

# 2021 Annual Report

## South Carolina Alzheimer's Disease Registry



**Office for the Study of Aging**  
Arnold School of Public Health

# 2021 Annual Report South Carolina Alzheimer's Disease Registry

**ARNOLD SCHOOL OF PUBLIC HEALTH  
UNIVERSITY OF SOUTH CAROLINA**

Data included in this report covers  
January 1, 2017 through December 31, 2017,  
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 2021 Annual Report on the South Carolina Alzheimer's Disease Registry. 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 describe 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 51% of those over age 85. Caring for someone with ADRD can cause a major burden for caregivers and other family members.

The South Carolina Alzheimer's Disease Registry is one of only three statewide population-based registries of ADRD in the United States and is the oldest and most comprehensive. 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 trainings 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](mailto: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 (UofSC) 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 UofSC 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.*

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## Since January 1, 1988, the Registry has identified 304,901 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

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 UofSC, for core support;
- The **SC Revenue and Fiscal Affairs Office Health and Demographics Section**, for its extensive cooperation in maintaining the Registry;
- The **UofSC 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**; for access to data; and
- The **SC Department on Aging**, for its continued collaboration.

## Introduction

***Someone in America develops Alzheimer's every 65 seconds; by mid-century someone will develop Alzheimer's every 33 seconds.<sup>1</sup>***

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 25<sup>th</sup> 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 23<sup>rd</sup>. 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 15<sup>th</sup> in the nation for the percentage of residents over 65 years of age.<sup>1</sup>

ADRD represent an ever-increasing area of concern for families and the healthcare community. An estimated 6.2 million people in the United States are currently living with AD. By 2050, the number of people age 65 and older with AD may grow to a projected 12.7 million.<sup>2</sup> 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 2017. Registry cases in this report are defined as AD, vascular dementia, 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 - 5<sup>th</sup> 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.<sup>3</sup> 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.

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<sup>1</sup> US Census Bureau, Population Division, October 2021.

<sup>2</sup> Alzheimer's Association, 2021 Alzheimer's Disease Facts and Figures.

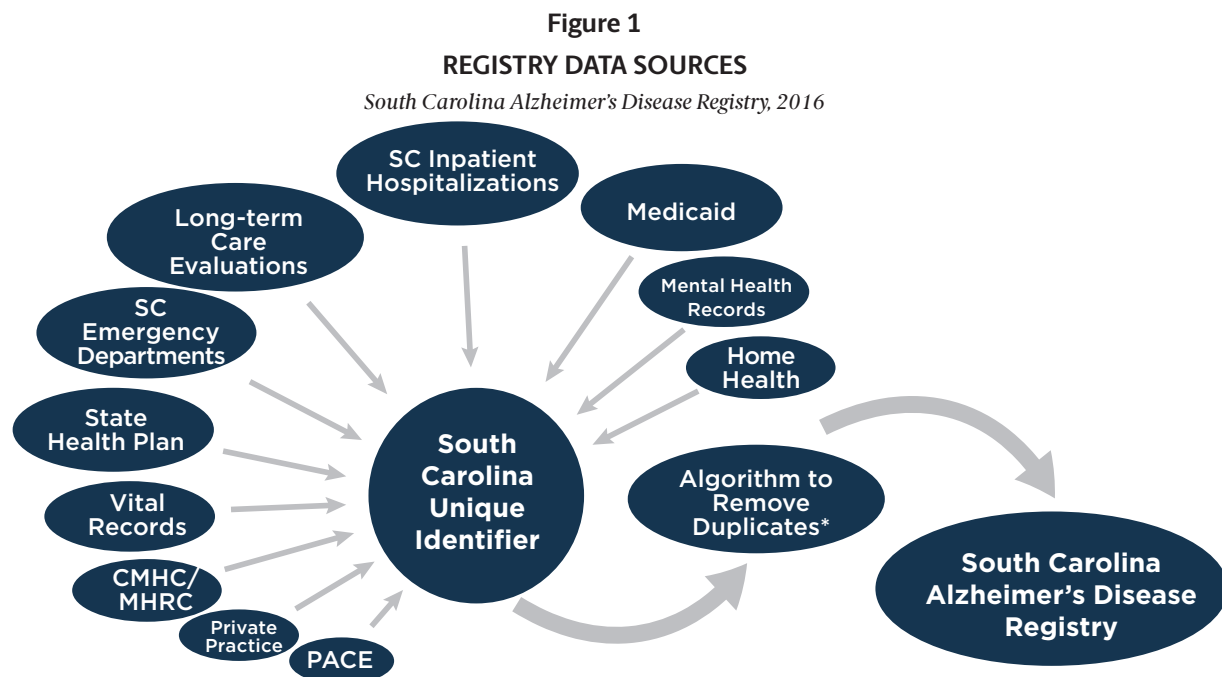
<sup>3</sup> American Psychiatric Association, 2013, Diagnostic and statistical manual of mental disorders (5<sup>th</sup> ed.). Washington, DC.

## ADRD in South Carolina

The prevalence of AD in the United States is currently estimated to be 10% among persons aged 65 and older.<sup>1</sup> In 2017, there were 864,156 South Carolina residents 65 years and older, representing 17.2% of the total population, an almost 78% increase since the Registry began in 1988.<sup>2</sup>

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.<sup>3</sup> *With that being said, 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.<sup>4,5</sup>

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.



**NOTE:** 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.

<sup>1</sup> Alzheimer's Association, 2021 Alzheimer's Disease Facts and Figures.

