*As noted within, data included in this report covers two periods
1) January 1, 2011 through December 31, 2011,
2) January 1, 2012 through December 31, 2012, the most current years with available and comprehensive data.
EXECUTIVE SUMMARY ................................................................. 1

ACKNOWLEDGMENTS ............................................................. 2

INTRODUCTION ................................................................. 3
  Alzheimer's Disease and Related Disorders in South Carolina ............... 4

REGISTRY PROCEDURES ...................................................... 5
  Core data items .............................................................. 6

HISTORY OF THE REGISTRY .................................................. 7

CHARACTERISTICS OF Alzheimer's Disease and Related Disorders (ADRD) IN SOUTH CAROLINA, 2011
  Type and Location of ADRD ............................................... 11
  Dementia in Other Medical Conditions .................................. 12
  Age ............................................................. 14
  Gender ............................................................. 15
  Race ............................................................. 16
  Deaths ............................................................. 17

CHARACTERISTICS OF Alzheimer's Disease and Related Disorders (ADRD) IN SOUTH CAROLINA, 2012
  Type and Location of ADRD ............................................... 21
  Dementia in Other Medical Conditions .................................. 22
  Age ............................................................. 24
  Gender ............................................................. 25
  Race ............................................................. 26
  Deaths ............................................................. 27

SPECIAL REPORT
  Chronic Traumatic Encephalopathy (CTE) .................................. 28

RESEARCH PROJECTS AND OTHER ACTIVITIES ............................. 29

STAFF .................................................................................... 35

AFFILIATED STAFF ............................................................. 36

AFFILIATED FACULTY .......................................................... 36

OFFICE FOR THE STUDY OF AGING PUBLICATIONS ...................... 37

FURTHER INFORMATION ....................................................... 40
List Of Tables

Table 1 Classification of ADRD by ICD-9-CM Codes, 2011-2012 .......................................................... 5
Table 2 Registry Core Data Items, 2011-2012 .......................................................... 6
Table 3 Registry Cases by Dementia Type and Community, Nursing Facility or Unknown Location, 2011 .... 12
Table 4 Dementia in Other Medical Conditions by Age Group, 2011 ....................................................... 13
Table 5 Registry Cases by Age Group and Dementia Type, 2011 ....................................................... 14
Table 6 Registry Cases by Gender, Age Group and ADRD Type, 2011 ....................................................... 15
Table 7 Registry Cases by Race and ADRD Type, 2011 .......................................................... 16
Table 8 Length of Time from Entry to Death by ADRD Type, 2011 ....................................................... 17
Table 9 Top 10 Underlying Causes of Death, 2011 .......................................................... 17
Table 10 Registry Cases by Dementia Type and Community, Nursing Facility or Unknown Location, 2012 .... 22
Table 11 Dementia in Other Medical Conditions by Age Group, 2012 ....................................................... 23
Table 12 Registry Cases by Age Group and Dementia Type, 2012 ....................................................... 24
Table 13 Registry Cases by Gender, Age Group and ADRD Type, 2012 ....................................................... 25
Table 14 Registry Cases by Race and ADRD Type, 2012 .......................................................... 26
Table 15 Length of Time from Entry to Death by ADRD Type, 2012 ....................................................... 27
Table 16 Top 10 Underlying Causes of Death, 2012 .......................................................... 27

List Of Figures

Figure 1 Registry Data Sources .......................................................... 4
Figure 2 Registry Cases by Community, Nursing Facility or Unknown Location, 2011 .................. 12
Figure 3 Registry Cases in Community, Nursing Facility or Unknown Location by Dementia Type, 2011 .... 12
Figure 4 Registry Cases by Age Group, 2011 .......................................................... 14
Figure 5 Registry Cases by Age Group in Community, Nursing Facility or Unknown Location, 2011 .... 14
Figure 6 Registry Cases by Gender, 2011 .......................................................... 15
Figure 7 Registry Cases by Gender and ADRD Type, 2011 .......................................................... 15
Figure 8 Registry Cases by Race, 2011 .......................................................... 16
Figure 9 Registry Cases by Race in Community, Nursing Facility or Unknown Location, 2011 ........ 16
Figure 10 Registry Cases by Community, Nursing Facility or Unknown Location, 2012 .................. 22
Figure 11 Registry Cases in Community, Nursing Facility or Unknown Location by Dementia Type, 2012 .... 22
Figure 12 Registry Cases by Age Group, 2012 .......................................................... 24
Figure 13 Registry Cases by Age Group in Community, Nursing Facility or Unknown Location, 2012 .... 24
Figure 14 Registry Cases by Gender, 2012 .......................................................... 25
Figure 15 Registry Cases by Gender and ADRD Type, 2012 .......................................................... 25
Figure 16 Registry Cases by Race, 2012 .......................................................... 26
Figure 17 Registry Cases by Race in Community, Nursing Facility or Unknown Location, 2012 .......... 26
Executive Summary

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

This report is submitted to the people of South Carolina in fulfillment of the requirement section 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 the Office for the Study of Aging with its upkeep, management, and the dissemination of an annual report.

This report uses the abbreviation ADRD to indicate “Alzheimer’s disease or related disorders.” The term “related disorders” refers to dementias associated with vascular disease, mixed dementia and with other medical conditions such as Parkinson’s disease. Where we refer specifically to “Alzheimer’s disease” (AD), we limit the analysis to individuals with AD only.

Since January 1, 1988, the Registry has identified 225,938 cases of ADRD.

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 the OSA:

In addition to maintaining the Registry and conducting research using this valuable state resource, the OSA works to provide South Carolina’s older persons and their families with access to quality, reliable health and long term care service delivery systems. Specifically, OSA’s focus includes 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 and the SC Vulnerable Adult Guardian Ad Litem Program
• 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 programs in aging at the Office for the Study of Aging have been due to the support of many individuals and organizations. We particularly want to acknowledge the contribution of:

- The Arnold School of Public Health at UofSC, for core support;

- The 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 Employee Insurance Program, for access to data;

- The SC Department of Health and Environmental Control, Vital Records and Public Health Statistics; and

- The Lieutenant Governor’s Office, Office on Aging, for its continued support.
Introduction

Someone in America develops Alzheimer’s every 67 seconds; by mid-century someone will develop Alzheimer’s every 33 seconds.¹

In 2011, the U.S. Census Bureau estimated that there were 657,391 people 65 years of age and over living in South Carolina, and the state was ranked 23rd among other states for the highest percentage of persons aged 65 years and older. Since that time, the elderly 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.²

Alzheimer’s disease and related disorders (ADRD) represent an ever-increasing area of concern for families and the healthcare community. Nationwide, an estimated 5.2 million people in the United States are currently living with Alzheimer’s disease. By 2030, this estimate is expected to reach 7.1 million; by 2050, the number of people age 65 and older with Alzheimer’s disease may nearly triple, from 5 million to a projected 13.8 million.¹

With increasing age as a leading risk factor for Alzheimer’s disease, 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.

ADRD is an umbrella term that encompasses many types of neurocognitive disorders. The Diagnostic and Statistical Manual of Mental Disorder (Fifth Edition) (DSM-5) states that Alzheimer’s disease 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). Alzheimer’s disease (AD) is a type of ADRD with an insidious onset and gradual progression of cognitive and behavioral symptoms³. 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), AIDS, and alcohol or drug abuse.

This report covers calendar year 2011 (those alive on January 1, 2011) and calendar year 2012 (those alive on January 1, 2012). Due to improvements in reporting from our data sources, this year we have the unique opportunity to report registry data over a 2-year time frame. The 2011 and 2012 data are reported separately starting on page 11. Registry cases in this report are defined as Alzheimer’s disease (AD), vascular (Vascular), mixed dementias (Mixed) and ADRDs in other medical conditions (Other). Registry cases are 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.

