

South Carolina Alzheimer's Disease Research Center (SC-ADRC) Update

JANUARY 30, 2024

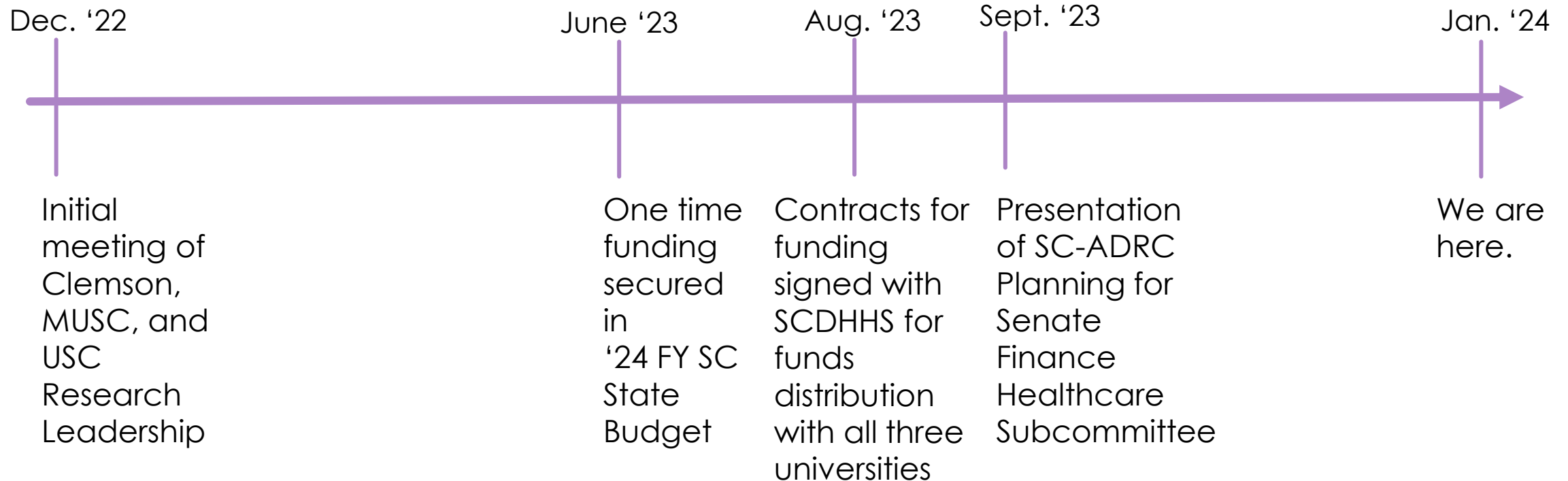
WAYS AND MEANS HEALTHCARE SUBCOMMITTEE

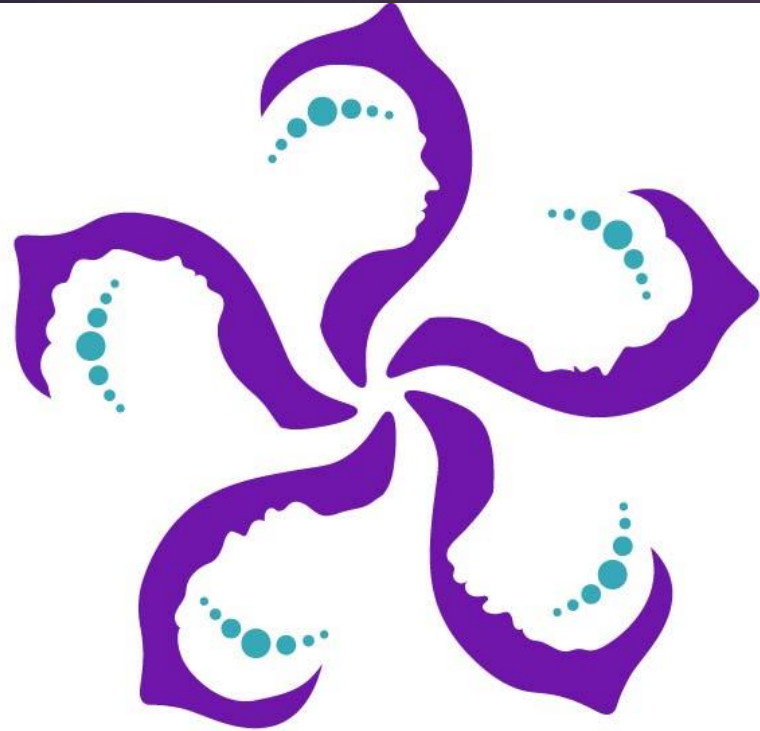
ADRC Definition

- ▶ Alzheimer's Disease Research Centers (ADRCs) work to translate research advances into improved diagnosis and care, as well as find ways to treat and possibly prevent Alzheimer's disease and related dementias in all people. ¹
- ▶ For patients and families affected by Alzheimer's disease, the ADRCs offer:
 - ▶ Help with obtaining diagnosis and medical management
 - ▶ Information about the disease, services, and resources
 - ▶ Outreach to include diverse populations in research opportunities, including clinical trials and research registries
 - ▶ Support groups and other special programs for volunteers and their families ¹

1. Alzheimer's Disease Research Centers. (n.d.). National Institute on Aging. <https://www.nia.nih.gov/research/adrc#:~:text=About%20the%20ADRCs&text=Researchers%20at%20these%20Centers%20are,are%20NIH%20Centers%20of%20Excellence>.

SC-ADRC Timeline





South Carolina
Alzheimer's Disease
Research Center

This logo is inspired by all who struggle with Alzheimer's disease and the challenges faced by them and their families.

The shape is indicative of the forget-me-not, the flower of Alzheimer's.

Inside each "petal" is a silhouette of a different face, symbolizing the global and varied impact of this disease.

The small circles represent the memory of loved ones and their struggles to "connect the dots".

The logo has a strong circular motion, reminiscent of a wheel or clock, showing the forward momentum of the ongoing research being conducted to develop a cure.

SC-ADRC Cores

Administrative Core

Clinical Core

Neuropathology Core

**Data Management
& Statistical Core**

**Research Education
Component**

Digital Biomarker Core

Neuro-Imaging Core

**Outreach, Recruitment,
& Engagement Core**

**Cellular & Molecular
Biomarker Core**



National Engagement

- ▶ SC-ADRC Administrative Core leadership attended the National Alzheimer's Coordinative Center Fall ADRC Meeting in San Diego, CA (Oct. '23)
- ▶ SC-ADRC began process to collaborate with:
 - ▶ National Centralized Repository for Alzheimer's Disease and Related Dementias (NCRAD)
 - ▶ Alzheimer's Disease Genetics Consortium (ADGC)
 - ▶ Standardized Centralized Alzheimer's & Related Dementias Neuroimaging (SCAN)
 - ▶ Brain Watch Coalition (global public-private coalition advancing equitable solutions for brain healthcare)