<sup>2</sup> US Census Bureau, Population Division, Interim State Population Projections, 2017.

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

<sup>4</sup> West Virginia Alzheimer's Disease Registry. <https://wvadr.hsc.wvu.edu/>. Accessed November 2021

<sup>5</sup> Georgia Alzheimer's Disease and Related Dementia Registry. <https://dph.georgia.gov/AlzheimersDisease>. Accessed November 2021



## 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 UofSC. 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 UofSC 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 UofSC, where it continues to be 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 20<sup>th</sup> anniversary in 2008.

**2015**



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

**2018** The 30<sup>th</sup> 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 South Carolinians.

## 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, 10<sup>th</sup> revision, Clinical Modification (ICD-10-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 6).

**Table 1**  
**CLASSIFICATION OF ADRD BY ICD-10-CM CODES**  
*South Carolina Alzheimer's Disease Registry, 2017*

<b>ALZHEIMER'S DISEASE</b>		
F03.90 – F03.91	Senile or presenile dementia	
G30.0 – G30.9	Alzheimer's Disease	
<b>VASCULAR DEMENTIA</b>		
F01.50 – F01.51	Arteriosclerotic dementia	
G45.0 – G45.9	Cerebrovascular disease (with a dementia code*)	
I67.0-I67.9		
I69.00-I69.998		
<b>MIXED DEMENTIA</b> (see note below)		
Both Alzheimer's disease and Vascular dementia		
<b>DEMENTIA IN OTHER MEDICAL CONDITIONS</b>		
F10.27 – F10.97	Alcohol dementia	
F19.97	Drug-induced dementia	
F02.80-F02.81	Dementia with other conditions	
G31.83	Dementia with Lewy bodies	
G31.01	Pick's Disease	
G31.09	Frontotemporal dementia	
The following conditions are included with a dementia code*:		
A81.00-A81.09	Creutzfeldt-Jakob disease	
F04-F09	Organic brain syndrome	
F48.2		
F07.81	Chronic traumatic encephalopathy	
G31.1 – G31.9	Other cerebral degeneration	
G91.0-G91.9		
G93.7-G94		
G20	Parkinson's disease	
G21.11-G21.8		
G10	Huntington's disease	
B20 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: F03.90 – F03.91, G30.0 – G30.9, F01.50 – F01.51, F10.27 – F10.97, F19.97, F02.80-F02.81, G31.83

**Registry Core Data Items**

The registry core data set consists of case-identifying data (for matching purposes only), diagnostic data (ICD 9 + 10 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 2017 the Registry maintained information on 111,818 individuals living with ADRD.
- Based on the Registry and 2017 population estimates from the United States Census:
  - 11% of South Carolinians age 65 or over have ADRD;
  - 51% 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 45% more likely to have ADRD as are non-Hispanic whites.**

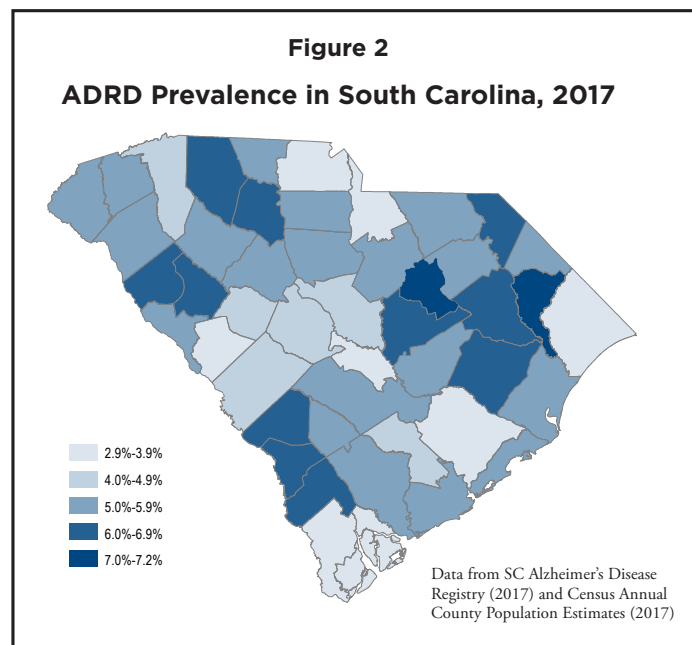
## Registry Overview:

Of South Carolinians with diagnosed ADRD in 2017:

- 73% have AD;
- 9% have a dementia due to stroke;
- 16% have a dementia related to other chronic conditions;
- 25% live in an institution at the time of diagnosis;
- 62% are women;
- 24% 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 2017. The county prevalence rates vary from a low of about 3.0% to a high of 7.2%. 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.



## Characteristics of ADRD in South Carolina

Since 1988, 304,901 cases of ADRD have been identified in South Carolina. This report describes demographic characteristics and medical information for the 111,818 cases who were alive on January 1, 2017 displayed by type of ADRD.

### Type of ADRD

Among the 111,818 Registry cases in 2017, 72% had a diagnosis of AD and 9% 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 (3% of all Registry cases). The additional 16% 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.