¹ Alzheimer’s Association, 2015 Alzheimer’s Disease Facts and Figures.
² US Census Bureau, Population Division, September, 2013.
Alzheimer’s Disease and Related Disorders in South Carolina

The prevalence of Alzheimer’s Disease in the United States, is currently estimated to be 11 percent among persons aged 65 and older, and about 32 percent among those aged 85 and older.\(^1\) By 2000, there were 485,333 South Carolina residents 65 years and older. In 2013, there were 727,768 South Carolina residents 65 years and older, representing 15.2% of the total population, an almost 50% increase.\(^2\)

We do not know the total number of persons with ADRD in South Carolina 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 our Registry data. Previous studies suggest that the number of individuals with ADRD may be nearly 50% greater than the number with diagnosed ADRD.\(^3\) What we do know is that the South Carolina Alzheimer’s Disease Registry is the best 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 May 2008.\(^4\) The second is in Georgia and began collecting data in 2014.\(^5\) Our South Carolina Registry uses data from a wide variety of sources to capture as many diagnoses as possible.

![Figure 1](image)

*Figure 1
Registry Data Sources
South Carolina Alzheimer’s Disease Registry, 2012 *

1. Alzheimer’s Association, 2015 Alzheimer’s Disease Facts and Figures
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, as 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).

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

<table>
<thead>
<tr>
<th>South Carolina Alzheimer’s Disease Registry, 2011, 2012</th>
</tr>
</thead>
</table>

**ALZHEIMER’S DISEASE**
- 290.0 - 290.3  Senile or presenile dementia
- 290.8 - 290.9  Alzheimer’s disease
- 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)**
- 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 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 (Table 2) consists of case-identifying data and diagnostic data (ICD 9 CM codes), and the place from which the records were obtained. Other information collected, if available, includes other medical diagnoses, educational status, caregiver contact data for follow up and marital status.

Table 2
Registry Core Data Items

*South Carolina Alzheimer’s Disease Registry, 2011, 2012*

<table>
<thead>
<tr>
<th>Data Item</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identification of case</td>
<td>for matching purposes only</td>
</tr>
<tr>
<td>Location of case</td>
<td>for follow-up</td>
</tr>
<tr>
<td>Name and location of caregiver/contact person</td>
<td>if available</td>
</tr>
<tr>
<td>Sociodemographic data</td>
<td>education, marital status, gender, race, age</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>current dementia diagnosis and other medical diagnoses</td>
</tr>
</tbody>
</table>
History of the Registry

1988

The Alzheimer’s Disease Registry, previously the Statewide Alzheimer’s Disease and Related Disorders Registry, was established in 1988 to record specific information about South Carolinians who develop Alzheimer’s disease and related disorders (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 Disorders Registry located within the Arnold School of Public Health at the University of South Carolina. The law has strict confidentiality requirements but does allow Registry staff to contact the families and physicians of persons diagnosed as having Alzheimer’s disease or a related disorder to collect relevant data and to provide information about public and private health care resources available to them.

1993

From July 1993 to May 1996, the Registry was located at 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 SC Department of Mental Health.

1997

The Registry was moved back to the Arnold School of Public Health. The Registry is currently maintained by the Office for the Study of Aging located within the Arnold School of Public Health.

2009

In 2009 the Alzheimer’s Disease Registry celebrated its 20th anniversary. It is one of only three statewide registries for Alzheimer’s disease and related disorders in the United States. It continues to collect and provide prevalence data to public and private entities for planning, advocate for caregivers, and foster research in risk factors for ADRD including the risk of institutionalization.

The registry continues to receive widespread support and interest from the academic community, lay support groups, state agencies, and other public and private organizations as part of a statewide effort to study the growing impact of Alzheimer’s disease on the health and welfare of older South Carolinians.

2015

The 2013-14 report marks the 25th Registry report and the 25th anniversary of the legislation that creates the registry being signed into law.
2011 South Carolina Alzheimer’s Disease Registry Report
2011 South Carolina Alzheimer's Disease Registry Report

During calendar year 2011, the Registry maintained information on 88,157 individuals alive on January 1, 2011.

South Carolina Population Prevalence of ADRD

Based on the Registry and 2011 population estimates from the United States Census:

- 11.6% of South Carolinians age 65 or over have ADRD
- 44.2% of South Carolinians age 85 or over have ADRD
- Alzheimer's disease prevalence rates vary notably among SC counties
- African Americans are at notably higher risk of an Alzheimer's disease diagnosis than are non-Hispanic whites. At ages 65 and older, for example, African American South Carolinians are 1.68 times more likely to have ADRD as are non-Hispanic whites

Registry Overview:

Of South Carolinians with diagnosed ADRD:

- 61.4% have Alzheimer’s disease
- 11.4% have a dementia due to stroke
- 23% have a dementia related to other chronic conditions
- 29.1% live in an institution
- 64.1% are women
- 27.6% are African American
- 37.9% of those with AD are 85 years or older

CHARACTERISTICS OF ADRD IN SOUTH CAROLINA

BASED ON 2011 ALZHEIMER’S DISEASE REGISTRY DATA

Since January 1, 1988, 213,017 cases of Alzheimer’s disease and related disorders (ADRD) have been identified in South Carolina. This report describes demographic characteristics and medical information for the 88,157 cases alive on January 1, 2011 displayed by type of ADRD.

Type of ADRD

Among the 88,157 current Registry cases, 61 percent had a diagnosis of Alzheimer’s disease and 11 percent had a diagnosis of vascular dementia, which is often associated with stroke. In the event of records showing both Alzheimer’s disease and vascular dementia the case was reported in a Mixed dementia category. Four percent of all Registry cases are in the Mixed category. The additional 24%, for the total number of “Other Conditions,” had a dementia related to other medical conditions, such as Parkinson’s disease (see Table 4 for complete listing). The diagnosis shown represents the most current diagnosis in the data received.
Location

More registry cases resided in the community (67%) than in a nursing facility (29%) or unknown locations (5%) (Figure 2). As shown in Figure 3, the distribution of the types of ADRD was similar in the community and in nursing facilities.

Dementia in Other Medical Conditions

In addition to Alzheimer’s disease, 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 2011 Registry, there are 20,701 persons with a dementia associated with one of these conditions, who do not also have a diagnosis of Alzheimer’s disease or vascular dementia. Six percent have dementia associated with Parkinson’s disease, and 26% have an indication of dementia associated with some other medical condition (please see Table 4 footnote). The percentages in the table are not mutually exclusive due to the fact that some persons’ records indicate that they have more than one medical condition. A few individuals have as many as three such conditions.
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 Alzheimer's disease and Parkinson's disease. Like Alzheimer's disease, 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 Dementia with Lewy Bodies. Medications used to treat Alzheimer's disease, Parkinson's disease, and depression are typically used to manage DLB symptoms. National estimates suggest that DLB accounts for approximately 20% of all dementia cases.\(^1\) In the South Carolina Registry, DLB accounts for 8% of the dementia in other medical conditions category and only 2% of all dementia cases.