- ▶ Collaboration with Data Management and Statistical core leads at NYU, University of Michigan, and Wake Forest University to get REDCap software they have constructed to support SC-ADRC database

Application update

- ▶ All Core leadership has developed specific aims and have begun to develop the NIA ADRC grant application for submission June 2024.
- ▶ Ralph H. Johnson VAHCS is now the national coordinating center for veterans with neurodegenerative diseases and is coordinating with the SC-ADRC with leadership appointed to the Steering Center of the ADRC CARENet VA system
 - ▶ The Clinical Core has defined the participant population as 50% military/veteran and 50% non veteran from rural and urban areas of the state (Recruitment regions have been assigned to each institution)
- ▶ NIA ADRC required pilot grant program has been established and is soliciting application for a third round of grants focused on neurodegenerative disease.
- ▶ Servers have been set up to host the SC-ADRC website, required by the NIA ADRC. Website content has been written and a vendor is in the process of designing the website.

Collaboration

- ▶ SC-ADRC co-sponsored the MUSC Center for Healthy Aging Fall Research Symposium where 200 attendees heard speakers from all three research institutions present on their cutting age aging and dementia related research
- ▶ Clinical Cores at MUSC, USC and Clemson have developed a strategy to ensure enrollment of clinical trial participants in rural areas of SC through utilizing the Healthy Brain Aging Network at USC, Tiger PALS database, and the SC Alzheimer's Network at MUSC
 - ▶ Recruiting participants in the early stages of dementia to be provided with assessments required by the National Alzheimer's Coordinating Center (NACC) to be eligible quickly for local clinical trials.
- ▶ Cellular and Molecular Biomarker Core has purchased at an almost 50% discount the Quanterix HD-X system that allows for more in depth biomarker research in dementia diagnosis.
 - ▶ This testing will be offered to all three universities to improve diagnostics for clinical trial participants, improving diagnostic accuracy and earlier detection of the disease in SC citizens.
- ▶ MUSC Neuropathology Core is providing Cellular and Molecular Biomarker Core at USC with cerebrospinal fluid (CSF) and blood from the collection to create more sensitive biomarker tests to accurately identify individuals in the earliest stages of dementia.

