Session to Begin Soon
Alzheimer’s Association
Advocacy & Public Policy
Mission

To eliminate Alzheimer’s disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.
Vision

A world without Alzheimer’s disease®.
Strategic Objectives

• Increasing concern and awareness
• **Advancing public policy**
• Enhancing care and support
• Accelerating research
The Issue At a Glance

ALZHEIMER’S DISEASE IS THE 6TH LEADING CAUSE OF DEATH IN THE UNITED STATES

1 IN 3 seniors dies with Alzheimer’s or another dementia

EVERY 65 SECONDS someone in the United States develops the disease
The Issue At a Glance

IT KILLS MORE THAN
breast cancer and prostate cancer
COMBINED

Between 2000 and 2015 deaths from heart disease have decreased
11%

while deaths from Alzheimer's disease have increased
123%
The Issue At a Glance

16.1 MILLION AMERICANS
provide unpaid care for people with
Alzheimer’s or other dementias

These caregivers provided an estimated
18.4 BILLION HOURS
of care valued at over
$232 BILLION
The Issue At a Glance

In 2017, Alzheimer’s and other dementias will cost the nation $259 billion. By 2050, these costs could rise as high as $1.1 TRILLION.
Federal Update

What about Congress?
FEDERAL ADVOCACY VICTORIES

ALZHEIMER’S AND DEMENTIA NIH RESEARCH FUNDING

<table>
<thead>
<tr>
<th>Year</th>
<th>Funding</th>
<th>Event</th>
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<tbody>
<tr>
<td>2011</td>
<td>$448M</td>
<td>National Alzheimer’s Project Act</td>
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<tr>
<td>2012</td>
<td>$503M</td>
<td>2025 Goal Set</td>
</tr>
<tr>
<td>2013</td>
<td>$504M</td>
<td></td>
</tr>
<tr>
<td>2014</td>
<td>$562M</td>
<td>Alzheimer’s Accountability Act</td>
</tr>
<tr>
<td>2015</td>
<td>$631M</td>
<td>PJB</td>
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<tr>
<td>2016</td>
<td>$991M</td>
<td></td>
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<tr>
<td>2017</td>
<td>$1.4 B</td>
<td>Medicare begins covering care planning</td>
</tr>
<tr>
<td>2018</td>
<td>$1.9 B</td>
<td>BOLD RAISE</td>
</tr>
<tr>
<td>2019</td>
<td>$2.3 B</td>
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THE BRAINS BEHIND SAVING YOURS
We have FOUR new asks in 2019

• Increase the commitment to Alzheimer’s research AND public health response
  – Letter of Support for an additional $350 Million to NIH for research for Alzheimer’s & other dementias
  – Letter of Support to fully fund the BOLD Infrastructure Act signed into law in 2018 for $20 million to CDC for public health activities

Despite the growing burden of the disease, the investment in Alzheimer’s research falls far short of the need.
Federal “Asks” cont’d:

• Support education & outreach on Alzheimer’s care planning services covered under Medicare
  – Cosponsor the “Improving HOPE for Alzheimer’s Act” (S. 880/H.R. 1873)

• Improve access to services for individuals with younger-onset Alzheimer’s.
  – Cosponsor the “Younger-Onset Alzheimer’s Disease Act” (S. 901/H.R.1903)
Volunteer on an Alzheimer’s Congressional Team

Beth Sudikowski @bcomediasmuse - Feb 20
Enjoyed talking with @RepSteveDuncan today about ways to advance the cause. Thanks for all your support! #ENDALZ @ALZIMPACT @ALZC

laurajoseph @PharmGJALZ - 21 Aug 2018
Thank you @RepJoeWilson for your sponsorship of #BOLDAlzheimersAct & GECHA! It was a pleasure to meet you at the Greater Irmo Chamber of Commerce this morning! Thank you for being a champion of support to #ENDALZ

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THE BRAINS BEHIND SAVING YOURS:
NOT ALL POLICY IS FEDERAL!

• Alzheimer's is a growing public health crisis and state governments must take bold action. Elected officials should be concerned!

• State measures can reduce the long-term impact of the disease on state budgets, and improve the lives of individuals living with dementia and their family caregivers.