### Table 4
#### Dementia in Other Medical Conditions by Age Group

<table>
<thead>
<tr>
<th>Condition</th>
<th>Under 65</th>
<th>65–74</th>
<th>75–84</th>
<th>85+</th>
<th>Total N</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alcohol dementia</td>
<td>18%</td>
<td>7%</td>
<td>2%</td>
<td>1%</td>
<td>1368</td>
<td>6%</td>
</tr>
<tr>
<td>Drug-induced dementia</td>
<td>1%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>68</td>
<td>0%</td>
</tr>
<tr>
<td>Organic brain syndrome</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>16</td>
<td>0%</td>
</tr>
<tr>
<td>Other cerebral degenerations</td>
<td>53%</td>
<td>59%</td>
<td>52%</td>
<td>46%</td>
<td>12050</td>
<td>52%</td>
</tr>
<tr>
<td>Parkinson's disease</td>
<td>2%</td>
<td>5%</td>
<td>7%</td>
<td>8%</td>
<td>1388</td>
<td>6%</td>
</tr>
<tr>
<td>Huntington's disease</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>22</td>
<td>0%</td>
</tr>
<tr>
<td>HIV/AIDS dementia</td>
<td>3%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>153</td>
<td>1%</td>
</tr>
<tr>
<td>Dementia with Lewy Bodies</td>
<td>3%</td>
<td>8%</td>
<td>10%</td>
<td>9%</td>
<td>1834</td>
<td>8%</td>
</tr>
<tr>
<td>Frontotemporal dementia</td>
<td>1%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>92</td>
<td>0%</td>
</tr>
<tr>
<td>Pick's disease</td>
<td>1%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>57</td>
<td>0%</td>
</tr>
<tr>
<td>Creutzfeldt-Jakob disease</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>6</td>
<td>0%</td>
</tr>
<tr>
<td>TBI Dementia</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>73</td>
<td>0%</td>
</tr>
<tr>
<td>Chronic Traumatic Encephalopathy</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>6</td>
<td>0%</td>
</tr>
<tr>
<td>Dementia with other conditions*</td>
<td>19%</td>
<td>19%</td>
<td>27%</td>
<td>35%</td>
<td>5867</td>
<td>26%</td>
</tr>
<tr>
<td><strong>Total (N)</strong></td>
<td>3982</td>
<td>5710</td>
<td>7648</td>
<td>5660</td>
<td>23000</td>
<td></td>
</tr>
</tbody>
</table>

*Dementia with other conditions includes those with an ICD-9-CM code in 294.3 (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 5 shows that 43% of persons with Alzheimer’s disease are 85 years of age or older. Figure 4 shows this information graphically for all dementias included in ADRD, with 38% of persons over 85 years of age. Figure 5 indicates that for people with ADRD, over 68% of those 75 to 84 years of age are being cared for in the community. Living in the community is most often the location of choice for the individual and family. However, as Figure 5 indicates, with age comes an increase in movement to nursing facilities.

Table 5
Registry Cases by Age Group and Dementia Type
South Carolina Alzheimer’s Disease Registry, 2011*

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Total</th>
<th>AD</th>
<th>VASCULAR</th>
<th>MIXED</th>
<th>OTHER</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 65</td>
<td>3313</td>
<td>6</td>
<td>1367</td>
<td>14</td>
<td>5</td>
<td>8558</td>
</tr>
<tr>
<td>65 – 74</td>
<td>8930</td>
<td>17</td>
<td>2209</td>
<td>23</td>
<td>19</td>
<td>16513</td>
</tr>
<tr>
<td>75 – 84</td>
<td>17726</td>
<td>34</td>
<td>3092</td>
<td>32</td>
<td>36</td>
<td>27911</td>
</tr>
<tr>
<td>85 +</td>
<td>22531</td>
<td>43</td>
<td>3062</td>
<td>31</td>
<td>40</td>
<td>32454</td>
</tr>
<tr>
<td>Total</td>
<td>52500</td>
<td>62</td>
<td>9730</td>
<td>31</td>
<td>40</td>
<td>85436</td>
</tr>
</tbody>
</table>

*2721 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 or senile dementia; VASCULAR=Vascular dementia; MIXED=both Alzheimer’s disease and Vascular dementia; OTHER=dementia in other medical conditions.
Gender and ADRD in South Carolina

Table 6 shows Registry cases by gender, dementia type, and age group. For each dementia type, the number of women is 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 is almost 3 times the number of men with ADRD. More women than men in this population were diagnosed with ADRD (Figure 6). 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 7.

Table 6
Registry Cases by Gender, Age Group and ADRD Type
South Carolina Alzheimer’s Disease Registry, 2011

<table>
<thead>
<tr>
<th></th>
<th>AD</th>
<th>VASCULAR</th>
<th>MIXED</th>
<th>OTHER</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>MEN</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 65</td>
<td>1509</td>
<td>9</td>
<td>756</td>
<td>20</td>
<td>99</td>
</tr>
<tr>
<td>65 – 74</td>
<td>3699</td>
<td>22</td>
<td>1046</td>
<td>27</td>
<td>329</td>
</tr>
<tr>
<td>75 – 84</td>
<td>6003</td>
<td>36</td>
<td>1219</td>
<td>31</td>
<td>481</td>
</tr>
<tr>
<td>85 +</td>
<td>5558</td>
<td>33</td>
<td>864</td>
<td>22</td>
<td>402</td>
</tr>
<tr>
<td>WOMEN</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 65</td>
<td>1801</td>
<td>5</td>
<td>607</td>
<td>10</td>
<td>84</td>
</tr>
<tr>
<td>65 – 74</td>
<td>5224</td>
<td>15</td>
<td>1148</td>
<td>20</td>
<td>322</td>
</tr>
<tr>
<td>75 – 84</td>
<td>11701</td>
<td>33</td>
<td>1859</td>
<td>32</td>
<td>786</td>
</tr>
<tr>
<td>85 +</td>
<td>16913</td>
<td>47</td>
<td>2175</td>
<td>38</td>
<td>995</td>
</tr>
</tbody>
</table>

*2969 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.

Figure 6
Registry Cases by Gender
South Carolina Alzheimer’s Disease Registry, 2011

Figure 7
Registry Cases by Gender and ADRD Type
South Carolina Alzheimer’s Disease Registry, 2011
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 Alzheimer’s Disease Registry (28%)(Table 7). Seventy percent of African Americans with ADRD reside in the community, compared to 64% of Whites living in the community (Figure 9).

Table 7
Registry Cases by Race and ADRD Type

<table>
<thead>
<tr>
<th></th>
<th>AD</th>
<th>VASCULAR</th>
<th>MIXED</th>
<th>OTHER</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>RACE</td>
<td></td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>White</td>
<td>34969</td>
<td>65</td>
<td>5381</td>
<td>54</td>
<td>2126</td>
</tr>
<tr>
<td>African-American</td>
<td>13465</td>
<td>25</td>
<td>3842</td>
<td>38</td>
<td>1043</td>
</tr>
<tr>
<td>Hispanic</td>
<td>207</td>
<td>&lt;1</td>
<td>45</td>
<td>&lt;1</td>
<td>5</td>
</tr>
<tr>
<td>All Others</td>
<td>5294</td>
<td>10</td>
<td>714</td>
<td>7</td>
<td>365</td>
</tr>
<tr>
<td>Total</td>
<td>53935</td>
<td>62</td>
<td>9982</td>
<td>11</td>
<td>3539</td>
</tr>
</tbody>
</table>

*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 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, 134,519 have died. 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. We use the first date that a person entered one of the systems reporting to us as their entry date (Table 8).