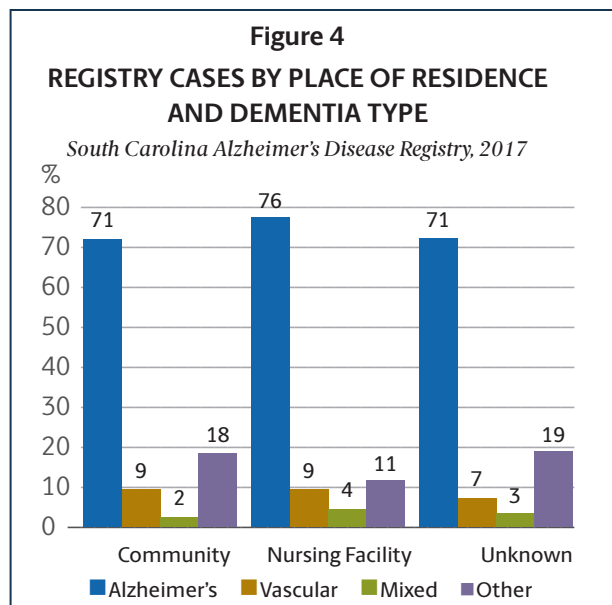
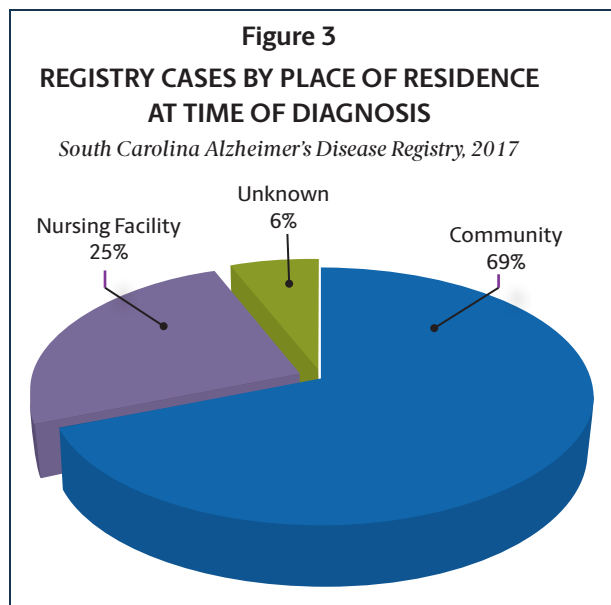
### Location

As shown in Figure 3, 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 4).

**Table 2**  
**REGISTRY CASES BY DEMENTIA TYPE AND PLACE OF RESIDENCE**  
*South Carolina Alzheimer’s Disease Registry, 2017*

Dementia Type	Community		Nursing Facility		Unknown		Total	
	N	%	N	%	N	%	N	%
Alzheimer’s disease	54,950	71	21,076	76	4,925	71	80,951	70
Vascular dementia	6,550	9	2,498	9	491	7	9,539	9
Mixed dementia	1,907	2	1,075	4	202	3	3,184	3
Other conditions	13,640	18	3,359	11	1,344	19	18,144	18
<b>Total</b>	<b>77,047</b>	<b>69</b>	<b>27,809</b>	<b>25</b>	<b>6,962</b>	<b>6</b>	<b>111,818</b>	<b>100</b>

**NOTE:** 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 2017 Registry, there were 20,455 persons with a dementia associated with one of these conditions who did not also have a diagnosis of AD or vascular dementia. Eight percent had dementia associated with Parkinson's disease and 35% 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.<sup>1</sup> In the South Carolina Registry, DLB accounted for 10% of the dementia in other medical conditions category and only 2% of all dementia cases.

<sup>1</sup> Alzheimer's Association. <http://www.alz.org/dementia/dementia-with-lewy-bodies-symptoms.asp> Accessed October 7, 2021.

**Table 3**  
**DEMENTIA WITH OTHER MEDICAL CONDITIONS BY AGE GROUP**

*South Carolina Alzheimer's Disease Registry, 2017*

	<b>Under 65</b>	<b>65–74</b>	<b>75–84</b>	<b>85+</b>	<b>Total</b>	
	%	%	%	%	N	%
Alcohol dementia	23	11	4	2	1,463	9
Drug-induced dementia	1	0	0	0	49	0
Organic brain syndrome	1	1	1	1	138	1
Other cerebral degenerations	39	63	65	45	9,121	54
Parkinson's disease	2	6	11	10	1,319	8
Huntington's disease	0	0	0	0	21	0
HIV/AIDS dementia	6	1	0	0	217	1
Dementia with Lewy Bodies	3	9	15	10	1,673	10
Frontotemporal dementia	3	2	2	1	273	2
Pick's disease	1	1	0	0	71	0
Creutzfeldt-Jakob disease	0	0	0	0	6	0
Traumatic Brain Injury Dementia	1	1	1	0	93	1
Chronic Traumatic Encephalopathy	0	0	0	0	24	0
Dementia with other conditions*	36	28	39	38	5,987	35
<b>Total (N)</b>	1,040	1,241	1,971	5,987	20,455	

**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-10-CM code F02.80 - F02.81 (dementia in conditions classified elsewhere) on their medical record. This code is listed along with the ICD-10-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 2017, 44% of persons with AD were 85 years of age or older. Figure 5 shows this information graphically for all dementias included in ADRD, with 41% of persons over 85 years of age.

Figure 6 indicates that for people with ADRD, 73% 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.

