Arnold School of Public Health

Office for the Study of Aging

University of South Carolina



2018 Annual Report
South Carolina
Alzheimer's
Disease
Registry

Celebrating 30 years of promoting broader research, training, and other collaborative activities that enhance quality of life for our state's older adult population, their families, and their caregivers.





2018 ANNUAL REPORT

South Carolina ALZHEIMER'S DISEASE REGISTRY

ARNOLD SCHOOL OF PUBLIC HEALTH UNIVERSITY OF SOUTH CAROLINA

As noted within, data included in this report covers January 1, 2014 through December 31, 2014, the most current years with available and comprehensive data.

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ALZHEIMER'S DISEASE REGISTRY ANNUAL REPORT

We are pleased to present the 2018 Annual Report on the South Carolina Alzheimer's Disease Registry - the 30th year of the Registry's existence! This report is issued by the Office for the Study of Aging at the University of South Carolina's Arnold School of Public Health.

The following pages reflect the significant and multifaceted impact of Alzheimer's disease and related dementias (ADRD) on our state. ADRD affect 11% of the population of South Carolina aged 65 years and older and 44% of those over age 85. Caring for someone with ADRD imposes a major burden for caregivers and other family members.

The Alzheimer's Disease Registry is one of only three statewide population-based registries of ADRD in the United States and is the most comprehensive and active. Data have been collected on South Carolinians with ADRD since 1988. The Registry was established and is maintained by the Office for the Study of Aging with the invaluable support of the South Carolina Department of Health and Human Services and the Revenue and Fiscal Affairs Office. In this Annual Report you will also find a wide range of research, evaluations, programs, and training that address the needs of older South Carolinians and their families.

The Office for the Study of Aging is proud to provide services that strive to improve the quality of life of our older adult population, their families and their caregivers. We hope you will visit our website at http://sph.sc.edu/osa.

If you have any questions about the Alzheimer's Registry or our Office's activities, please contact Dr. Maggi Miller, Registry Manager (803-777-0214 or chandlmj@mailbox.sc.edu).

Best Regards,

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Executive Summary

The Office for the Study of Aging (OSA) at the University of South Carolina (USC) Arnold School of Public Health, in cooperation with the South Carolina Department of Health and Human Services (SCDHHS), the South Carolina Department of Mental Health, the USC School of Medicine, and the South Carolina Revenue and Fiscal Affairs Office, maintains a statewide Registry of South Carolina residents diagnosed with Alzheimer's disease and related dementias (ADRD).

This report is published in fulfillment of the requirement of South Carolina Code of Law Section 44 36 10 and Section 44 36 50 which established the registry for the people of South Carolina and tasked the Arnold School of Public Health and OSA with its upkeep, management, and the dissemination of an annual report.

This report uses the abbreviation ADRD to indicate "Alzheimer's disease and related dementias." The term "related dementias" refers to dementias associated with vascular disease, mixed dementia and with other medical conditions such as Parkinson's disease. Where the report refers specifically to "Alzheimer's disease" (AD), analysis is limited to individuals with AD only.

Since January 1, 1988, the Registry has identified 251,416 cases of ADRD in South Carolina.

Registry Goals:

- Maintain the most comprehensive and accurate state registry of ADRD in the nation
- Provide disease prevalence estimates to enable better planning for social and medical services
- Identify differences in disease prevalence among demographic groups
- Help those who care for individuals with ADRD
- Foster research into risk factors for ADRD

Other Activities of OSA:

In addition to maintaining the Registry and conducting research using this valuable state resource, OSA works to promote broader research, training and other collaborative activities that enhance quality of life for our state's older adult population. Specifically, OSA's activities include the following:

- Provide education on ADRD management
- **Develop training** on long-term care issues
- Contribute technical assistance for programs for older South Carolinians
- Develop programs including Dementia Dialogues®
- Evaluate programs for South Carolina's aging population
- Conduct research on aging and public health issues

Acknowledgments

Over the past 30 years, the South Carolina Alzheimer's Disease Registry has developed into one of the nation's most important and premier resources for understanding ADRD. The growth and development of the Registry and the related research and training programs at OSA have been due to the support of many organizations and agencies. The leadership and staff of OSA want to acknowledge the particular contributions of:

- The Arnold School of Public Health at USC, for core support;
- The SC Revenue and Fiscal Affairs Office Health and Demographics Section, for its extensive cooperation in maintaining the Registry;
- The **USC School of Medicine** (Department of Medicine, Division of Geriatrics), for providing collaboration;
- The SC Department of Mental Health, for access to data;
- The **SC Department of Health and Human Services,** for core support and access to data;
- The **SC Public Employee Benefit Authority**, for access to data;
- The SC Department of Health and Environmental Control, Vital Records and Public Health Statistics; and
- The SC Lieutenant Governor's Office on Aging, for its continued support.

Introduction

Someone in America develops Alzheimer's every 66 seconds; by mid-century someone will develop Alzheimer's every 33 seconds.¹

In 1988, the U.S. Census Bureau estimated that there were 474,073 people 65 years of age and older living in South Carolina, and the state was ranked 25th among other states with regard to the percentage of persons aged 65 years and older. In 2010, there were 631,784 people 65 years of age and older living in South Carolina, and the state was ranked 23rd. Since that time, the older adult population in South Carolina has grown at a rapid rate. In fact, by 2030, the U.S. Census Bureau projects that South Carolina will be home to 1.1 million people ages 65 years and older, potentially propelling South Carolina to a ranking of 15th in the nation for the highest percentage of residents over 65 years of age.¹

ADRD represent an ever-increasing area of concern for families and the healthcare community. An estimated 5.4 million people in the United States are currently living with AD. By 2025, this estimate is expected to reach 7.1 million; by 2050, the number of people age 65 and older with AD may nearly triple, from 5.2 million to a projected 13.8 million.² With increasing age as a leading risk factor for AD, South Carolina's rapidly growing population of persons aged 65 years and older presents a challenge to families, communities and those who plan and deliver services for the state.

This report covers data from calendar year 2014. Registry cases in this report are defined as AD, vascular (vascular), mixed dementias (mixed) and ADRD in other medical conditions (other). Registry cases are also identified by location of residence; either in a facility (nursing facilities or residential care facilities), in the community (home or adult day care) or in an unknown location. Exclusions of some demographic information are due to the voluntary method of data collection. It should be noted that many cases may be identified at a late stage of the disease rather than at onset. This affects the time from entry into the Registry until death.