Table 8
Length of Time from Entry to Death by ADRD Type
South Carolina Alzheimer’s Disease Registry, 2011*

<table>
<thead>
<tr>
<th>ENTRYto DEATH</th>
<th>AD N  %</th>
<th>VASCULAR N  %</th>
<th>MIXED N  %</th>
<th>OTHER N  %</th>
<th>TOTAL N  %</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 2 years</td>
<td>50988 58</td>
<td>10143 62</td>
<td>4296 55</td>
<td>14372 65</td>
<td>79799 59</td>
</tr>
<tr>
<td>2–5 years</td>
<td>23818 27</td>
<td>3936 24</td>
<td>2346 30</td>
<td>4815 22</td>
<td>34915 26</td>
</tr>
<tr>
<td>5 + years</td>
<td>13510 15</td>
<td>2274 14</td>
<td>1128 15</td>
<td>2893 13</td>
<td>19805 15</td>
</tr>
<tr>
<td>Total</td>
<td>88316 66</td>
<td>16353 12</td>
<td>7770 6</td>
<td>22080 16</td>
<td>134519 100</td>
</tr>
</tbody>
</table>

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 9 lists the top 10 underlying causes of death for persons 65 years of age or older in the South Carolina Alzheimer’s Disease Registry who died during 2011. The #1 underlying cause of death for these persons was attributed to senility and organic mental disorders. This category includes Alzheimer’s disease 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, Alzheimer’s disease, diabetes, influenza and pneumonia, accidents, nephritis, and septicemia. As can be seen in the table below, the underlying causes of death for those with ADRD in the Registry nearly mirror the national trend.

Table 9
Top 10 Underlying Causes of Death Among Those 65 Years or Older
South Carolina Alzheimer’s Disease Registry, 2011*

<table>
<thead>
<tr>
<th>Rank</th>
<th>Cause of Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Senility and organic mental disorders</td>
</tr>
<tr>
<td>2</td>
<td>Acute cerebrovascular disease</td>
</tr>
<tr>
<td>3</td>
<td>Coronary atherosclerosis and other heart disease</td>
</tr>
<tr>
<td>4</td>
<td>Chronic obstructive pulmonary disease and bronchiectasis</td>
</tr>
<tr>
<td>5</td>
<td>Acute myocardial infarction</td>
</tr>
<tr>
<td>6</td>
<td>Cancer of bronchus; lung</td>
</tr>
<tr>
<td>7</td>
<td>Congestive heart failure; nonhypertensive</td>
</tr>
<tr>
<td>8</td>
<td>Parkinson’s disease</td>
</tr>
<tr>
<td>9</td>
<td>Other nutritional; endocrine; and metabolic disorders</td>
</tr>
<tr>
<td>10</td>
<td>Septicemia (except in labor)</td>
</tr>
</tbody>
</table>

*Only includes persons who died during the 2011 calendar year.
**Excludes pneumonia caused by tuberculosis or sexually transmitted disease.

2012 South Carolina Alzheimer’s Disease Registry Report
2012 South Carolina Alzheimer’s Disease Registry Report

During calendar year 2012, the Registry maintained information on 90,040 individuals alive on January 1, 2012.

South Carolina Population Prevalence of ADRD

Based on the Registry and 2012 population estimates from the United States Census:

- 11.2% of South Carolinians age 65 or over have ADRD
- 43.8% of South Carolinians age 85 or over have ADRD
- Alzheimer's disease prevalence rates vary notably among SC counties
- African Americans are at notably higher risk of an Alzheimer's disease diagnosis than are non-Hispanic whites. At ages 65 and older, for example, African American South Carolinians are 1.57 times more likely to have ADRD as are non-Hispanic whites

Registry Overview:

Of South Carolinians with diagnosed ADRD:

- 60.7% have Alzheimer's disease
- 11.7% have a dementia due to stroke
- 23.6% have a dementia related to other chronic conditions
- 27.3% live in an institution
- 63.7% are women
- 27.5% are African American
- 38.3% of those with AD are 85 years or older

CHARACTERISTICS OF ADRD IN SOUTH CAROLINA

BASED ON 2012 ALZHEIMER’S DISEASE REGISTRY DATA

Since January 1, 1988, 225,938 cases of Alzheimer's disease and related disorders (ADRD) have been identified in South Carolina. This report describes demographic characteristics and medical information for the 90,040 cases alive on January 1, 2012, displayed by type of ADRD.

Type of ADRD

Among the 90,040 current Registry cases, 60 percent had a diagnosis of Alzheimer's disease and 12 percent had a diagnosis of vascular dementia, which is often associated with stroke. In the event of records showing both Alzheimer’s disease and vascular dementia the case was reported in a Mixed dementia category. Four percent of all Registry cases are in the Mixed category. The additional 24%, for the total number of “Other Conditions,” had a dementia related to other medical conditions, such as Parkinson's disease (see Table 11 for complete listing). The diagnosis shown represents the most current diagnosis in the data received.
Location

More registry cases resided in the community (68%) than in a nursing facility (27%) or unknown locations (5%) (Figure 10). As shown in Figure 11, the distribution of the types of ADRD was similar in the community and in nursing facilities.

### Table 10

<table>
<thead>
<tr>
<th>Dementia Type</th>
<th>Community</th>
<th>Nursing Facility</th>
<th>Unknown</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Alzheimer’s disease</td>
<td>36439</td>
<td>60</td>
<td>15237</td>
<td>63</td>
</tr>
<tr>
<td>Vascular dementia</td>
<td>7056</td>
<td>12</td>
<td>3055</td>
<td>13</td>
</tr>
<tr>
<td>Mixed dementia</td>
<td>2246</td>
<td>4</td>
<td>1165</td>
<td>5</td>
</tr>
<tr>
<td>Other conditions</td>
<td>15503</td>
<td>25</td>
<td>4751</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>61244</td>
<td>68</td>
<td>24208</td>
<td>27</td>
</tr>
</tbody>
</table>

Dementia in Other Medical Conditions

In addition to Alzheimer’s disease, 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 2012 Registry, there are 21,597 persons with a dementia associated with one of these conditions, who do not also have a diagnosis of Alzheimer’s disease or vascular dementia. Six percent have dementia associated with Parkinson’s disease, and 26% have an indication of dementia associated with some other medical condition (please see Table 11 footnote). The percentages in the table are not mutually exclusive due to the fact that some persons’ records indicate that they have more than one medical condition. A few individuals have as many as three such conditions.
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 Alzheimer's disease and Parkinson's disease. Like Alzheimer's disease, it can cause confusion, memory loss, and depression, while other possible symptoms are slowed movement, rigid muscles, and tremors, these 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 Dementia with Lewy Bodies. Medications used to treat Alzheimer's disease, Parkinson's disease, and depression are typically used to manage DLB symptoms. National estimates suggest that DLB accounts for approximately 20% of all dementia cases. In the South Carolina Registry, DLB accounts for 8% of the dementia in other medical conditions category and only 2% of all dementia cases.

Table 11
Dementia in Other Medical Conditions by Age Group
South Carolina Alzheimer's Disease Registry, 2012*

<table>
<thead>
<tr>
<th>Under 65</th>
<th>65–74</th>
<th>75–84</th>
<th>85+</th>
<th>Total</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alcohol dementia</td>
<td>18</td>
<td>8</td>
<td>2</td>
<td>1</td>
<td>1491</td>
<td>6</td>
</tr>
<tr>
<td>Drug-induced dementia</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>66</td>
<td>0</td>
</tr>
<tr>
<td>Organic brain syndrome</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>13</td>
<td>0</td>
</tr>
<tr>
<td>Other cerebral degenerations</td>
<td>51</td>
<td>59</td>
<td>52</td>
<td>46</td>
<td>12918</td>
<td>52</td>
</tr>
<tr>
<td>Parkinson's disease</td>
<td>2</td>
<td>5</td>
<td>8</td>
<td>7</td>
<td>1489</td>
<td>6</td>
</tr>
<tr>
<td>Huntington's disease</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>23</td>
<td>0</td>
</tr>
<tr>
<td>HIV/AIDS dementia</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>170</td>
<td>1</td>
</tr>
<tr>
<td>Dementia with Lewy Bodies</td>
<td>3</td>
<td>7</td>
<td>10</td>
<td>9</td>
<td>1972</td>
<td>8</td>
</tr>
<tr>
<td>Frontotemporal dementia</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>113</td>
<td>0</td>
</tr>
<tr>
<td>Pick's disease</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>59</td>
<td>0</td>
</tr>
<tr>
<td>Creutzfeldt-Jakob disease</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Chronic Traumatic Encephalopathy</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>90</td>
<td>0</td>
</tr>
<tr>
<td>TBI Dementia</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>11</td>
<td>0</td>
</tr>
<tr>
<td>Dementia with other conditions*</td>
<td>20</td>
<td>19</td>
<td>27</td>
<td>35</td>
<td>6369</td>
<td>26</td>
</tr>
<tr>
<td><strong>Total (N)</strong></td>
<td>4342</td>
<td>6110</td>
<td>8060</td>
<td>6276</td>
<td>24788</td>
<td></td>
</tr>
</tbody>
</table>