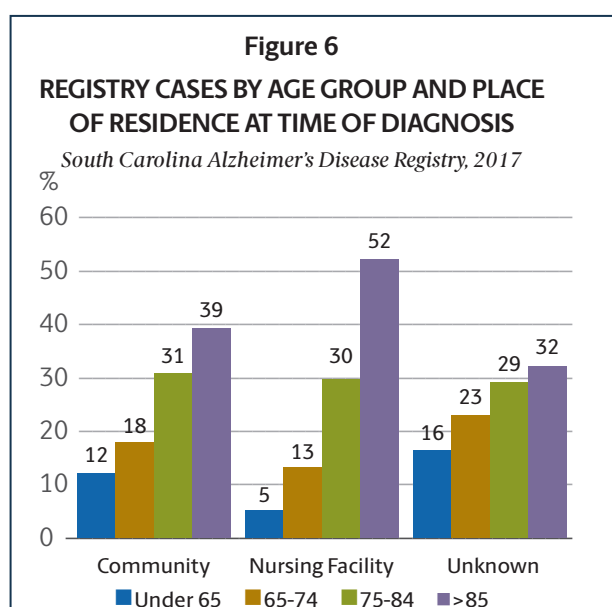
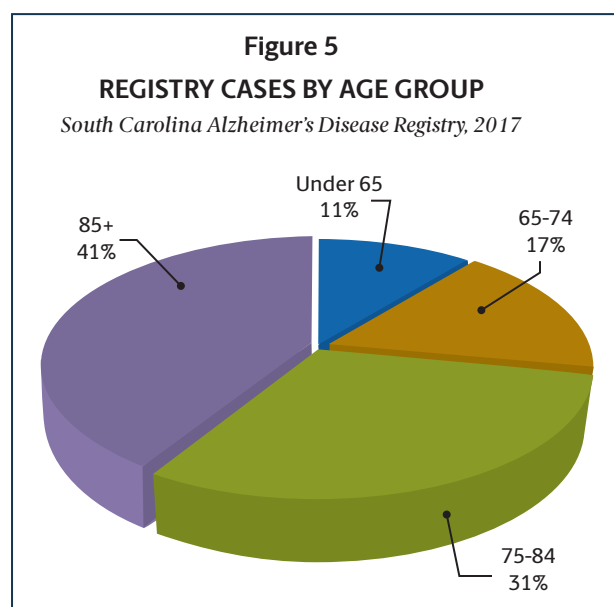
**Table 4**  
**REGISTRY CASES BY AGE GROUP AND DEMENTIA TYPE**

*South Carolina Alzheimer's Disease Registry, 2017*

	AD		Vascular		Mixed		Other		Total	
	N	%	N	%	N	%	N	%	N	%
Age										
Under 65	4,267	5	1,250	14	127	4	2,917	17	8,561	8
65 – 74	13,995	18	2,149	23	628	20	4,370	26	21,142	20
75 – 84	25,542	33	2,665	29	1,014	32	4,434	26	33,655	31
85 +	34,525	44	3,116	34	1,358	43	5,254	31	44,253	41
<b>Total</b>	<b>78,829</b>	<b>73</b>	<b>9,180</b>	<b>9</b>	<b>3,127</b>	<b>3</b>	<b>16,975</b>	<b>16</b>	<b>107,611</b>	<b>100</b>

\*4208 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.

**NOTE:** 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 more than two times the number of men with ADRD. More women than men in this population were diagnosed with ADRD (Figure 7). 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 8.

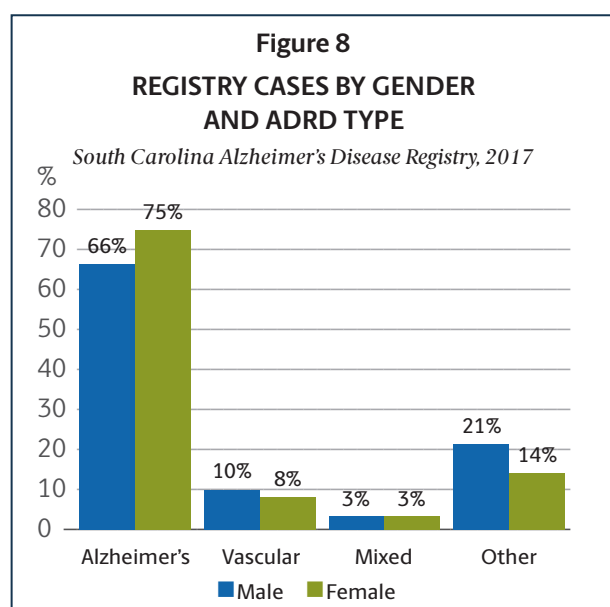
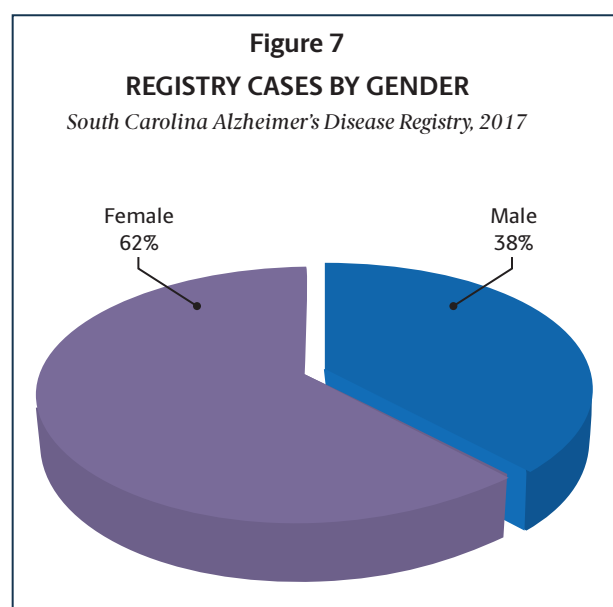
**Table 5**  
**REGISTRY CASES BY GENDER, AGE GROUP AND ADRD TYPE**