In this report, ADRD is an umbrella term that encompasses many types of neurocognitive disorders. The Diagnostic and Statistical Manual of Mental Disorders - 5th Edition (DSM-5) states that AD can be diagnosed with a level of certainty if there is 1) clear evidence of decline in memory and learning and at least one other cognitive domain (based on detailed history or serial neuropsychological testing), 2) steadily progressive, gradual decline in cognition, without extended plateaus, and 3) no evidence of mixed etiology (i.e., absence of other neurodegenerative or cerebrovascular disease, or another neurological, mental, or systemic disease or condition likely contributing to cognitive decline). AD is a type of ADRD with an insidious onset and gradual progression of cognitive and behavioral symptoms.³ Other types of ADRD include those related to stroke, mixed dementia (with both Alzheimer's and vascular dementia), and dementias associated with medical conditions such as Parkinson's disease, Huntington's disease, dementia with Lewy Bodies (DLB), frontotemporal, AIDS, and alcohol or drug abuse.

¹ US Census Bureau, Population Division, January, 2018.

 $^{^{\}rm 2}$ Alzheimer's Association, 2017 Alzheimer's Disease Facts and Figures.

³ American Psychiatric Association, 2013, Diagnostic and statistical manual of mental disorders (5th ed.). Washington, DC.

ADRD in South Carolina

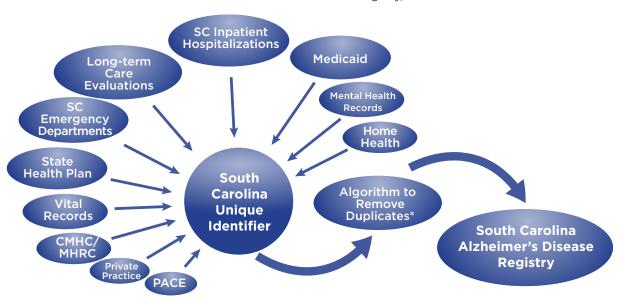
The prevalence of AD in the United States is currently estimated to be 10% among persons aged 65 and older. In 2016, there were 830,232 South Carolina residents 65 years and older, representing 16.7% of the total population, a 75% increase since the Registry began in 1988.²

The total number of persons with ADRD in South Carolina is not known with certainty. National estimates of ADRD prevalence vary widely from one study to another. Individuals who have mild forms of the disease, but lack a diagnosis, do not appear in the Registry data. Previous research suggests that the number of individuals with ADRD may be nearly 50% greater than the number with diagnosed ADRD. Even noting that fact, the South Carolina Alzheimer's Disease Registry is the oldest and most comprehensive population-based Registry of ADRD in the country. There are only two other such registries in existence. One, is located in West Virginia and began collecting data in 2008 and the second is in Georgia and began collecting data in 2014.

Individuals with ADRD are usually identified when they (or their family members) seek provider services. Since no single system identifies all newly diagnosed patients with ADRD, cases in the Registry are collected from several sources (see Figure 1). This ensures that the Registry captures as many diagnoses as possible.

Figure 1 Registry Data Sources

South Carolina Alzheimer's Disease Registry, 2014



CMHC = Community Mental Health Center; MHRC = Mental Health and Rehabilitation Clinics; PACE = Program of All-inclusive Care for the Elderly

^{*}Duplicates occur because individuals often use more than one name, social security number, or other identifying information when using health or social services.

¹ Alzheimer's Association, 2017 Alzheimer's Disease Facts and Figures.

² US Census Bureau, Population Division, Interim State Population Projections, 2017.

³ Hebert et al. Alzheimer's Disease in the US Population: Prevalence estimates using the 2000 Census. Archives of Neurology, 2003; Vol. 60, 119-1122.

⁴ West Virginia Alzheimer's Disease Registry. www.wvadr.hsc.wvu.edu/Pages/. Accessed January 4, 2018

⁵ Georgia Alzheimer's Disease and Related Dementia Registry. http://dph.georgia.gov/alzheimers-registry. Accessed January 4, 2018

History of the Registry

1988

The Alzheimer's Disease Registry was established in 1988 to record specific information about South Carolinians who develop ADRD.

1990

On May 31, 1990, Governor Carroll A. Campbell, Jr. signed a state law authorizing the Registry. This law (R653, H4924) amended Title 44, Code of Laws of South Carolina 1976, relating to health, by adding Chapter 36 establishing a voluntary Statewide Alzheimer's Disease and Related Dementias Registry located within the School of Public Health at USC. The law has strict confidentiality requirements but does allow Registry staff to contact the families and physicians of persons diagnosed as having ADRD to collect relevant data and provide information about public and private health care resources available to them.

1993

From July 1993 to May 1996, the Registry was moved to the James F. Byrnes Center for Geriatric Medicine, Education, and Research, a geriatric research hospital jointly sponsored by the USC School of Medicine and the South Carolina Department of Mental Health.

1997

The Registry was moved back to the Arnold School of Public Health at USC, where it is currently maintained by the Office for the Study of Aging. It provides prevalence data to public and private entities for planning and fosters research on risk factors for ADRD, including the risk of institutionalization.

2008

The Registry celebrated its 20th anniversary in 2008.

2015

The 25th Registry report was published, with a celebration of the 25th anniversary of the legislation authorizing the Registry being signed into law.

2018

The 30th Anniversary celebrating the establishment of the Registry, which continues to receive widespread support and interest from the academic community, support groups, state agencies, and other public and private organizations as part of a statewide effort to study the growing impact of ADRD on the health and welfare of older South Carolinians.

1988

The Alzheimer's Disease Registry was established to record specific information about South Carolinians who develop ADRD.



On May 31,1990, Governor Carroll A. Campbell, Jr. signed a state law authorizing the Registry.

1993

1996.

The Registry was located at the James F. Byrnes Center for Geriatric Medicine, Education, and Research until May



1997

The Registry was moved back to the School of Public Health at USC.



The Alzheimer's Disease Registry celebrated its 20th anniversary.



2015

25th anniversary of the legislation authorizing the Registry being signed into law.



The 30th Anniversary celebrating the estab-

lishment of

the Registry.

Alzheimer's Disease Registry Timeline

Registry Procedures

A definitive diagnosis of ADRD is difficult, especially in the early stages. The Registry staff is not directly involved in diagnosis; the physician's diagnosis is collected from the individual's medical records through codes using the International Classification of Diseases, 9th revision, Clinical Modification (ICD-9-CM, 2010). An individual is then classified into four general categories for reporting purposes as shown in Table 1.