*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 12 shows that 43% of persons with Alzheimer’s disease are 85 years of age or older. Figure 12 shows this information graphically for all dementias included in ADRD, with 38% of persons over 85 years of age. Figure 13 indicates that for people with ADRD, over 69% of those 75 to 84 years of age are being cared for in the community. Living in the community is most often the location of choice for the individual and family. However, as Figure 13 indicates, with age comes an increase in movement to nursing facilities.

**Table 12**

*Registry Cases by Age Group and Dementia Type*

<table>
<thead>
<tr>
<th></th>
<th>AD</th>
<th>VASCULAR</th>
<th>MIXED</th>
<th>OTHER</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>AGE</td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>Under 65</td>
<td>3464</td>
<td>7</td>
<td>1470</td>
<td>14</td>
<td>176</td>
</tr>
<tr>
<td>65 - 74</td>
<td>9100</td>
<td>17</td>
<td>2305</td>
<td>23</td>
<td>663</td>
</tr>
<tr>
<td>75 - 84</td>
<td>17429</td>
<td>33</td>
<td>3195</td>
<td>31</td>
<td>1227</td>
</tr>
<tr>
<td>85+</td>
<td>22942</td>
<td>43</td>
<td>3241</td>
<td>32</td>
<td>1407</td>
</tr>
<tr>
<td>Total</td>
<td>52935</td>
<td>62</td>
<td>10211</td>
<td>11</td>
<td>3473</td>
</tr>
</tbody>
</table>

*2838 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 or senile dementia; VASCULAR=Vascular dementia; MIXED=both Alzheimer’s disease and Vascular dementia; OTHER=dementia in other medical conditions.

**Figure 12**

*Registry Cases by Age Group*

South Carolina Alzheimer’s Disease Registry, 2012

**Figure 13**

*Registry Cases by Age Group in Community, Nursing Facility or Unknown Location*

South Carolina Alzheimer’s Disease Registry, 2012
Gender and ADRD in South Carolina

Table 13 shows Registry cases by gender, dementia type, and age group. For each dementia type, the number of women is 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 is almost 3 times the number of men with ADRD. More women than men in this population were diagnosed with ADRD (Figure 14). 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 15.

Table 13
Registry Cases by Gender, Age Group and ADRD Type
South Carolina Alzheimer’s Disease Registry, 2012

<table>
<thead>
<tr>
<th>Gender</th>
<th>AD</th>
<th>VASCULAR</th>
<th>MIXED</th>
<th>OTHER</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>MEN</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 65</td>
<td>1575</td>
<td>9</td>
<td>820</td>
<td>20</td>
<td>85</td>
</tr>
<tr>
<td>65 – 74</td>
<td>3719</td>
<td>22</td>
<td>1119</td>
<td>27</td>
<td>326</td>
</tr>
<tr>
<td>75 – 84</td>
<td>5983</td>
<td>35</td>
<td>1299</td>
<td>31</td>
<td>489</td>
</tr>
<tr>
<td>85 +</td>
<td>5731</td>
<td>34</td>
<td>912</td>
<td>22</td>
<td>378</td>
</tr>
<tr>
<td>WOMEN</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 65</td>
<td>1885</td>
<td>5</td>
<td>644</td>
<td>11</td>
<td>91</td>
</tr>
<tr>
<td>65 – 74</td>
<td>5377</td>
<td>15</td>
<td>1169</td>
<td>20</td>
<td>336</td>
</tr>
<tr>
<td>75 – 84</td>
<td>11426</td>
<td>32</td>
<td>1882</td>
<td>31</td>
<td>735</td>
</tr>
<tr>
<td>85 +</td>
<td>17148</td>
<td>48</td>
<td>2301</td>
<td>38</td>
<td>1023</td>
</tr>
</tbody>
</table>

*3079 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.

Figure 14
Registry Cases by Gender
South Carolina Alzheimer’s Disease Registry, 2012

Figure 15
Registry Cases by Gender and ADRD Type
South Carolina Alzheimer’s Disease Registry, 2012
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 (39%) and in the overall Alzheimer’s Disease Registry (28%) (Table 14). Seventy two percent of African Americans with ADRD reside in the community, compared to 66% of Whites living in the community (Figure 17).

Table 14
Registry Cases by Race and ADRD Type
South Carolina Alzheimer’s Disease Registry, 2012*

<table>
<thead>
<tr>
<th></th>
<th>AD</th>
<th>VASCULAR</th>
<th>MIXED</th>
<th>OTHER</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>RACE</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>35237</td>
<td>66</td>
<td>5534</td>
<td>53</td>
<td>2091</td>
</tr>
<tr>
<td>African-American</td>
<td>13480</td>
<td>25</td>
<td>4037</td>
<td>39</td>
<td>1051</td>
</tr>
<tr>
<td>Hispanic</td>
<td>217</td>
<td>&lt;1</td>
<td>51</td>
<td>&lt;1</td>
<td>9</td>
</tr>
<tr>
<td>All Others</td>
<td>5540</td>
<td>10</td>
<td>840</td>
<td>8</td>
<td>356</td>
</tr>
<tr>
<td>Total</td>
<td>54474</td>
<td>60</td>
<td>10462</td>
<td>1212</td>
<td>3507</td>
</tr>
</tbody>
</table>

*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 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, 145,395 have died. 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. We use the first date that a person entered one of the systems reporting to us as their entry date (Table 15).

Table 15
Length of Time from Entry to Death by ADRD Type

<table>
<thead>
<tr>
<th>South Carolina Alzheimer’s Disease Registry, 2012*</th>
</tr>
</thead>
<tbody>
<tr>
<td>AD</td>
</tr>
<tr>
<td>-----</td>
</tr>
<tr>
<td>ENTRYto DEATH</td>
</tr>
<tr>
<td>&lt; 2 years</td>
</tr>
<tr>
<td>2–5 years</td>
</tr>
<tr>
<td>5 + years</td>
</tr>
<tr>
<td>Total</td>
</tr>
</tbody>
</table>

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 16 lists the top 10 underlying causes of death for persons 65 years of age or older in the South Carolina Alzheimer’s Disease Registry who died during 2012. The #1 underlying cause of death for these persons was attributed to senility and organic mental disorders. This category includes Alzheimer’s disease 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, Alzheimer’s disease, diabetes, accidents, influenza and pneumonia, nephritis, and septicemia.\(^1\) As can be seen in the table below, the underlying causes of death for those with ADRD in the Registry nearly mirror the national trend.

Table 16
Top 10 Underlying Causes of Death Among Those 65 Years or Older

<table>
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<tr>
<th>South Carolina Alzheimer’s Disease Registry, 2012*</th>
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Chronic Traumatic Encephalopathy (CTE): An Emerging Dementia Among Professional Athletes and Others

Chronic traumatic encephalopathy, commonly known as CTE, is a progressive neurodegenerative disease caused by repetitive head trauma. Persons with CTE suffer a progressive decline of memory and cognition. They may also experience depression, suicidal behavior, poor impulse control, aggressiveness, parkinsonism, and eventually, dementia.