Collaboration (cont'd)

- ▶ Outreach, Recruitment, and Engagement (ORE) Cores at all three universities are collaborating to create a first of its kind state wide Caregiver Registry.
 - ▶ To help better understand the impact of dementia on families and individuals to provide better support
- ▶ ORE and Clinical Core at all three Universities are collaborating with the SC Alzheimer's Disease Registry on assessing longevity of enrollees of the Registry
 - ▶ This will help determine how those enrolled on the registry can access clinical trials, longitudinal studies, etc.
- ▶ Research Education Component (REC) Core at all three universities has established the virtual Dementia Seminar Series directed towards improving education of healthcare providers caring for individuals facing dementia in SC, as well as future dementia researchers.
- ▶ Neuropathology Core has established weekly Neurodegenerative Disease Microscopic Consensus Conferences where neuropathologists can join and review cases to reach consensus on diagnosis for all three universities.
 - ▶ Also includes "Brain Cutting Conferences" for gross pathology study of the brains from participants with neurodegenerative diseases.

Core Collaboration Across Disciplines

- ▶ Clinical Core and Neuropathology Core have partnered with Ralph H Johnson on an approach to sequence genomes of South Carolina citizens and veteran populations to be deposited into the NCRAD and ADGC to help search for the new genetic variants causing dementia and any genetic abnormalities that may contribute to dementia in SC.
 - ▶ Also offers opportunity to offer genetic counseling to SC citizens at high risk for developing dementia.
- ▶ Leaders from ORE Core and Digital Biomarkers (DB) Core are capitalizing on an NIA funded grant to explore biological, behavioral, social, environmental factors linked to cognitive decline/ADRD risk in middle age or older African Americans utilizing digital health assessments.
- ▶ DM Core is also consulting with researchers interested in utilizing Clemson's developed app so that it can be added to the Clemson Marketplace to ensure it is available to all SC-ADRC universities and beyond
 - ▶ Prelim findings were presented at the Gerontological Society of America in Nov. '23

New Partners

- ▶ The ORE Core participated in the Clementa C. Pinkney Outreach and Ministry Community Health Fair Oct. '23
- ▶ SC-ADRC leadership has been appointed to the Neuropathology Working Group, T21 Research society to explore Down syndrome-associated Alzheimer's disease.
- ▶ In collaboration with the MUSC Hollings Cancer Center, the Cellular and Molecular Biomarker Core has obtained two cutting-edge platforms for sequencing genomes in single cells.
- ▶ In its ninth implementation year, the SC Advancing Diversity in Aging Research program (SC-ADAR), an undergraduate program that matches USC faculty with students from SC HBCUs to demonstrate aging research, will be adding a neuroimaging research module through the REC Core.

Additional Ongoing Research in SC-ADRC

- ▶ USC Nursing and USC Social Work schools are collaborating on a project to monitor the health and wellbeing of caregivers for people living with dementia.
- ▶ Expansion of the SC Alzheimer's Disease Registry (USC Arnold School of Public Health) to include linkages to Medicare and Veterans Affairs.
- ▶ USC and MUSC are identifying clinical determinants of outcomes for people living with dementia in SC.
- ▶ USC and MUSC are continuing their collaboration with neuroimaging determinants of brain integrity and vascular dementia, notably on advanced MRI and diffusion methods.
- ▶ USC is leading a project to determine if brain health across the lifespan is associated with sentence comprehension.
- ▶ Clemson undergrad scholars working with the ORE Core have developed automated record identified senior independent living for outreach and local resources for collaboration and referral.
- ▶ The ORE Core is leveraging two large current NIH grants through Clemson for cognitive training to prevent dementia.
- ▶ The SC-ADRC is leveraging two other NIH funded prevention trials to foster publications and collaborations across all three universities.



Questions?

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