Individuals with ADRD are usually identified, when they or their family members seek provider services. Since no single system identifies all newly diagnosed patients with ADRD, cases are collected from several sources (see Figure 1, page 7).

Table 1 Classification of ADRD by ICD-9-CM Codes

South Carolina Alzheimer's Disease Registry, 2014

ALZHEIMER'S DISEASE

290.0 - 290.3 Senile or presenile dementia

290.8 - 290.9

331.0 Alzheimer's disease

VASCULAR DEMENTIA

290.4 - 290.43 Arteriosclerotic dementia

435 - 438 Cerebrovascular disease (with a dementia code*)

MIXED DEMENTIA

Both Alzheimer's disease and Vascular dementia

DEMENTIA IN OTHER MEDICAL CONDITIONS (see note below)

	The state of the s
291.2	Alcohol dementia
292.82	Drug-induced dementia
294.1	Dementia with other conditions
331.82	Dementia with Lewy bodies
331.11	Pick's disease
331.19	Frontotemporal dementia
The following o	conditions are included with a dementia code*:
046.1	Creutzfeldt-Jakob disease
310.1	Organic brain syndrome
310.2	Chronic traumatic encephalopathy
331.1 - 331.9	Other cerebral degeneration
332.0 - 332.1	Parkinson's disease
333.4	Huntington's disease
042	HIV

NOTE: In the case where a person's record contains multiple indicators of the above categories, Alzheimer's disease and vascular dementia take precedence, except in the case where there are indications of both Alzheimer's disease and vascular dementia. In this case, the person is classified as having mixed dementia. Those classified with dementia in other medical conditions have no indications of Alzheimer's disease or vascular dementia.

^{*}One of the following dementia codes must also be present: 290.0-290.3, 290.8-290.9, 331.0, 290.4-290.43, 291.2, 292.82, 294.10, 294.11, 331.82.

Registry Core Data Items

The registry core data set consists of case-identifying data (for matching purposes only), diagnostic data (ICD 9 CM codes), the place from which the records were obtained, location of case (facility or community), gender, race, and age. Other information collected, if available, includes other medical diagnoses, educational status, marital status, and name and location of caregiver/contact person for follow up.

South Carolina Alzheimer's Disease Registry Report

South Carolina Population Prevalence of ADRD

- In 2014 the Registry maintained information on 93,310 individuals living with ADRD.
- Based on the Registry and 2014 population estimates from the United States Census:
 - 11% of South Carolinians age 65 or over have ADRD;
 - 44% of South Carolinians age 85 or over have ADRD;
 - ADRD prevalence rates vary notably among SC counties; and
 - African Americans are at notably higher risk of an ADRD diagnosis than are non-Hispanic whites. At ages 65 and older, for example, African American South Carolinians are 66% more likely to have ADRD as are non-Hispanic whites.

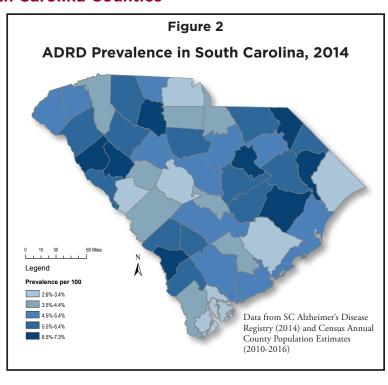
Registry Overview:

Of South Carolinians with diagnosed ADRD in 2014:

- 58% have AD;
- 12% have a dementia due to stroke;
- 26% have a dementia related to other chronic conditions;
- 25% live in an institution at the time of diagnosis;
- 63% are women;
- 28% are African American; and
- 44% of those with AD are 85 years or older.

ADRD Prevalence across South Carolina Counties

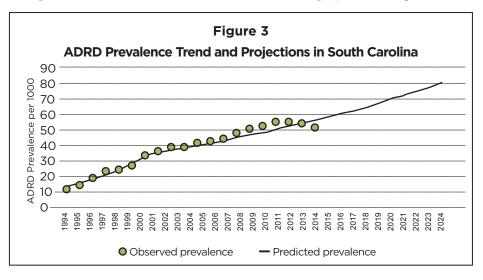
Figure 2 shows the percentage of individuals age 50 or over with ADRD in 2014. The county prevalence rates vary from a low of about 2.6%, to a high of about 7.3%. This county variation provides an important starting point for epidemiological studies of ADRD. It should be noted that counties with a larger older adult population are likely to have greater percentages of individuals with ADRD. This is because the risks of ADRD rise dramatically at older ages. The map is useful because it illustrates where the greatest service needs are for the oldest old, who are more likely than others to require institutional care.



Prevalence of ADRD in South Carolina: A 30 Year Perspective

The longevity of the Registry provides a unique opportunity to gain a 30-year perspective about ADRD prevalence in South Carolina. For this report, Registry data and interim state population projections from the Census Bureau were combined to calculate a 20-year prevalence for ADRD in South Carolina. A trend analysis and 10-year prevalence projection was performed using Joinpoint trend analysis software. For individuals 50 and over, ADRD prevalence was estimated from 1994 to 2014 and projected through 2024.

The green dots in Figure 3 illustrate the observed ADRD prevalence and the solid line represents the projected prevalence. While there are fluctuations in the observed prevalence, the overall trend is steadily increasing. ADRD prevalence increased with an average rate of 14.8% annually from 1994



through 2001 and then 3.5% until 2014. This finding has been mirrored in other research that suggests more education and better treatment and management of cardiovascular disease have reduced the age-specific risk of ADRD in the United States over the past two decades.² In addition, the slight downward trend from 2011-2014 was not statistically significant. Although these findings may indicate ADRD prevalence is decreasing slightly, it should be noted that annual percent change of ADRD prevalence is expected to continue to increase due to the population's shift to older ages. A continued and potentially dramatic increase is expected after as the first members of the Baby Boom generation turn 72 in 2018, putting them in the age range of greatest risk for ADRD.

It should be noted that the prevalence projections are for the Registry. The population prevalence of ADRD will be higher than the projections shown in the figure in any given year because the Registry includes records only for individuals diagnosed through Registry data sources (i.e., individuals who use health care and social services). Individuals who do not use such services, primarily those with early stages of cognitive impairment, are not represented in the Registry or in the projections.