Dr. Harrison Martland first described CTE in his 1928 article “Punch Drunk”, published in the *Journal of the American Medical Association*, after observing a number of symptoms among boxers. Since then, CTE has gained more prominence through association with several sports, including football, wrestling, hockey, and soccer, as well as with other circumstances where repetitive mild head trauma is likely, such as epileptic seizures, physical abuse, and among military veterans.

Similar to Alzheimer’s disease, the onset of CTE is often gradual and does not progress rapidly. Persons suffering from CTE may often be diagnosed with Alzheimer’s disease or frontotemporal dementia, depending on the age of onset and symptoms. In older individuals experiencing memory problems, a diagnosis of Alzheimer’s disease may be made when in fact the individual may have both Alzheimer’s and CTE. In younger individuals (ages 40-50) exhibiting behavioral issues, a diagnosis of frontotemporal dementia may be made instead of CTE.

Research into CTE is still evolving. So far, little is known about the number of head injuries or severity necessary to lead to CTE later in life. Currently, the only way to definitively diagnosis CTE is by examining brain tissue after death. However, researchers are working to discover biological indications of the disease to detect CTE prior to death, to monitor its progression, and to develop effective treatments to prevent, delay, or potentially reverse the condition.

The SC Alzheimer’s Disease Registry has begun surveillance of the occurrence of CTE among South Carolinians. Future research into statewide prevalence, demographics, and related conditions is planned.

Research Projects & Other Activities

In addition to registering and tracking individuals with ADRD, the staff at the Office for the Study of Aging (OSA) also conduct other activities focused on aging issues of older individuals.

Research

Association between Behavioral Disturbances and Nursing Home Admission in Patients with Alzheimer’s disease

The Office for the Study of Aging was provided funding in September 2010 to conduct phone interviews with caregivers of individuals with Alzheimer’s disease to determine risk factors for the decision to place the individuals in institutions (cases) rather that keeping them at home (controls). The drug company that provided funding was particularly interested in validating a particular tool called the Neuropsychiatric Inventory (NPI). It asked questions about 12 different sets of problem behaviors and the frequency, severity and bothersomeness of the behavior to the caregiver. Those behaviors were delusions, hallucinations, agitation/aggression, depression, anxiety, elation/euphoria, apathy/indifference, disinhibition, irritability, aberrant motor behavior, sleep and nighttime behavior disorders, and appetite and eating changes. We also asked questions from the Zarit Burden Interview and the CES-D depression scale and captured information on the caregivers’ feelings of role captivity, competency, and demographics.

OSA completed 705 interviews, including 363 cases (individuals with Alzheimer’s disease in nursing homes) and 342 controls (individuals with Alzheimer’s disease cared for at home). These individuals were identified, using the Alzheimer’s Disease Registry, with Alzheimer’s disease by self-report and the diagnosis confirmed by ICD-9 code found on a hospital discharge or emergency room visit files.

By using a propensity score matching system to match on race, gender, age within 5 years and assessment for nursing home placement eligibility within 120 days of study initiation, 354 cases matched with 289 controls. The race of the caregivers and the clients were almost the same with 163 controls and caregivers of the controls being African American and 156 cases and 157 caregivers of cases being African American. 126 controls and caregivers of controls were Caucasian and 196 cases and caregivers of cases (195) were Caucasian. More than 75% of the caregivers were females (253 cases; 211 controls) and 80% of the caregivers for cases reported being a high school graduate or higher education while 72% of the control caregivers reported being a high school graduate.

The results showed that the NPI Total Score was found to be a statistically significant predictor of Nursing Home Admission (NHA), where each 10% increase in score (i.e., more impairment) resulted in 30% greater odds of NHA; the NPI-4 Score (consisting of the combined scores from the following behaviors: agitation/aggression, irritability, disinhibition, and aberrant motor behavior) resulted in a 21% greater odds of NHA.

Nursing home admissions were more likely to occur if the caregivers were males or married. NHA was also more likely if the person with AD had more psychiatric conditions or had an increased risk for morbidity based on the Charleston Comorbidity Index (a widely used index of comorbid conditions derived from the assessment for nursing home placement).

We also asked the open-ended question “What was the main reason for placing your ____ (relationship) in the nursing home? (cases) or What is the main reason for keeping your ____ (relationship) at home? (controls).
The qualitative analysis of the open-ended questions showed that overall, in our control group, the most frequently reported theme was *issues with caregivers* which contained themes involving a sense of obligation (n=161), emotions (n=20), help (n=25), and opportunity (n=27). The results of our qualitative analysis suggest that caregivers’ issues play a major role in the decision to keep ones loved one at home rather than placing them in a nursing home.

Among the cases, the most frequently reported theme was *issues with the patient* which contained themes involving physical health problems (n=219), behavior problems (n=121), hospice (n=7), loss of ability to self care (n=56), and medication problems (n=12). The results of our qualitative analysis suggest that patient issues play a major role in the decision to place a loved one in a nursing home rather than at home.

Although our work with the drug company is complete, a manuscript “The Influence of Caregivers and Behavioral Disturbances on Nursing Home Placement of Persons with Alzheimer’s Disease” is under review. Additionally, both quantitative and qualitative results from this project have been presented widely at local and national conferences.

**Faith and Health**

The USC Faith and Health Project explored the complex patterns related to social capital, aspects of faith, and health through in-depth interviews and brief survey instruments. Study groups included United Methodist members who had participated in a holistic health program, regular attendees of United Methodist churches (not part of the holistic health program) and infrequent /non-attendees of religious services, with each category stratified by race (African American and Caucasian). Based on findings and existing literature, a survey instrument has been developed to assess social capital, health outcomes, and multiple dimensions of faith and practice. A psychometric analysis of the scale has been performed and two manuscripts have been published describing the validity of the measure. The questionnaire can be used by community researchers to measure the quality of relationships in community- and congregation-based groups and investigate if participation in these groups is associated with positive mental health outcomes.
**Exercise**

**Move for Life**

OSA in collaboration with a Duke Endowment Grant and other Arnold School of Public Health Departments has developed an exercise DVD designed to increase physical activity. These exercises are for adults who are 50 years and older and younger people who have not been exercising regularly or who have limitations. The DVD contains exercise instructions, deep breathing and stretching, strength and balance exercises and a cardio routine in 10 minute segments or a full routine of 28 minutes. Further information can be found at www.sph.sc.edu/osa.

**Placemat Strength Training Program**

Training home care workers to assist clients in maintaining independence by improving physical functioning through strength training has resulted in the Placemat Strength Training Program (PSTP). This exercise program has been specifically designed for the person who has met nursing home level of care and has chosen to remain at home. This program is being implemented through Community Long-Term Care and is also available to the public at large. Further information can be found at www.sph.sc.edu/osa.

**Training**

**Dementia Dialogues**

“Dementia Dialogues” consists of 5 sessions, each approximately 1.5 hours in length. Session 1 consists of “The Basic Facts”, an overview of Alzheimer's disease and other dementias, Session 2 “Keeping the Dialogue Going”, strategies for effective communication, Session 3 “It's a Different World”, understanding the impact of the environment and ways to promote independence in activities of daily living, Session 4 “It's Nothing Personal”, addresses challenging behaviors and Session 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 www.sph.sc.edu/OSA/programs_dementia.html.

