



ALZNET and NACC:

Opportunities for Collaboration and Synergy

Gil Rabinovici, MD

Director, UCSF ADRC

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What is ALZ-NET?



A **voluntary health care provider-enrolled patient network** that collects longitudinal data on patients being evaluated or treated for Alzheimer's disease.



Currently **enrolling patients being evaluated for or treated with novel Alzheimer's treatments** approved by the FDA in 2021 or after, including treatments that slow disease progression, or address cognition/function, or address neuropsychological/behavioral symptoms.



Implemented in real-world clinical practice, ALZ-NET is **not a clinical trial**.

ALZ-NET will expand and evolve over time



Must acknowledge the enormous contributions of our current Investigators, Advisors and Partners

CO-PRINCIPAL INVESTIGATORS

Maria Carrillo Alzheimer's Association
Gil Rabinovici Memory and Aging Center, UCSF
Michael Rafii ATRI / Keck School of Medicine USC

STUDY INVESTIGATORS

Alireza Atri Banner Sun Health Research Institute
Kirk Daffner Harvard Medical School
Rebecca Edelmayer Alzheimer's Association
Constantine Gatsonis Brown University School of Public Health
Oscar Lopez University of Pittsburgh School of Medicine
Andrew March American College of Radiology
Anton Porsteinsson University of Rochester School of Medicine
Katherine Possin Memory and Aging Center, UCSF
Stephen Salloway Butler Hospital / Warren Alpert Medical School of Brown University
Mary Sano Mount Sinai School of Medicine
Heather Snyder Alzheimer's Association
Christopher Whitlow Wake Forest School of Medicine / American College of Radiology
Consuelo Wilkins Vanderbilt University Medical Center
Charles Windon Memory and Aging Center, UCSF

STUDY ADVISORS

Jerome Barakos Sutter Health California
Sharon Brangman SUNY Upstate Medical University
Greg Jicha University of Kentucky
John Jordan American College of Radiology / American Society of Neuroradiology / Providence Little Company of Mary Medical Center-Torrance
Jennifer Lingler University of Pittsburgh School of Nursing
Klaus Romero Critical Path Institute
Sudhir Sivakumaran Critical Path Institute
Mia Yang Wake Forest School of Medicine





Develop a multi-site network for enrollment and data collection.



Build and implement resources for clinical readiness in a new phase of treatment (i.e., education and training).



Collect patient data at the start of treatment and over time, including measures of cognition, function and safety.



Collect and archive brain scans, as well as genetic and biomarker data and blood samples.