¹The National Cancer Institute, Division of Cancer Control and Population Sciences provides Joinpoint software, a surveillance research program for the analysis of trends using piecewise-linear regression models. https://surveillance.cancer.gov/joinpoint/, Accessed on 1/8/2018

² Alzheimer's Association, 2017 Alzheimer's Disease Facts and Figures.

Characteristics of ADRD in South Carolina

Since 1988, 251,416 cases of ADRD have been identified in South Carolina. This report describes demographic characteristics and medical information for the 93,310 cases that were alive on January 1, 2014 displayed by type of ADRD.

Type of ADRD

Among the 93,310 Registry cases in 2014, 58% had a diagnosis of AD and 12% had a diagnosis of vascular dementia, which is often associated with stroke. In the event of records showing both AD and vascular dementia, the case was reported in a mixed dementia category (4% of all Registry cases). The additional 26% for the total number of "Other Conditions" had a dementia related to other medical conditions, such as Parkinson's disease (see Table 3 for complete listing). The diagnosis shown represents the most current diagnosis in the data received.

Location

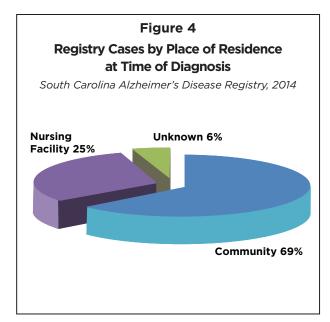
As shown in Figure 4, more Registry cases resided in the community (69%) than in a nursing facility (25%) or unknown locations (6%). The distribution of the types of ADRD was similar in the community and in nursing facilities (Table 2, Figure 5).

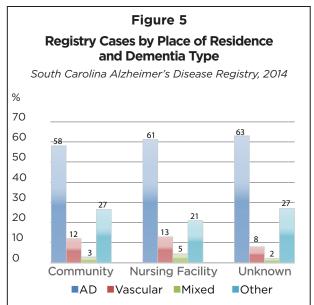
Table 2
Registry Cases by Dementia Type and Place of Residence

South Carolina Alzheimer's Disease Registry, 2014

Dementia Type	Comm	unity	Nursing	Facility	Unkn	own	Total		
	N	%	N	%	N	%	N	%	
Alzheimer's disease	37,336	58	13,906	60	3,455	63	54,697	58	
Vascular dementia	7,563	12	3,132	14	437	8	11,132	12	
Mixed dementia	2,186	3	1,124	5	117	2	3,427	4	
Other conditions	17,798	27	4,772	21	1,484	27	24,054	26	
Total	64,883	69	22,934	25	5,493	6	93,310	100	

^{*}Mixed dementia = both Alzheimer's and Vascular dementia; Other conditions = dementia in other medical conditions.





Dementia in Other Medical Conditions

In addition to AD, the Registry tracks dementias that are associated with other medical conditions, such as Parkinson's disease, alcohol and drug abuse, and HIV/AIDS. In the 2014 Registry, there were 22,951 persons with a dementia associated with one of these conditions who did not also have a diagnosis of AD or vascular dementia. Seven percent had dementia associated with Parkinson's disease and 31% had an indication of dementia associated with some other medical condition (Table 3 footnote). The percentages in the table are not mutually exclusive due to the fact that some records indicate more than one medical condition.

Dementia with Lewy Bodies

Dementia with Lewy Bodies (DLB) is a progressive brain disease characterized by abnormal round structures in the areas of the brain that control thinking and movement. Hence, DLB causes symptoms similar to those commonly associated with both AD and Parkinson's disease. Like AD, it can cause confusion, memory loss, and depression, while other possible symptoms are slowed movement, rigid muscles, and tremors, symptoms normally found in those with Parkinson's disease. Persons with DLB may also have hallucinations and experience day-to-day changes in their symptoms. Currently, there is no cure for DLB. Medications used to treat AD, Parkinson's disease, and depression are typically used to manage DLB symptoms. National estimates suggest that DLB accounts for approximately 10-25% of all dementia cases. In the South Carolina Registry, DLB accounted for 10% of the dementia in other medical conditions category and only 2% of all dementia cases.

¹ Alzheimer's Association. http://www.alz.org/dementia/dementia-with-lewy-bodies-symptoms.asp Accessed February 5, 2018.

Table 3

Dementia with Other Medical Conditions by Age Group

South Carolina Alzheimer's Disease Registry, 2014*

	Under 65	65-74	75-84	85+	Tota	al
	%	%	%	%	Ν	%
Alcohol dementia	21	10	3	1	1,734	8
Drug-induced dementia	1	0	0	0	65	0
Organic brain syndrome	0	0	0	0	14	0
Other cerebral degenerations	58	76	76	55	15,303	67
Parkinson's disease	2	7	11	8	1,725	8
Huntington's disease	0	0	0	0	24	0
HIV/AIDS dementia	4	0	0	0	192	1
Dementia with Lewy Bodies	3	9	15	11	2,343	10
Frontotemporal dementia	2	1	1	0	170	1
Pick's disease	0	0	0	0	55	0
Creutzfeldt-Jakob disease	0	0	0	0	8	0
Traumatic Brain Injury Dementia	1	1	1	0	134	1
Chronic Traumatic Encephalopathy	0	0	0	0	25	0
Dementia with other conditions*	23	23	37	37	7,079	31
Total (N)	4,241	5,686	6,511	6,513	22,951	

NOTE: The percentages in the table are not mutually exclusive due to the fact that some records indicate more than one medical condition.

^{*}Dementia with other conditions includes those with an ICD-9-CM code in 294.1 (dementia in conditions classified elsewhere) on their medical record. This code is listed along with the ICD-9-CM code of the dementia-causing condition. However, the dementia-causing condition may not be identifiable from the record, and therefore, may not be in the above table.

Age and ADRD in South Carolina

Table 4 shows that in 2014, 44% of persons with AD were 85 years of age or older. Figure 6 shows this information graphically for all dementias included in ADRD, with 39% of persons over 85 years of age. Figure 7 indicates that for people with ADRD, 70% of those 75 - 84 years of age were being cared for in the community at the time of diagnosis. Living in the community is most often the location of choice for the individual with ADRD and the family. However, as Figure 7 indicates, with age comes an increase in the numbers of those who reside in nursing facilities.