**Elder Mistreatment Prevention Training**

The OSA, in collaboration with the Center for Child and Family Studies in the College of Social Work and with the support of the SC Department of Health and Human Services has developed an Elder Mistreatment Prevention Training called We Each Have a Story which is available for nursing home management and direct care staff.
Recruitment and Retention Training

Partnerships around CNA Training and Mentoring (PACT) Program

OSA staff in collaboration with Goodwill Industries of Upstate/Midlands South Carolina, Inc. completed a pilot program that trains and supports nurse aides to become certified, employed and retained. This project was in response to:

- the increased need for trained direct care workers in long term care facilities
- employers’ desire for experienced workers
- the need for new CNAs to acquire enhanced training beyond the basic CNA training
- the turnover of direct care workers

OSA was involved in training mentors in the placement facilities as well as providing enhanced monthly training to the newly placed CNAs and facility mentors by providing monthly “Lunch & Learn” sessions on Chronic Disease Management for one year at participating facilities.

The CNAs involved in the PACT program increased their knowledge of Chronic Disease through the modules presented at the Lunch & Learn Sessions. Mentoring increased CNA job satisfaction and retention.

Technical Assistance & Evaluation

Person-Centered Hospital Discharge Planning Model

Consumer direction is a philosophy and orientation to the delivery of home and community-based services whereby informed consumers make choices about the services they receive. The person-centered approach allows consumer-direction to take place. In collaboration with the SC Lt. Governor’s Office on Aging, OSA staff was involved in a Center for Medicare and Medicaid services grant to identify and evaluate a person-centered hospital discharge planning model. Activities include being members of the core planning team, providing training and technical assistance in person-centered planning, and outcome evaluation.

Caregiver Coaching Service

The OSA staff worked in collaboration with the South Carolina Department of Health and Human Service Community Long Term Care (CLTC) staff to pilot a Caregiver Coaching Service (CCS) to provide training to family caregivers of CLTC participants in order to improve the caregivers’ competence in specific areas. Topics include Dementia care, Incontinence care, and a Wellness module to promote resilience and empowerment of the caregivers.

Thirty caregivers received this service; fifteen caregivers completed both the pre and post survey. Although a small sample size prohibits the ability to make true statistical inferences, the descriptive data from the pre and post surveys provide some preliminary information about the effectiveness of the CCS; caregiver burden, depression and perceived stress were reduced. There was an increase in reporting of the positive aspects of caregiving.

Each unit of the CCS was documented by the Caregiver Coach in the CCS Summary Report. Analysis of the reports shows that employing the collaborative coaching approach engages, educates, and empowers caregivers to identify and take action to address their concerns. The 30 caregivers identified specific concerns of varying natures. Even when similar concerns were identified, caregivers addressed them differently based on their values, resources, and support.
South Carolina Vulnerable Adult Volunteer Guardian ad Litem Program (SCVAGAL)

In 2014 in South Carolina, there were over 3,600 cases of abuse, neglect, or exploitation of vulnerable adults. Approximately 600 of these reports resulted in court proceedings. The Office for the Study of Aging, in collaboration with the Department of Health and Human Services, Department of Social Services, Adult Protective Service, Adult Protection Coordinating Council, the South Carolina Bar, and the South Carolina Legal Services and Court Administration, developed a program that recruits, trains, and supports volunteer Guardians ad Litem to act in the best interest for vulnerable adults under Adult Protective Services custody in cases of abuse, neglect, and exploitation.

The statewide program became operational August 1, 2011. There are currently 22 active volunteers with 17 in training. After completing training, volunteers are responsible for gathering information, interviewing the vulnerable adult and other involved parties, and making recommendations to the court as to what is in the best interest of the vulnerable adult. Volunteers are court appointed and appear in court on behalf of the vulnerable adult. Since August 1, 2011, 617 vulnerable adults have been served in 38 counties. Most cases are self-neglect and of these, a large percentage has a diagnosis of dementia.

Enabling legislation (S764) for the SCVAGAL program was signed into law by Governor Nikki Haley on Friday, May 16, 2014. The program is a part of the Lieutenant Governor’s Office on Aging, and will remain housed at the University of South Carolina’s Office for the Study of Aging during this time. Funding for state financial year 2015-16 comes from the Lieutenant Governor’s budget. Persons interested in additional information or in becoming a volunteer Guardian ad Litem can contact SCVAGAL at (803) 629-0277 or by email at SCVAGAL@mailbox.sc.edu.

Program Development

HOME CARE +

The Office for the Study of Aging received a Centers for Medicare and Medicaid Services Innovation Challenge Award. In partnership with select Personal Care Provider Agencies across South Carolina, a unique care coordination model has been implemented targeting dual eligible, frail elderly individuals who desire to remain in their homes. The program addresses three main issues: 1) Better Care by utilizing person-centeredness and health care coaching, 2) Better Health through chronic disease management and medication adherence education and a team approach 3) Lower Cost through these improvements. The project trained personal care aides to serve as “Home Care Specialists” who work on teams with “Home Care Consultants” to provide chronic disease management and health care coaching. The “Home Care Consultant” provides education, support and care coordination to the individual and his/her family on a long-term basis. The program goal is to reduce avoidable hospitalizations and emergency room visits and delay referral to nursing homes. Fourteen sites across the state have implemented HOME CARE + with 592 beneficiaries enrolled since the program’s inception.

Health Connections Prime Training

Healthy Connections Prime is a new option for seniors 65 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 Medicaid and Medicare Services (CMS). Through Healthy Connections Prime, members will receive the full range of services, managed by a single Healthy Connections Prime Medicare-Medicaid Plan.
South Carolina is one of 16 states selected to design new coordinated care approaches for seniors (65 and over) who are eligible for both Medicare and Medicaid.

Through this partnership, the Office for the Study of Aging is contracting with Health Connections Prime to provide training and technical support for all Healthy Connections Prime Medicare-Medicaid Plans and their provider networks. Healthy Connections Prime Medicare-Medicaid Plans will coordinate the full range of services and benefits for individuals who enroll in the Healthy Connections Prime program through a Care Coordination Model. The Office for the Study of Aging will support the SC Department of Health and Human Services in shaping the dually-eligible service delivery system.

**Community Outreach**

The staff of the Office for the Study of Aging consults and collaborates with South Carolina’s organizations serving older adults. The OSA also builds networks and provides expertise and technical assistance to the community through its involvement on several committees and its collaboration with organizations that serve the needs of South Carolina’s aging populations including:

- Alzheimer’s Association-SC Chapter
- Alzheimer’s Resource Coordination Center
- South Carolina Department of Health and Human Services
- Advisory Committee for Nurse Aide Training
- Nurse Aide Training Coordinators & Instructors Annual Workshop
- National Association of Social Workers-SC Chapter
- The South Carolina Institute of Medicine and Public Health Long Term Care Task Force
- The South Carolina Respite Coalition
- Carolina Centers for Medical Excellence
- Revenue and Fiscal Affairs
- APCC (Adult Protection Coordinating Council)

**All About Alzheimer’s**, a one day workshop focusing on caregivers was held November 5, 2014 in Columbia. This collaborative effort was sponsored by the Alzheimer’s Association, AARPSC, the Catawba Area Agency on Aging, the South Carolina Geriatric Education Consortium, South Carolina Department of Health and Human Services, South Carolina Caregiver Coalition, and Office for the Study of Aging.

**Aging Advisory/Stakeholder Group** was developed to enhance services and programs through the provision of guidance and collaboration on training initiatives, research projects, program development, and evaluation. Meetings are scheduled on a quarterly basis and are attended by over 60 researchers, faculty, providers, advocates, consumers, state agencies, and funders statewide.
Registry Staff

Brenda Hyleman, LISW-AP & CP, CG, CMC. Director, Office for the Study of Aging (OSA). She is particularly interested in prevention, wellness, ADRC, caregivers (both formal and informal), social determinants, retirement planning, and advanced care planning.