*South Carolina Alzheimer's Disease Registry, 2017*

	AD		Vascular		Mixed		Other		Total	
	N	%	N	%	N	%	N	%	N	%
<b>Male</b>										
Under 65	1,655	6	585	16	56	5	1,657	21	3,953	17
65 – 74	5,514	22	1,012	27	297	24	2,266	29	9,089	39
75 – 84	9,110	36	1,118	30	431	35	2,056	26	12,715	54
85 +	9,330	36	985	27	447	36	1,829	23	12,591	54
<b>Female</b>										
Under 65	1,927	4	493	10	67	4	1,087	13	3,574	6
65 – 74	7,411	16	956	20	273	18	1,741	21	10,645	17
75 – 84	14,658	31	1,349	28	543	30	2,204	27	18,770	30
85 +	23,273	49	1,977	41	884	48	3,212	39	29,367	47

\*4207 records for individuals have missing values for gender or have ages either less than 50 or greater than 110.

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



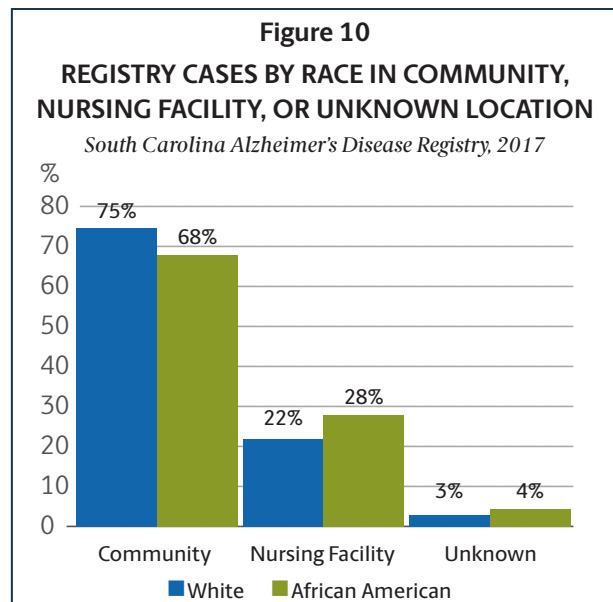
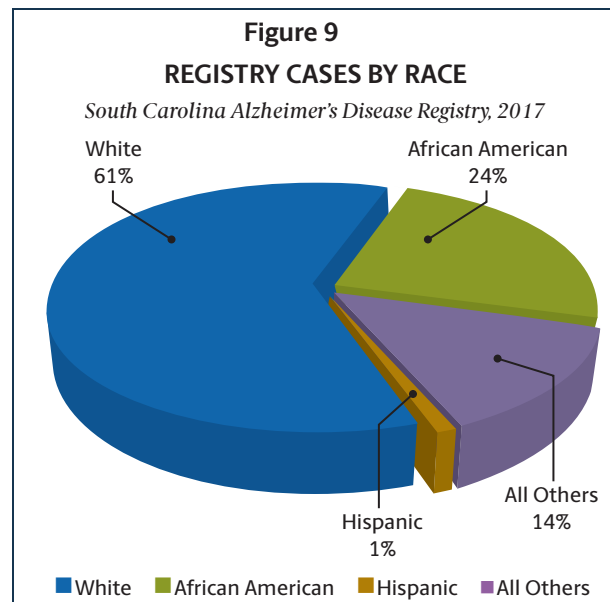
## Race and ADRD in South Carolina

Compared with whites, African Americans, who comprise approximately 22% of the population 65 years and older, were over-represented in vascular dementia of the South Carolina and in the overall Registry (34%; Table 6). At ages 65 and older, for example, African American South Carolinians were 59% more likely to have ADRD than non-Hispanic whites\*. Seventy five percent of African Americans with ADRD resided in the community compared to 68% of whites (Figure 10).

**Table 6**  
**REGISTRY CASES BY RACE AND ADRD TYPE**  
*South Carolina Alzheimer's Disease Registry, 2017\**

	AD		Vascular		Mixed		Other		Total	
	N	%	N	%	N	%	N	%	N	%
Race										
White	51,157	63	4,840	51	1,881	59	10,874	60	68,752	61
African-American.	18,104	22	3,201	34	929	29	4,999	28	27,233	24
Hispanic.	201	<1	30	<1	7	<1	54	<1	292	< 1
All Others	11,489	15	1,468	15	367	12	2,217	12	15,541	14
<b>Total</b>	<b>80,951</b>	<b>72</b>	<b>9,539</b>	<b>9</b>	<b>3,184</b>	<b>3</b>	<b>18,144</b>	<b>16</b>	<b>111,818</b>	<b>100</b>

\*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, 179,761 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, 2017\**

	<b>AD</b>		<b>Vascular</b>		<b>Mixed</b>		<b>Other</b>		<b>Total</b>	
Years in Registry	N	%	N	%	N	%	N	%	N	%
< 2 years	41,177	40	7,729	45	3,237	40	13,118	47	65,261	42
2–5 years	38,884	38	6,189	36	3,426	42	9,918	36	58,417	37
5 + years	23,098	22	3,303	19	1,467	18	4,687	17	32,555	21
<b>Total</b>	<b>103,159</b>	<b>66</b>	<b>17,221</b>	<b>11</b>	<b>8,130</b>	<b>5</b>	<b>27,723</b>	<b>18</b>	<b>156,233</b>	<b>100</b>

\*38006 records for individuals have missing values

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 2017. 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, malignant neoplasms, accidents, chronic lower respiratory diseases, cerebrovascular disease, AD, diabetes, influenza and pneumonia, nephritis, and chronic liver disease and cirrhosis.<sup>1</sup> 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, 2017*

<b>Rank</b>
1 Senility and organic mental disorders.
2 Alzheimer's disease
3 Atherosclerotic heart disease of native coronary artery without angina pectoris
4 Sequelae of cerebrovascular disease
5 Chronic obstructive pulmonary disease and bronchiectasis
6 Acute myocardial infarctions
7 Malignant neoplasms of unspecified part of bronchus or lung
8 Heart failure
9 Parkinson's disease
10 Pneumonia

\*Only includes persons who died during the 2017 calendar year.