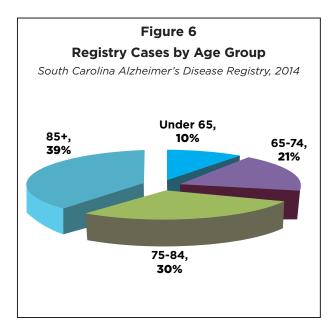
Table 4
Registry Cases by Age Group and Dementia Type

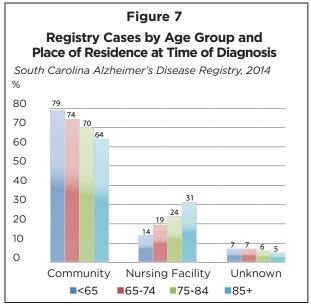
South Carolina Alzheimer's Disease Registry, 2014*

					,00000,100	- $ -$					
	AD		Vasc	Vascular		Mixed		Other		Total	
	N	%	N	%	N	%	N	%	N	%	
Age											
Under 65	3,446	7	1,481	14	166	5	4,255	19	9,348	10	
65 - 74	9,730	18	2,500	23	665	20	5,692	25	18,587	21	
75 - 84	16,298	31	3,325	30	1,147	34	6,512	28	27,282	30	
85 +	23,513	44	3,547	33	1,405	41	6,517	28	34,982	39	
Total	52,987	59	10,853	12	3,383	4	22,976	25	90,199	100	

^{*3,111} records for individuals have missing values for the variables required for inclusion in this table or have ages either less than 50 or greater than 110.

AD=Alzheimer's disease; Vascular=vascular dementia; Mixed=both Alzheimer's disease and vascular dementia; Other=dementia with other medical conditions.





Gender and ADRD in South Carolina

Table 5 shows Registry cases by gender, ADRD type, and age group. For each dementia type, the number of women was notably larger than the number of men in all but the youngest age category. In particular, among those age 85 or over, the number of women with ADRD was almost three times the number of men with ADRD. More women than men in this population were diagnosed with ADRD (Figure 8). This is likely due to the larger number of women alive after age 75. The differences in the ADRD diagnoses by gender are shown graphically in Figure 9.

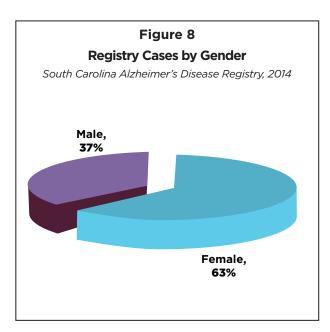
Table 5
Registry Cases by Gender, Age Group and ADRD Type

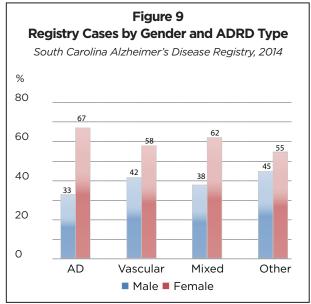
South Carolina Alzheimer's Disease Registry, 2014*

	AD		Vasc	Vascular		Mixed		Other		Total	
	N	%	N	%	N	%	N	%	N	%	
Male											
Under 65	1,553	9	808	18	84	6	2,530	25	4,975	15	
65 - 74	3,915	23	1,251	28	306	24	2,940	28	8,412	25	
75 - 84	5,707	33	1,402	31	495	38	2,778	27	10,382	31	
85 +	6,068	35	1,048	23	417	32	2,040	20	9,573	29	
Female											
Under 65	1,889	5	668	11	82	4	1,720	14	4,359	8	
65 - 74	5,805	16	1,234	20	358	17	2,746	22	10,143	18	
75 - 84	10,581	30	1,909	30	651	32	3,720	29	16,861	30	
85 +	17,385	49	2,478	39	980	47	4,433	35	25,276	44	

^{*3,329} records for individuals have missing values for gender or have ages either less than 50 or greater than 110.

AD=Alzheimer's disease or senile dementia; Vascular=Vascular dementia; Mixed=both Alzheimer's disease and Vascular dementia; Other=dementia in other medical conditions.





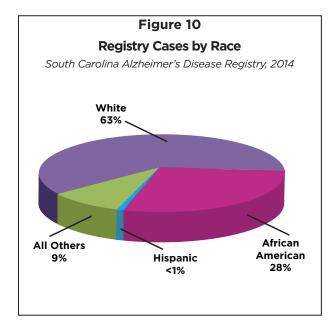
Race and ADRD in South Carolina

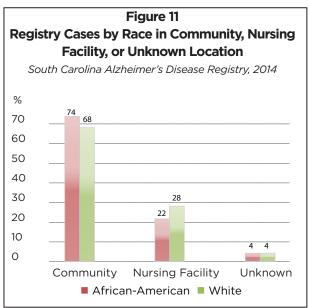
Compared with whites, African Americans, who comprise approximately 20% of the South Carolina population 65 years and older, were over-represented in vascular dementia (38%) and in the overall Registry (28%; Table 6). At ages 65 and older, for example, African American South Carolinians were 68% more likely to have ADRD as were non-Hispanic whites*. Seventy four percent of African Americans with ADRD resided in the community compared to 68% of whites (Figure 11).

Table 6
Registry Cases by Race and ADRD Type

	S	outh Car	rolina Alzhe	imer's D	isease Regi	stry, 201	14*			
	Al	AD		Vascular		Mixed		ner	Total	
	N	%	N	%	N	%	N	%	N	%
Race										
White	35,399	65	5,958	53	2,070	61	15,027	62	58,454	63
African-America	an 13,679	25	4,279	38	1,033	30	7,111	30	26,102	28
Hispanic	236	<1	58	1	13	<1	134	1	441	<1
All Others	5,383	10	837	8	311	9	1,782	7	8,313	9
Total	54,697	58	11,132	12	3,427	4	24,054	26	93,310	

^{*}AD=Alzheimer's disease or senile dementia; Vascular=Vascular dementia; Mixed=both Alzheimer's disease and Vascular dementia; Other=dementia in other medical conditions.





Deaths Among Individuals in the Registry

The individual's first date of diagnosis may not be known to the Registry in every instance. For example, if an individual is first diagnosed during a physician office visit, then that diagnosis is not available to the Registry. The Registry uses the first date that a person entered one of the systems reporting to us as their entry date. The Alzheimer's Disease Registry data are linked with death certificates to summarize the deaths occurring among persons in the Registry. Of those people identified with ADRD since 1988, 168,885 have died. Table 7 illustrates the number of years from date of diagnosis to death.