Maggi Miller, M.S., Ph.D., Epidemiologist for the Alzheimer’s Disease Registry and related projects. She also works with program coordination and evaluation. Her research interests include aging, Alzheimer’s disease, caregivers of individuals with Alzheimer’s disease, survey development, and social capital.

Ana Teixeira, Ph.D., is a Research Assistant Professor in the Department of Epidemiology and Biostatistics, Arnold School of Public Health. Her research interests include aging, Alzheimer’s disease and other dementias, the economic and social determinants of older adults’ health, end of life decision-making, migration and ageing, and formal and informal caregivers. She also works with program implementation and evaluation.

Macie Smith, Ed.D, LBSW, C-SWCM, SW-G is the Program Development and Training Manager. She conducts research, develops training programs, and coordinates program design and implementation. She also manages the Dementia Dialogues program. Her focus is to improve the quality of life of South Carolina’s aging population through applicable education practices.

Gelareh Rahimi, M.S. is a statistical graduate assistant for the Alzheimer’s Disease Registry. She is currently pursuing her PhD in biostatics at USC.

Maria Patton, B.SW., Director, South Carolina Vulnerable Adult Guardian ad Litem Program (SCVAGAL). Maria’s interests include geriatrics, promoting community based services for the elderly and working with the vulnerable population. She is also a certified Geriatric Care Manager.

Brenda Stalzer, LMSW, Assistant Director, South Carolina Vulnerable Adult Guardian ad Litem Program (SCVAGAL). Her interests include advocating for vulnerable adults and recruiting and training volunteers.

Lorraine Cleeton, Ph.D., Regional Coordinator for the Charleston area, South Carolina Vulnerable Adult Guardian ad Litem Program (SCVAGAL). Her interests include mental and physical disabilities, assistive technology accommodations and modifications for vulnerable adults. She is an advocate for adults and children with disabilities.

Joanne Metcalf, serves as Upstate Regional Coordinator for the South Carolina Vulnerable Adult Guardian ad Litem Program. Joanne is a licensed social worker and certified adoptions investigator. She began her career with the program as a GAL volunteer.

Louise Wood, M.ED., LMSW, Upstate Coordinator for the South Carolina Vulnerable Adult Guardian ad Litem Program, has a special interest in vulnerable adults and their families. She has volunteered as a health coach for older adults with chronic conditions and has interned with Hospice of the Foothills and the Center for Engaged Aging at Clemson University. She has also worked in a pilot program as a Caregiver Coach.

LaToya Reese, B.A., Administrative Assistant, coordinates administrative activity, data entry for all projects, and assists with the HOME CARE + program.

Robert Roscoe, M.A., Research Associate, oversees budgets and provides grant coordination for all projects.
Affiliated Staff

Carol Cornman, R.N., P.A., Principal Investigator for the Centers for Medicare and Medicaid Service’s Innovation Challenge Award “Home Cares”, an enhanced long term community care coordination model based on a person-centered team approach. Her research interests include incorporating wellness activities that maintain independence in the elderly, person-centered care and preventing avoidable ER and hospital admissions.

Courtney Davis, M.H.A., is the Program Manager for the Center for Medicare and Medicaid Innovation Challenge Award, HOME CARE +.

Marcia Lane, M.P.H., Data Manager for the HOME CARE + program. Her research interests include older women’s health issues, physical activity, ADRD, medication adherence, elder mistreatment, quality of life in long-term care, and consumer-directed care.

Dorothy Davis, B.A., serves as a Consultant for various projects at OSA including Alzheimer’s Disease Registry and Community Long Term Care (CLTC) reports.

Aaron Guest, B.A., is a research graduate assistant for the Office for the Study of Aging and SCDHHS funded projects. He is currently pursuing a dual Master’s degree in social work and public health at USC. His research interests include rural aging, environmental gerontology, aging health disparities, and health communication.

Claire Miller, B.A., is a research graduate assistant for the Office for the Study of Aging. She is currently pursuing a dual Master’s degree in social work and public health at USC.

Sarah Pace, B.A., is a graduate assistant for South Carolina Vulnerable Adult Guardian ad Litem Program. She also volunteers two days a week as a guardian ad litem as part of her field placement for the Masters in Social Work Program at USC. Her interests are working with vulnerable populations, advocating for people with disabilities to live more independently, and serving the Latino community.

Affiliated Faculty

Cheryl Addy, Ph.D., is Senior Associate Dean for Academic Affairs, Arnold School of Public Health.

Jenay Beer, Ph.D., is an Assistant Professor, with a joint appointment in the College of Social Work and the College of Engineering.

Steven Blair, Ph.D., is a Professor, Departments of Epidemiology and Biostatistics and Exercise Science, Arnold School of Public Health.

Shawn Chillag, M.D., is Chairman and Professor, UofSC School of Medicine, Department of Internal Medicine, Division of Geriatrics.

Sara Corwin, Ph.D., is Assistant Dean for Undergraduate Student Services and Director, Undergraduate Program in Public Health, Arnold School of Public Health.

Daniela Freidman, Ph.D., is an Associate Professor, Department of Health Promotion, Education and Behavior, Arnold School of Public Health.

Victor A. Hirth, M.D., is an Associate Professor and Medical Director, Geriatric Services, Department of Internal Medicine, UofSC School of Medicine.

Jim Hussey, PhD, is a Clinical Associate Professor and Chair of the Department of Epidemiology and Biostatistics, Arnold School of Public Health.
Sue LevKoff, ScD, is an Professor and the SmartState Endowed Chair and Director of SmartHOME, College of Social Work.

Jihong Liu, Ph.D., is an Associate Professor, Department of Epidemiology and Biostatistics, Arnold School of Public Health.

Robert Moran, Ph.D., is Clinical Assistant Professor, Department of Epidemiology and Biostatistics, Arnold School of Public Health.

Donna Ray, M.D., is an Assistant Professor, UofSC School of Medicine, Department of Internal Medicine.

Richard M. Schulz, Ph.D., is a Professor in the South Carolina College of Pharmacy.

Mindi Spencer, Ph.D., is an Associate Professor, Department of Health Promotion, Education and Behavior, Arnold School of Public Health.

Mei Sui, Ph.D., is an Assistant Professor and Head of the Health Aspects of Physical Activity Division and Graduate Director, Departments of Exercise Science, Arnold School of Public Health.

Myriam Torres, Ph.D., is Clinical Assistant Professor, Department of Epidemiology and Biostatistics, Arnold School of Public Health.

Ken Watkins, Ph.D., is a Clinical Associate Professor and Associate Chair and Graduate Director, Department of Health Promotion, Education and Behavior, Arnold School of Public Health.

Delia West, Ph.D., is a Professor and the SmartState Endowed Chair and Director, Technology Center to Promote Healthy Lifestyle (TecHealth), Departments of Exercise Science, Arnold School of Public Health.

Office Publications

The following is a list of the manuscripts and reports generated by the OSA staff. Reprints of these articles can be obtained from the Office for the Study of Aging by contacting osainformation@sc.edu.


Pope H, Lane M, Tolma EL, and Cornman C. A Descriptive Study for a Strength and Balance Program for Frail Older Adults in an Assisted-Living Facility. Activities, Adaptation & Aging 32 (3-4) 2008.


Laditka SB, Laditka JN, Cornman CB, Davis CB, and Chandlee MJ. Disaster Preparedness for Vulnerable Persons Receiving In-Home Long-Term Care in South Carolina. Prehospital and Disaster Medicine 23(2) 133-141. 2008.


Further Information

This Annual Report is available online at http://osa.sph.sc.edu/alzheimers_registry.html.

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, as time allows.

Contact Maggi Miller at chandlmj@mailbox.sc.edu