\*\*Excludes pneumonia caused by tuberculosis or sexually transmitted disease.

<sup>1</sup>CDC NCHS [https://www.cdc.gov/nchs/nvss/mortality\\_tables.htm](https://www.cdc.gov/nchs/nvss/mortality_tables.htm) Accessed October 28, 2021

## Additional Programs and Trainings at the OSA

### A. Dementia Dialogues®

- **FUNDING SOURCE:** South Carolina Department of Health and Human Services,
- **PRINCIPAL INVESTIGATOR:** Daniela B. Friedman, MSc, PhD
- **CO-PRINCIPAL INVESTIGATOR:** Lee Pearson, MS, DrPH
- **PROGRAM COORDINATOR:** Megan Byers, MSW, LMSW

**Dementia Dialogues®** is a 5-module, evidence-informed, nationally registered training course designed to educate community members and caregivers for persons who exhibit signs and symptoms of Alzheimer's disease and related dementias (ADRD).

Individuals who attend and complete all five modules of the training course will be awarded a **Dementia Dialogues®** Specialist Certificate. The five modules include the following:

1. **The Basic Facts:** An Overview of Alzheimer's Disease and related Dementias
2. **Keep the Dialogue Going:** Strategies for Effective Communication
3. **It's a Different World:** Understanding the Impact of the Environment & Ways to Promote Independence
4. **It's Nothing Personal:** Addressing Challenging Behaviors
5. **Now What Do We Do?** Creative Problem Solving

Since 2001, over 21,000 individuals have been trained in at least one module and over 10,000 individuals have completed the entire course. **Dementia Dialogues®** is provided at no cost to participants through the Office for the Study of Aging at the Arnold School of Public Health, University of South Carolina. For further information including training materials and contact information for trainers please visit: [https://sph.sc.edu/dementia\\_dialogues](https://sph.sc.edu/dementia_dialogues)

## **B. Evaluation Sub-Award for the Prisma Health Greenville – REACH Expansion Grant**

- **FUNDING SOURCE:** Administration for Community Living – Administration On Aging, 2019-2021
- **PRINCIPAL INVESTIGATOR:** Maggi Miller, MS, PhD
- **CO-INVESTIGATOR:** Mindi Spencer, PhD

OSA serves as the evaluator an 18-month REACH Expansion (PI: James Davis, MD). Prisma Health– REACH seeks to enhance the educational and supportive services to persons with ADRD and their caregivers through the provision of caregiver coaching and education. The focus is on high-risk patients and caregivers, including individuals who live in rural areas, those who identify as a racial/ethnic minority, or are living alone. The OSA evaluation team is responsible for designing the evaluation methodology and instruments, conducting analysis and program reporting. The 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. 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 crises.

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 is available online at: <https://sph.sc.edu/hcs>

#### **D. Carolina Center on Alzheimer's Disease and Minority Research (CCADMR)**

- **FUNDING SOURCE:** National Institute on Aging, P30 Alzheimer's disease-related Resource Center on Minority Aging Research, 2018-2023
- **PRINCIPAL INVESTIGATORS:** Sue E. Levkoff, ScD and Daniela B. Friedman, MSc, PhD

The overall goal of the Carolina Center on Alzheimer's Disease and Minority Research (CCADMR) is to increase the diversity of the research workforce focused on population health and determinants of ADRD disparities through sustained infrastructure that will support underrepresented and minority (URM) faculty focused on the health and well-being of minority elders. The Specific Aims are to:

1. increase the capacity of URM scholars to advance the science on the sociocultural, behavioral, and environmental factors that influence ADRD outcomes in order to reduce ADRD-related disparities, with a focus on African Americans, and
2. advance the science of ADRD research focused on population health and determinants of ADRD disparities through research education in population-based, secondary data analysis, interdisciplinary co-mentoring teams, well-established strategies for recruitment of AD-RCMAR Scientists, and education on Health Disparities and Minority Aging Research.

The CCADMR is a state-wide collaboration, providing mentorship and education on determinants of ADRD disparities using population-based datasets for URM faculty throughout South Carolina, at the three major research institutions, including University of South Carolina (UofSC), Medical University of South Carolina (MUSC), and Clemson University (CU), and three Historically Black Colleges and Universities (HBCUs), including Allen University, Claflin University, and South Carolina State University.

## **E. Promoting High-Impact Alzheimer's Disease Research through the Use of Statewide Registries: Expanding Diversity in Aging Research**

- **FUNDING SOURCE:** National Institutes of Health: National Institute on Aging, 2021 - 2026.
- **PRINCIPAL INVESTIGATORS:** Lucy A. Ingram, PhD (Contact PI), Daniela B. Friedman, MSc, PhD, Sue E. Levkoff, ScD
- **PROGRAM COORDINATOR:** Quentin McCollum, MPH

Establishing mechanisms for increasing the pipeline of scientists who conduct research in aging and Alzheimer's disease and related dementias (ADRD), and mentoring these scientists, are national public health priorities. The NIA-funded, annual conference series entitled, "Promoting High-Impact Alzheimer's Disease Research through the Use of Statewide Registries: Expanding Diversity in Aging Research" seeks to increase the number of underrepresented minority and minoritized (URM) scientists who conduct research in aging and ADRD, thus ultimately contributing to the long-term goal of creating a community of scientists that is representative of the entire US population. In particular, the conference series is an opportunity to highlight the regional impact of ADRD and establish a pipeline for URM researchers to address the growing disparities in this area.