^{*} Odds ratio was calculated comparing prevalence of ADRD in 65+ African Americans and Whites.

Table 7
Length of Time in Registry by ADRD Type

South Carolina Alzheimer's Disease Registry, 2014*

AD		Vasc	Vascular		Mixed		Other		Total	
Years in Registry	Ν	%	Ν	%	Ν	%	Ν	%	N	%
< 2 years	59,898	55	12,118	59	4,875	53	18,129	60	95,020	56
2-5 years	30,294	28	5,152	25	2,790	31	7,059	24	45,295	27
5 + years	18,951	17	3,354	16	1,473	16	4,792	16	28,570	17
Total	109,143	65	20,624	12	9,138	5	29,980	18	168,885	100

AD=Alzheimer's disease or senile dementia; Vascular=Vascular dementia; Mixed=both Alzheimer's disease and Vascular dementia; Other=dementia in other medical conditions..

Table 8 lists the top 10 underlying causes of death for persons 65 years of age or older in the Registry who died during 2014. The #1 underlying cause of death for these persons was attributed to senility and organic mental disorders. This category includes AD and many other dementing illnesses. Nationally, the leading causes of death for persons ages 65 years and older were heart disease, cancer, chronic lower respiratory diseases, cerebrovascular disease, AD, diabetes, accidents, influenza and pneumonia, nephritis, and septicemia. As can be seen in Table 8, the underlying causes of death for those with ADRD in the Registry closely mirror the national trend.

Table 8

Top 10 Underlying Causes of Death Among Registry Cases 65 Years or Older

South Carolina Alzheimer's Disease Registry, 2014*

Rank

- 1 Senility and organic mental disorders
- 2 Acute cerebrovascular disease
- 3 Coronary atherosclerosis and other heart disease
- 4 Chronic obstructive pulmonary disease and bronchiectasis
- 5 Acute myocardial infarction
- 6 Congestive heart failure; nonhypertensive
- 7 Parkinson's disease
- 8 Cancer of bronchus; lung
- 9 All external causes of injury and poisoning
- 10 Septicemia

^{*}Only includes persons who died during the 2014 calendar year.

^{**}Excludes pneumonia caused by tuberculosis or sexually transmitted disease.

¹ CDC Wonder, Underlying Cause of Death, 1999-2015 Request. http://wonder.cdc.gov/ucd-icd10.html. Accessed January 8, 2018.

Additional Programs and Trainings at the OSA

A. Dementia Dialogues®

Although much research has been conducted on the causes of and cure for AD, little information is available about hands-on care. Dementia Dialogues® provides the most current and practical information in the care of people with dementia. OSA's extensive research supports this training program.

Dementia Dialogues® is a training course designed to educate the community and individuals who care for persons who exhibit signs and symptoms associated with ADRD.

Dementia Dialogues® consists of five sessions, each approximately 1.5 hours in length.

- 1. "The Basic Facts" An overview of ADRD.
- 2. "Keeping the Dialogue Going" Strategies for effective communication.
- 3. "It's a Different World" Understanding the impact of the environment and ways to promote independence in activities of daily living.
- 4. "It's Nothing Personal" Addresses challenging behaviors.
- 5. "Now What Do I Do" Creative problem solving.

Each participant receives a certificate of participation for each session and a Dementia Specialist Certificate upon completing all five sessions. The program is offered at no cost to participants and is held regionally by approved trainers. *Over 21,000 professionals, non-professionals and family caregivers in South Carolina have received this training.* For further information including training materials and contact information for trainers please visit https://www.sc.edu/study/colleges_schools/public_health/research/research_centers/office_for_the_study_of_aging/projects_programs/dementia_dialogues/index.php.

B. Evaluation Sub-Award for the Greenville Health System - REACH Program (GHS - REACH)

- **FUNDING SOURCE:** Administration for Community Living Administration On Aging (Alzheimer's Disease Initiative Specialized Supportive Services), 2015-2018
- PRINCIPAL INVESTIGATOR: Ana Teixeira, PhD
- **CO-INVESTIGATOR:** Maggi Miller, PhD

OSA serves as the evaluator for the three-year program GHS-REACH (PI: James Davis, MD), that seeks to expand and enhance the educational and supportive services to persons with ADRD and their caregivers through the provision of caregiver coaching and education.

The OSA evaluation team is responsible for designing the evaluation methodology and instruments, conducting analysis and program reporting. The GHS-REACH evaluation aims are to assess whether program objectives were reached and develop tools for program monitoring and quality assurance. This evaluation uses a mixed-methods approach, consisting of multiple assessments pre-, during, and post-intervention.

C. Healthy Connections Prime Training

Healthy Connections Prime is a new option for seniors 65 years and older who are eligible for Medicare and Medicaid benefits. This program is a partnership between South Carolina Department of Health and Human Services and the Centers for Medicare and Medicaid Services. Through Healthy Connections Prime, members will receive the full range of services, managed by a single Healthy Connections Prime Medicare-Medicaid Plan.

OSA has developed six trainings for the three participating Medicare-Medicaid plans and providers. Trainings that have been developed include the following topics and associated outcomes:

1. Essential of Effective Care Planning (Assessment and Planning)

- Participants will understand the importance of assessments.
- Participants will learn motivational interviewing techniques.
- Participants will better understand the role of the Care Coordinator in the Assessment and Care Planning process.

2. Determinant of Abuse/Neglect and Safety Concerns

- Participants will better understand the various types of abuse.
- Participants will identify their role in the investigative process.
- Participants will better understand safety risks in the field.

3. Dealing with Difficult People

- Participants will better understand the meaning of resistance.
- Participant will understand the reasons behind resistance.
- Participants will identify strategies to address resistance.

4. Overview of Special Populations

- Participants will better understand the various populations that exist in the service delivery system.
- Participants become aware of the various services and supports that are available for special populations.

5. The Impact of Multi-Disciplinary Teams

- Participants will better understand the benefits and challenges to integrating multidisciplinary teams into a care coordination model.
- Participants will identify strategies to address barriers within multidisciplinary teams.
- Participants will develop strategies to building and sustaining effective multidisciplinary teams.

6. Improving Transitional Care Practices

- Participants will gain a better understanding of how care coordination intersects with care transitions.
- Participants will better understand how communication barriers impede successful transitions.
- Participants will be able to identify steps to improve the transition process.

D. Home Care Specialist Training

The Home Care Specialist course provides training on chronic disease management and is intended for Personal Care Aide (PCA) workers caring for people in their own homes.