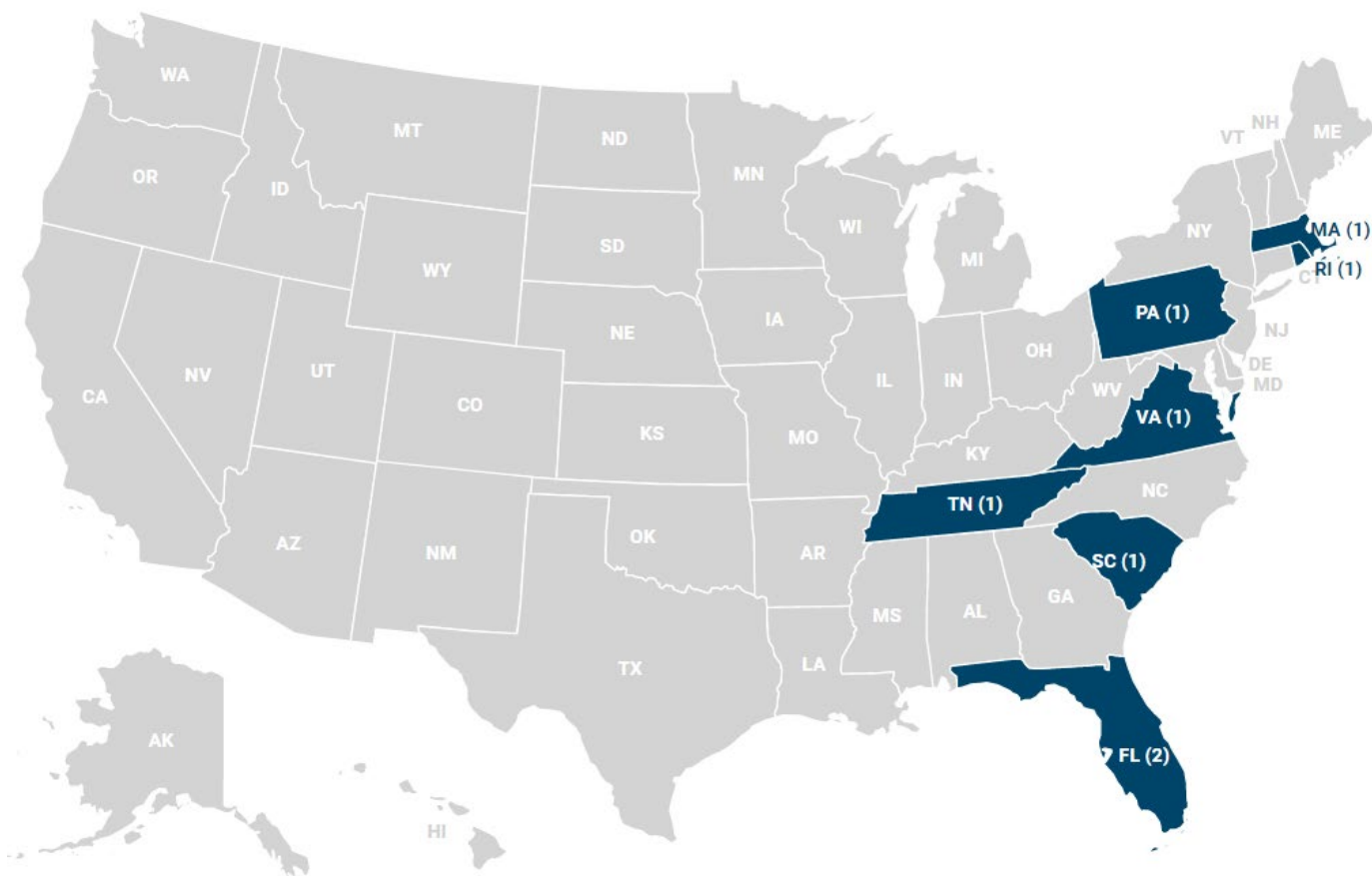


Track health outcomes and resource utilization of participants.



Share de-identified data, brain scans and blood samples with the research community.

ALZ-NET Activated Participating Sites



Over 100 sites in various stages of activation and start up

Active Sites
9

Patients Registered
21

Sites in Start Up
42

Next Invitation Cycle
May 2023

Sites in Queue
54

**As of 4/26/23*



Opportunities for ALZNET-NACC Collaboration

- **NACC/ALZNET co-enrollment enriches phenotyping**
 - ALZNET: MMSE/MoCA, FAQ (required); AD8, NPI (optional)
 - NACC: UDS, genetics, biomarkers, research-grade neuroimaging
 - ALZNET: detailed longitudinal AE data, treatment profile
- **Common data elements enable comparisons**
 - Compare ALZNET-enrolled participants with NACC historical and contemporaneous “controls”
- **Cross-validation between NACC and “Real World” data**
 - Longitudinal clinical and biomarker trajectories, predictive models

Optimizing ALZNET-NACC Synergy

- **Clinical care vs. research**
 - ALZNET activities are part of *clinical care*
 - ADRC visits are *observational research*
 - Integration between clinic and research will vary across ADRCs
- **Minimizing subject and site burden**
 - Avoiding redundant data collection and entry
- **Database integration and linkage**
 - Distinct database structures, subject IDs
- **Stay tuned for NACC survey & webinar this Summer!**

Scaling up Real World Data in ADRD

- **Need to expand to other data sources and types**
 - EHR/EMR
 - Patient and care-partner reported measures
 - Linkage to other existing cohorts and studies
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Department of Health and Human Services

Part 1. Overview Information

Participating Organization(s)

National Institutes of Health (NIH)

Components of Participating Organizations

National Institute on Aging (NIA)

National Institute of Neurological Disorders and Stroke (NINDS)

Funding Opportunity Title

Alzheimer's Disease (AD) and AD-Related Dementias (ADRD) Real-World Data Platform (U54 Clinical Trial Optional)

**Interested in
becoming a
site?**



Or visit, alz.org/alznetwork