The specific aims of the conference series are to: 1: Provide a forum for underrepresented minority (URM) and non-URM researchers to learn how to conduct high-impact ADRD research using statewide registries; 2: Provide a mechanism for senior faculty/experts to mentor junior URM researchers in AD registry research through the submission of a) an abstract for presentation at the following year's R13 conference, and b) a manuscript to a peer-reviewed journal; 3: Provide a mechanism to support ongoing networking among URM and non-URM researchers; and 4: Conduct process and outcome evaluations of the program, making modifications as needed.



## **F. Graduate Scholar in Aging Research Awards Program**

- **SPONSOR:** Gerry Sue and Norman J. Arnold Institute on Aging

The Arnold School of Public Health is in its third year of the annual Graduate Scholar in Aging Research Awards Program. Through the generous support of Norman and Gerry Sue Arnold, the Arnold School of Public Health is committed to developing future leaders in aging research. In response, the Arnold School has established this award which will recognize up to two outstanding graduate students who exemplify the highest standards of scholarship focused on aging.

## G. Arnold Aging Lecture Series

- **SPONSOR:** Gerry Sue and Norman J. Arnold Institute on Aging

OSA in the Arnold School of Public Health hosted two dynamic speakers to deliver the Annual Arnold Aging Lecture in 2018 and 2019, respectively. The first lecture was delivered on March 29, 2018 by Dr. Kenneth M. Langa on the topic of “Exploring the Risk of Alzheimer’s Disease: Epidemiological Evidence from Around the World.” His presentation is available online at <https://www.youtube.com/watch?v=xehFQFeALTc>. The second lecture was delivered by Dr. Keith Whitfield on the topic of “Biobehavioral Insights on Health and Aging Among African Americans” on March 28, 2019. Dr. Whitfield’s presentation is available online at <https://www.youtube.com/watch?v=kfRNdeM0yeE>. The 2020 and 2021 lectures were postponed due to COVID-19 but it will be rescheduled for a future date.

## OSA Directory

### Core Team

#### **Daniela B. Friedman**, *Co-Director*

Daniela Friedman, Professor and Chair of the Department of Health Promotion, Education, and Behavior, is the Co-Director of the Arnold School of Public Health's OSA. She is a leader in gerontology and community- engaged health promotion in South Carolina, dedicated to improving health literacy and reducing health disparities among older adults across the state. Dr. Friedman's federally funded research network, includes the Centers for Disease Control and Prevention-funded South Carolina Cancer Prevention and Control Research Network, focusing 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. In 2014, he helped to lead a statewide taskforce on long-term care. 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 co-director of OSA. In that role, he works with the entire 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 chairs the board of the SC chapter of the Alzheimer's Association.

He has previously served on the Joint Legislative Committee to Study Services, Programs and Facilities for the Aging.

#### **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 conducts research on caregiving and mental health among American Indian and African American elders. 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 15 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 the 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 dementia and aging research, in addition to, program evaluation. Her research interests include Alzheimer's disease and related dementias and caregivers of individuals with dementia.

**Megan Byers, Program Coordinator**

Megan Byers (she/her/hers) is the Program Coordinator for the Office for the Study of Aging. Ms. Byers has developed policies and training curricula, monitored legislative sessions to determine their impact on vulnerable adults, educated stakeholders on issues of adult maltreatment and dementia, taught at universities as an adjunct instructor, presented at state and national conferences, and is a published author. She holds a Master of Social Work, a Graduate Certificate in Gerontology, and Certificates in Research Administration, and in Innovative and Experimental Learning. Ms. Byers is a Licensed Master Social Worker in South Carolina.

**Matthew Lohman, Assistant Professor**

Dr. Lohman is an Assistant Professor of Epidemiology in the Department of Epidemiology and Biostatistics and is a core faculty member of the OSA. His primary research areas are in psychiatric epidemiology, gerontology, geriatric mental health services, and the epidemiology of adverse health outcomes such as falls, hospitalizations, and acquired disabilities among older adults. Dr. Lohman is particularly interested in the role of long-term care services and settings, such as nursing homes and home health care nursing, in the prevention of age-related cognitive and physical decline. He is the current recipient of a grant from the National Institute on Aging to study mechanisms increasing fall risk among older adults with depression. He currently teaches epidemiological methods and psychiatric epidemiology for masters and doctoral students.