This course provides PCAs with an extra level of training about chronic disease conditions affecting their clients. PCAs learn about warning signs and symptoms of nearing health crisis, and receive practical information about what to do and who to call to help prevent or better manage their clients' health crisis.

The training consists of 13 self-paced online modules:

- 1. Introduction to the Home Care Specialist Training
- 2. Congestive Heart Failure
- 3. Dehydration
- 4. Pneumonia
- 5. Incontinence and Urinary Tract Infections
- 6. Heart Attack
- 7. Chronic Obstructive Pulmonary Disease
- 8. Hypertension
- 9. Stroke
- 10. Diabetes
- 11. Dementia and Mental Status Change
- 12. The Final Phase of Life
- 13. Falls

The Home Care Specialist training course is provided at **no cost.** Upon completion PCAs earn a Home Care Specialist certificate. This course and additional information will be available online at https://web.asph.sc.edu/osa/.

E. South Carolina Healthy Brain Research Network (SC-HBRN) Collaborating Center

- FUNDING SOURCE: Centers for Disease Control and Prevention (CDC), 2014-2019
- PRINCIPAL INVESTIGATOR: Daniela B. Friedman, MSc, PhD
- CO-INVESTIGATORS:
- Sue E. Levkoff, ScD
- Sara Wilcox, PhD
- CONSULTANT: Rebecca H. Hunter, MEd, University of North Carolina at Chapel Hill

USC was selected to serve in the role of Collaborating Center in the CDC Prevention Research Centers' (PRC) Healthy Brain Research Network (HBRN). The SC-HBRN has three specific aims: (1) establish a research agenda concerning cognitive health and healthy aging, (2) advance research in the areas of cognitive health and healthy aging, and (3) support fellowship training of

students. We share the funder's goal of advancing the public health and aging agenda by making a major contribution to CDC's Healthy Brain Research and working with other HBRN Centers and public health partners to increase their capacity to implement actions in *The Public Health Road Map for State and National Partnerships, 2013–2018. The work of the SC-HBRN is aligned with the Healthy People 2020 topic area,* "Dementias, including Alzheimer's disease," The National Plan to Address Alzheimer's Disease, and The Public Health Road Map for State and National Partnerships, 2013–2018.

To learn more about the SC-HBRN, please contact Dr. Daniela Friedman at: dbfriedman@sc.edu

F. Nurse Aide Training Conference

The OSA along with the SCDHHS and its community partners hosted the 14th Annual Nurse Aid Training Coordinators and Instructors Workshop on April 12, 2017 at the Brookland Banquet and Conference Center. This workshop included guest speakers, skills sessions, a best practices panel, and networking, and was held to bring together nurse aid training coordinators and instructors who are responsible for the training of nurse aides for the purpose of learning, sharing ideas, networking and assuring consistency of excellence in nurse aide training programs.

The featured speaker, Corinne Hoisington, a professor of Information Technologies at Central Virginia Community College; engaged the audience with the Topic: Being a Health Care Hero: Less Talking and More Doing! Additional featured speakers and panelists were from universities, colleges and teaching facilities across the state.

The objectives of this workshop were:

- 1. To provide interactive training;
- 2. To provide opportunity for networking;
- 3. To build capacity to be better instructors.

OSA Directory

Core Team

Daniela Friedman, Co-Director

Daniela Friedman is professor and chair of the Department of Health Promotion, Education, and Behavior, is the co-director of the Arnold School of Public Health's Office for the Study of Aging. She is a leader in gerontology and community- and partner-engaged health promotion in South Carolina, dedicated to improving health literacy and reducing health disparities among older adults across the state. Friedman's federally funded research networks, including the Centers for Disease Control and Prevention-funded South Carolina Healthy Brain Research Network and South Carolina Cancer Prevention and Control Research Network, are focused on the communication and dissemination of evidence-based health messages and programs. Dr. Friedman also directs the university-wide Certificate of Graduate Study in Health Communication.

Lee Pearson, Co-Director

Lee Pearson has more than 20 years of experience in addressing public health priorities in South Carolina, including a specific focus on the unique needs of the state's aging population. Most recently, he helped to lead a statewide taskforce to identify needed improvements in the state's long-term care system. Dr. Pearson holds a doctor of public health degree in health promotion, education, and behavior, as well as a graduate certificate in gerontology. He serves as the codirector of OSA. In that role, he works with the OSA team to advance the core mission and promote expanded opportunities with collaborative partners. In addition to his role with OSA, Dr. Pearson is the associate dean for operations and accreditation in the Arnold School of Public Health, and he is a clinical associate professor in the Department of Health Promotion Education, and Behavior. He also serves on the board of the SC chapter of the Alzheimer's Association.

Mindi Spencer, Associate Director of Research

Mindi Spencer is an associate professor in the Department of Health Promotion, Education, and Behavior, with a joint appointment in the Institute for Southern Studies. Broadly, her research focuses on how cultural and psychosocial factors influence health in older adulthood. She also continues to conduct research on caregiving and mental health among American Indian and African American elders. More recently, she has extended her work on the regional context of health to include a critical analysis of the opioid epidemic in Appalachia. Dr. Spencer is the Principal Investigator of the "Youth Empowered Against HIV!" Project and a partner in the "Equalize Health" LGBT cultural competence training program for health care providers. Dr. Spencer serves on the Lt. Governor's Alzheimer's Resource Coordination Center and on the Minority Task Force of the Gerontological Society of America.

Maggi Miller, Registry Manager

Maggi Miller has over 12 years of experience in aging related public health research and practice. She received her MS in health promotion from the University of Delaware and a PhD in epidemiology from University of South Carolina Arnold School of Public Health. She is a research assistant professor in the Department of Epidemiology and Biostatistics. At the OSA, Dr. Miller manages the SC Alzheimer's Disease Registry and focuses on aging research and program evaluation. Her research interests include Alzheimer's disease and related disorders and caregivers of individuals with dementia.

Macie Smith, Program Development and Training Manager

Macie Smith is a Licensed Social Worker, Certified Social Work Case Manager, and a Social Worker in Gerontology with over 17 years of experience working with the aging and vulnerable populations. Dr. Smith holds a Doctor of Education degree in Higher Education Leadership with a specialization in Adult Education from Nova Southeastern University. She is the Program Development and Training Manager for OSA. She provides research, development of training programs, and coordinates program design and implementation. Dr. Smith also manages the Dementia Dialogues® program. She provides direction, guidance, oversight, and management of recruitment, training the trainers, and program evaluation.

