.** Advisory committee; membership; duties; prohibition against compensation.

(A) The School of Public Health shall appoint an advisory committee to assist in maintaining this registry which must include, but is not limited to, a representative of:

(1) South Carolina Alzheimer’s Association chapters;

(2) American Association of Retired Persons, South Carolina Chapters;

(3) Clemson University;

(4) Department of Disabilities and Special Needs;

(5) Department of Health and Environmental Control;

(6) Department of Mental Health;

(7) Department of Social Services;

(8) Department of Health and Human Services;

(9) Medical University of South Carolina;

(10) National Association of Social Workers, South Carolina Chapter;

(11) South Carolina Adult Day Care Association;

(12) South Carolina Association of Area Agencies on Aging;

(13) South Carolina Association of Council on Aging Directors;

(14) South Carolina Association of Nonprofit Homes for the Aging;

(15) South Carolina Association of Residential Care Homes;

(16) South Carolina Health Care Association;

(17) South Carolina Home Care Association;

(18) South Carolina Hospital Association;

(19) South Carolina Medical Association;

(20) South Carolina Nurses’ Association;

(21) Alzheimer’s Disease and Related Disorders Resource Coordination Center, Office of the Governor, Division on Aging;

(22) University of South Carolina;

(23) South Carolina State University.

(B) The advisory committee shall assist the registry in:

(1) defining the population to be included in the registry including, but not limited to, establishing criteria for identifying patient subjects;

(2) developing procedures and forms for collecting, recording, analyzing, and disseminating data;

(3) developing protocols and procedures to be disseminated to and used by health care providers in identifying subjects for the registry;

(4) developing procedures for approving research projects or participation in research projects.

(C) Members of the advisory committee are not entitled to mileage, per diem, subsistence, or any other form of compensation.

**SECTION 44‑36‑30.** Confidentiality; release of identifying information upon consent.

(A) The School of Public Health and all persons to whom data is released shall keep all patient information confidential. No publication of information, biomedical research, or medical data may be made which identifies the patients. For purposes of maintaining this registry, the School of Public Health may access appropriate confidential data reported to the Office of Research and Statistics in accordance with Section 44‑6‑170.

(B) Except for use in collecting data on deaths from the Bureau of Vital Statistics, Department of Health and Environmental Control, no identifying information collected or maintained by the registry may be released unless consent is obtained from the subject or the subject’s legal representative.

**SECTION 44‑36‑40.** Immunity from liability for divulging confidential information.

Neither the registry or the School of Public Health nor a person, medical facility, or other organization providing or releasing information in accordance with this article may be held liable in a civil or criminal action for divulging confidential information unless the person or organization acted in bad faith or with malicious purpose.

**SECTION 44‑36‑50.** Annual report requirement.

The registry shall submit an annual report to the Office of the Governor, Division on Aging, Alzheimer’s Disease and Related Disorders Resource Coordination Center, the Department of Health and Environmental Control, and the Budget and Control Board, Division of Research and Statistics, Health Statistics.

ARTICLE 3.

 ALZHEIMER’S DISEASE AND RELATED DISORDERS RESOURCE COORDINATION CENTER

**SECTION 44‑36‑310.** Alzheimer’s Disease and Related Disorders Resource Coordination Center created; purpose.

There is created in the Office of the Governor, Division on Aging, the Alzheimer’s Disease and Related Disorders Resource Coordination Center to provide statewide coordination, service system development, information and referral, and caregiver support services to individuals with Alzheimer’s disease and related disorders, their families, and caregivers.

**SECTION 44‑36‑320.** Duties of Center.

The center shall:

(1) initiate the development of systems which coordinate the delivery of programs and services;

(2) facilitate the coordination and integration of research, program development, planning, and quality assurance;

(3) identify potential users of services and gaps in the service delivery system and expand methods and resources to enhance statewide services;

(4) serve as a resource for education, research, and training and provide information and referral services;

(5) provide technical assistance for the development of support groups and other local initiatives to serve individuals, families, and caregivers;

(6) recommend public policy concerning Alzheimer’s Disease and related disorders to state policymakers;

(7) submit an annual report to the Joint Legislative Committee on Aging and to the General Assembly.

**SECTION 44‑36‑325.** Grant program development for Alzheimer’s Disease and related disorders; condition to receipt of grant.

The Alzheimer’s Disease and Related Disorders Resource Coordination Center shall develop a grant program to assist communities and other entities in addressing problems relative to Alzheimer’s disease and other related disorders. In awarding grants, consideration must be given to recommendations made by the advisory council to the Alzheimer’s Disease and Related Disorders Resource Coordination Center regarding priority needs and criteria for selecting grant recipients. As a condition to receiving a grant, the community or other entity shall provide matching funds or an in‑kind contribution equal to the amount of funds awarded in the grant.

**SECTION 44‑36‑330.** Advisory council; membership; compensation of members.

(A) The Alzheimer’s Disease and Related Disorders Resource Coordination Center must be supported by an advisory council appointed by the Governor including, but not limited to, representatives of:

(1) Alzheimer’s Association Chapters;

(2) American Association of Retired Persons;

(3) Clemson University;

(4) Department of Disabilities and Special Needs;

(5) Department of Health and Environmental Control;

(6) Department of Mental Health;

(7) Department of Social Services;

(8) Department of Health and Human Services.

(9) Medical University of South Carolina;

(10) National Association of Social Workers, South Carolina Chapter;

(11) South Carolina Adult Day Care Association;

(12) South Carolina Association of Area Agencies on Aging;

(13) South Carolina Association of Council on Aging Directors;

(14) South Carolina Association of Nonprofit Homes for the Aging;

(15) South Carolina Association of Residential Care Homes;

(16) South Carolina Health Care Association;

(17) South Carolina Home Care Association;

(18) South Carolina Hospital Association;

(19) South Carolina Medical Association;

(20) South Carolina Nurses’ Association;

(21) Statewide Alzheimer’s Disease and Related Disorders Registry;

(22) University of South Carolina;

(23) South Carolina State University.

(B) Members of the advisory council are not entitled to mileage, per diem, subsistence, or any other form of compensation.

ARTICLE 5.

 SPECIAL CARE DISCLOSURE

**SECTION 44‑36‑510.** Short Title.

This article may be cited as the “Alzheimer’s Special Care Disclosure Act”

**SECTION 44‑36‑520.** Information respecting form of Alzheimer’s care or treatment provided.

A nursing home, community residential care facility, or day care facility for adults licensed by the Department of Health and Environmental Control which offers to provide or provides an Alzheimer’s special care unit or program must include in its policies and procedures and disclose to the responsible party seeking a placement within the Alzheimer’s special care unit or program, the form of care or treatment provided that distinguishes it as being especially applicable to or suitable for persons with Alzheimer’s disease. The information that distinguishes the form of care or treatment shall include criteria for admission, transfer, and discharge; care planning; staffing patterns; staff training; physical environment; resident and participant activities; family role in care; and unique costs to the resident or participant associated with specialized service delivery.