**Katherine Leith, Research Associate**

Dr. Leith has been working and teaching in the fields of social work, aging, and public health for more than 20 years. She has extensive experience in both academia and community practice. Initially, Dr. Leith worked as social work case manager for the NC Department of Mental Health, as coordinator of an adult day program for persons with mental illness and intellectual disabilities. Later she served as medical social worker at a SC dialysis clinic. Her most recent clinical practice was with the SC Department of Mental Health, as social work supervisor at Bryan Psychiatric Hospital, Forensics. After joining the University of South Carolina, Dr. Leith collaborated with several SC State Agencies, such as the State Department of Aging, SC DHEC and SCDMH, where she served as evaluator on a number of evidence-based community prevention programs, primarily in the areas of mental health, chronic disease self-management education, and falls prevention. She also taught, and continues to teach, Social Welfare and Policy, Human Behavior in the Social Environment, Social Work Research, Aging, and Advanced Practice courses in the College of Social Work and in the Department of Health Promotion, Education and Behavior at the Arnold School of Public Health, as well as for Simmons College and for Walden University. Dr. Leith also serves as course lead and tutor for Apollon University in Bremen, Germany and as grant reviewer/panel chair for ACL, ACF, and CMS. She is an associate editor for *Frontiers in Public Health*. As a member of the Office for the Study of Aging in the Arnold School of Public Health, she is the Coordinator of the Certificate for Graduate Study in Aging and contributes to the research endeavors of the office's team on projects related to Alzheimer's, caregiving and other aging-related issues.

**Fanli Yi, PhD Student**

Fanli Yi is a third year Ph.D. Candidate of Epidemiology. Her research interests are on evaluating the impacts of cardiovascular procedures on the trend of coronary heart disease in Western Australia; the Affordable care act and Medicare on the incidence and mortality rates of colorectal cancer in South Carolina; and the periodontal antibodies on the cognitive function. Fanli has expertise in unique data linkages, administrative data claims analysis, data management of complex data systems, creation of complex data coding algorithms for clinical procedures, and analysis and interpretation of scientific findings.

## **Affiliate Faculty**

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

### **ARNOLD SCHOOL OF PUBLIC HEALTH**

#### **OFFICE OF THE DEAN**

**Sara Corwin**, *Clinical Associate Professor*

#### **COMMUNICATION SCIENCES AND DISORDERS**

**Jessica Klusek**, *Associate Professor*

**Jean Neils-Strunjas**, *Professor*

#### **EPIDEMIOLOGY & BIostatISTICS**

**Monique Brown**, *Assistant Professor*

**Angela Liese**, *Professor*

**Myriam Torres**, *Clinical Associate Professor*

**Jingkai Wei**, *Assistant Professor*

#### **HEALTH PROMOTION, EDUCATION, AND BEHAVIOR**

**Ken Watkins**, *Clinical Associate Professor, Associate Chair and Graduate Director*

**Lucy Ingram**, *Associate Professor, Associate Dean for Academic Affairs and Online Education*

#### **EXERCISE SCIENCE**

**Mei Sui**, *Assistant Professor*

**Delia West**, *Professor*

**Sara Wilcox**, *Professor*

**Chih-Hsiang “Jason” Yang**, *Assistant Professor*

#### **COLLEGE OF SOCIAL WORK**

**Sue Levkoff**, *Endowed Chair, SeniorSMART Center for Economic Excellence*

**Otis Owens**, *Associate Professor*

#### **SCHOOL OF MEDICINE**

**Donna Ray**, *Clinical Assistant Professor*

## **Advisors**

The OSA benefits from numerous partnerships and the active input of stakeholders from across South Carolina. The key advisors listed below provide strategic guidance on the mission and overall direction of OSA.

## **Community**

**Teresa Arnold**, *AARP*

**Darryl Broome**, *Advisor on Aging Services and State Policy*

**Marti Colluci**, *Leeza's Care Connection*

**Brenda Hyleman**, *Aging Life Care Professional*

**Beth Sulkowski**, *Alzheimer's Association South Carolina*

**Sam Waldrep**, *Advisor on Aging Services and State Policy*

## **Research and Clinical**

**James W. Davis**, *MD, Memory Health Program, PRISMA Health Upstate Network*

**Julius Fridriksson**, *PhD, Arnold School of Public Health, Department of Communication Sciences and Disorders*

**Jacobo Mintzer**, *MD, MBA, Roper St. Francis*

## 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/>

**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:** <https://www.cms.gov>

**Clemson University Institute for Engaged Aging:** <http://www.clemson.edu/centers-institutes/aging/>

**Department of Health and Human Services:** <https://www.scdhhs.gov/>

**Healthy Brain Research Network:** <http://prevention.sph.sc.edu/projects/braincenter.html>

**Leeza's Care Connection:** <http://www.leezascareconnection.org/>

**Palmetto Health/UofSC School of  
Medicine Division of Geriatrics:** <http://internalmedicine.med.sc.edu/patientcare/geriatrics.asp>

**South Carolina Area Health Education Consortium:** <http://www.scahec.net/>

**South Carolina Center  
on Aging:** <http://academicdepartments.musc.edu/neuro-research/research/centers/aging/>

**South Carolina Department on Aging:** <https://aging.sc.gov/>

**South Carolina Department of Health and Environmental Control:** [www.scdhec.net/](http://www.scdhec.net/)

**South Carolina Department of Health and Human Services:** <https://www.scdhhs.gov/>

**South Carolina Department of Mental Health:** <https://scdmh.net/>

**South Carolina Health Care Association:** [www.schca.org](http://www.schca.org)

**South Carolina Institute of Medicine and Public Health:** <http://www.imph.org>

**South Carolina Respite Coalition:** <http://www.screstitecoalition.org/>

**The Carolinas Center for Medical Excellence:** <http://www.thecarolinascenter.org/>

**The FriendShip Village:** <http://www.thefriendship.org/>

**University of South Carolina College of Social Work:** <http://www.cosw.sc.edu/>

This Annual Report is available online at  
<http://sph.sc.edu/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 Dr. Maggi Miller, Registry Manager,  
at [chandlmj@mailbox.sc.edu](mailto:chandlmj@mailbox.sc.edu) for further information.



**Office for the Study of Aging**  
Arnold School of Public Health