• Alzheimer’s public policies will be a priority when we engage elected officials. Other issues will take priority if we don’t.
Alzheimer’s Disease in South Carolina, 2018

92,000
number of people aged 65+
with Alzheimer’s disease
in SC

313,000
number of caregivers
in SC

+ =

357
million hours in unpaid care for loved ones
It’s an Economics Issue
Work-Related Changes Experienced by Alzheimer’s Caregivers

- Had to go in late/leave early/take time off: 54%
- Had to take a leave of absence: 15%
- Had to go from full-time to part-time work: 13%
- Had to take a less demanding job: 13%
- Had to quit work entirely: 9%
- Lost job benefits: 8%
South Carolina State Legislature

SC Senate
• 46 part-time citizen legislators
• 87,200 constituents per district
• Elected every 4 years

SC House
• 124 part-time citizen legislators
• 32,355 constituents per district
• Elected every 2 years

Both chambers together are called the “General Assembly.”
The General Assembly convenes from January through May each year.
SC operates in 2-year sessions. 2019 is the 1st year of a 2-year session.
In January the governor submits proposed budget to the legislature.

Both the House and the Senate pass a budget. If these versions do not match, a conference committee consisting of both House and Senate members is assembled to reconcile the differences.

**THIS IS ALMOST ALWAYS THE CASE!**

The legislative session adjourns in May, but they have until July 1 (the next fiscal year) to pass a budget with a simple majority. Once passed, the Governor may veto line items in the budget.
STATE ISSUE: CAREGIVER RESPITE

Funded at $900,000 through Department of Mental Health.

Provides financial assistance to dementia caregivers, giving them a much-needed break by helping them arrange care assistance.

Can be used for short-term respite stays in residential care settings.
STATE ISSUE: ALZHEIMER'S RESOURCE COORDINATION CENTER (ARCC)

Already established in state law, but no dedicated funding to implement all functions.

Seeking $85,000 in budget to establish dedicated full-time dementia coordinator in the ARCC to oversee Alzheimer’s State Plan, increase public awareness, conduct outreach on topics like early detection, identify unmet needs & more.
WE’RE ALSO ENGAGED IN THESE BILLS

**S 564** – would establish a tax credit for caregivers of a person 65+. $50 per month if caregiver employed, $100 per month if not employed.

**H 4127** – would modify loan forgiveness program to incentivize geriatricians to practice in South Carolina

**H 3752** – would require the Dept. on Aging to supply emergency response systems to all seniors.

**S 0197** – would shift all Adult Protective Services from the Dept. of Social Services to the Dept. on Aging

**H 3320** – would require the Dept. of Corrections to create a plan to care for inmates with dementia in SC prisons.
What is an Alzheimer’s State Champion?

- Highly trained go-to advocate for a specific state legislator
- May already have connection to legislator
- Personal or professional connection to Alzheimer’s or related dementia
- Can commit to 3 annual district visits and participation in SC State House Day
- Comfortable talking to the media
- Can be an early stage Alzheimer’s patient
- Agree to participate in letters to the editor/ and social media campaigns
- STRONG desire to see SC become more dementia friendly!
How can you help with advocacy?

• Become a Advocacy Team Member
  – For a small time commitment quarterly, you can help advocate both state and federal representatives to educate them on the Alzheimer’s crisis.

• Join the Alzheimer’s Impact Movement (AIM)
  – This 501c4 sister organization to the Alzheimer’s Association can actually gain access to key politicians to educate and update in real time during session.

• For more information, visit alz.org/sc
Text “SCCHAMP” to 52886

- Email or tweet your SC State Senators and SC State Representatives immediately as a State Champion!

- Quick and easy

- Opt into updates so you can take future action on time-sensitive issues!

- You can also text “ALZSC” to 52886 to opt in for state updates & actions.
Alzheimer’s Association Resources

How we help:

- 24-Hour Helpline: 800-272-3900
- Information & Referral
- Care Consultation
- Education Programs
- Online resources: alz.org/sc
- Early-Stage Support Services
- Caregiver Support Groups
- Caregiver Respite Assistance
- Safety Services for Wanderers
- Advocacy & Public Policy
Contact Info

Taylor Wilson
Director of State Policy
twilson@alz.org
803-509-7354
Thank you for participating

If you have any questions, please contact Joan Harris, JOANMH@mailbox.sc.edu
Thank you for participating!

Please give us your feedback about the session by answering a brief survey.

For the in-person attendees, we will have the survey available on the tablets at the end of the session.

For virtual attendees, we will be emailing a survey link to all participants, or you can access it through the QR code to the right, or the survey link.

The QR code appears here or it can be accessed via the Survey Link.