Ana Teixeira, Research Assistant Professor

Ana Teixeira is a research assistant professor in the Department of Epidemiology and Biostatistics, Arnold School of Public Health. Her research interests include aging, migrant health, the economic and social determinants of health, ADRD, end of life decision making, and program evaluation.

Seul Ki Choi, Postdoctoral Fellow

Seul Ki Choi is currently a postdoctoral fellow in the Healthy Brain Research Network and at the OSA. She earned her PhD in public health from the University of South Carolina. Her research interests include health policy process, health communication, health literacy, and Alzheimer's disease awareness and caregiving practices.

Gelareh Rahimi, Graduate Research Assistant

Gelareh Rahimi is a doctoral candidate pursuing a major in Biostatistics. She is now working with OSA as a graduate research assistant helping with statistical analysis and providing reports on the Registry data. As for her dissertation, she is currently developing a method for misreporting adjustments in count models.

Kate Olscamp, Masters Student

Kate Olscamp, a master's student in public health, is interested in the connection between physical activity and brain health, specifically how being active promotes positive mental health and cognitive functioning across the lifespan. She is interested in the relationship between exercise and dementia, particularly in terms of how the connection is communicated to target groups.

Weizhou Tang, Doctoral Student

Weizhou Tang is a doctoral candidate from College of Social Work who now works with Dr. Friedman's team as an HBRN scholar member. She also completed the Health Communication Certificate Program in Arnold School of Public Health in Fall 2016. Weizhou's current research interests are around family caregivers of persons with Alzheimer's disease. She is mostly interested in using quantitative research methods to understand caregiver's mental health across ethnic populations, and how it relates to coping skills, perceived social support, and care recipient's behavioral problems. In addition, she would like to promote public awareness of cognitive health through health communication.

Kristie Kannaley, Masters Student

Kristie Kannaley is in the Master of Speech Pathology program in the Department of Communication Sciences and Disorders (COMD). She is a student scholar of the Healthy Brain Research Network and also works as a research assistant at the university's Aphasia lab. Kristie completed her MA degree in linguistics and earned a graduate certificate in Teaching English as a Foreign Language. She transitioned to COMD to develop skills and competencies for working with older adults in a clinical setting as a speech-language pathologist. Kristie is interested in caregiver support/education, patient advocacy, cognitive retraining, and feeding and swallowing interventions. She is also interested in the development of clear strategies and techniques to help individuals with dementia live more empowered lives.

Affiliate Faculty

OSA is proud of its strong partnerships with faculty who represent multiple disciplines from across the USC campus.

Arnold School of Public Health

OFFICE OF THE DEAN

Sara Corwin, Associate Dean for Undergraduate Student Affairs

EPIDEMIOLOGY & BIOSTATISTICS

Cheryl Addy, Vice Provost and Dean of the Graduate School

Jim Hussey, Chair, Department of Epidemiology and Biostatistics

Angela Liese, Professor

Matthew Lohman, Assistant Professor

Robert Moran, Graduate Director

Myriam Torres, Clinical Assistant Professor

Kellee White, Assistant Professor

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Spencer Moore, Associate Professor

Katrina Walsemann, Associate Professor

Ken Watkins, Associate Chair and Graduate Director

EXERCISE SCIENCE

Diane Ehlers, Assistant Professor

Mei Sui, Assistant Professor

Delia West, Professor

Sara Wilcox, Professor

College of Nursing

Ronit Elk, Research Associate Professor

College of Social Work

Katherine Leith, Research Assistant Professor

Sue Levkoff, Endowed Chair, SeniorSMART Center of Economic Excellence

Otis Owens, Assistant Professor

School of Medicine

Donna Ray, Assistant Professor of Clinical Internal Medicine

University Technology Services

Mike Brown, Education Technologies Specialist and BlackBoard Administrator

Collaborators/Partners

The OSA collaborates with many organizations and agencies to improve the lives of older adults in South Carolina. These partnerships strengthen the OSA's ability to fulfill its mission through the sharing of resources and expertise.

AARP - South Carolina

http://states.aarp.org/region/south-carolina/

Aging Services of South Carolina

http://agingservicessc.org/

Alzheimer's Association - South Carolina Chapter

http://www.alz.org/sc/

Alzheimer's Resource Coordination Center

http://aging.sc.gov/programs/ARCC/Pages/default.aspx

Centers for Medicare and Medicaid Services

http://www.cms.hhs.gov/default.asp

Clemson University Institute for Engaged Aging

http://www.clemson.edu/centers-institutes/aging/

Leeza's Care Connection

http://www.leezascareconnection.org/

Palmetto Health/USC School of Medicine Division of Geriatric

http://internalmedicine.med.sc.edu/patientcare/geriatrics.asp

Real Choice System Change

http://www.cms.gov/CommunityServices/30 RCSC.asp

South Carolina Area Health Education Consortium

http://www.scahec.net/

South Carolina Budget and Control Board, Office of Research and Statistics

http://www.bcb.sc.gov/BCB/BCB-index.phtm

South Carolina Department of Health and Environmental Control

www.sc dhec.net/

South Carolina Department of Health and Human Services

http://www.dhhs.state.sc.us/dhhsnew/index.asp

South Carolina Department of Mental Health

http://www.state.sc.us/dmh/

South Carolina Institute of Medicine and Public

http://www.imph.org

South Carolina Lt. Governor's Office on Aging

http://www.aging.sc.gov

The Carolinas Center for Medical Excellence

http://www.thecarolinascenter.org/

South Carolina Nursing Home Association

803-278-2170

South Carolina Respite Coalition

http://www.screspitecoalition.org/

The FriendShip Village

http://www.thefriendship.org/

University of South Carolina College of Social Work

http://www.cosw.sc.edu/

Healthy Brain Research Network

http://prevention.sph.sc.edu/projects/braincenter.html

SC Center on Aging

http://academicdepartments.musc.edu/neuro-research/ research/centers/aging/

research centers aging/

Carolina Health Care Association

www.schca.org

This Annual Report is available online at http://sc.edu/publichealth/osa

Any state or local agency may request the registry staff to provide specific data summaries (without identifiers). These requests are handled on an individual basis and will be provided free of charge.

Contact Maggi Miller at chandlmj@mailbox.sc.edu for further information.

