



NCRAD Notes

Newsletter of the National Centralized Repository for Alzheimer's Disease and Related Dementias • Fall 2023 • Issue 31

Diversity and Health Equity in Research

In this issue, we are highlighting the importance of **diversity and health equity** in research. Including more heterogenous populations in biomedical research studies helps ensure that research produces results that are impactful for all people. It also gives us the opportunity to improve trust in science among populations that historically have been left out of, or even harmed by, the medical community. Additionally, recruiting a wider range of people to biomedical research and lifting up their voices is crucial to improving innovation, creativity and empathy among teams of scientists.

For these reasons and more, NCRAD has included funds in our most recently approved grant, specifically for collection and central banking of samples from Alzheimer's disease and related dementias (ADRD) studies focused on ethnically, racially, and socioeconomically diverse participants. Alzheimer's disease and related dementias are complex conditions that affect individuals from various cultural, socioeconomic and genetic backgrounds differently. To develop effective prevention strategies, diagnostics and treatments, it is crucial that research includes a broad range of participants. By doing so, researchers can uncover variations in dementia that may not be apparent within a homogenous group. For example, genetic variants differ across races. Because of this, research results from white, non-Hispanic participants may not directly apply to other races and ethnicities. Therefore, including diverse participants in ADRD research ensures that our understanding of dementia is comprehensive and that the benefits of scientific advancements can be shared by all people.

NCRAD Participates in Walk to End



Alzheimer's®

Several NCRAD team members enjoyed walking together in support of the Alzheimer's Association's mission to end Alzheimer's disease.

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The Asian Cohort for Alzheimer’s Disease (ACAD)



ACAD

Asian Cohort for Alzheimer’s Disease

The Asian Cohort for Alzheimer’s Disease (ACAD) study is an international collaboration with the goal of compiling a robust sample

size of Asian American and Asian Canadian subjects for Alzheimer’s disease (AD) research. Making up 6% and 10% of the US and Canadian populations respectively, Asians are the fastest growing populations in both countries, yet they are underrepresented in AD research. ACAD aims to address this gap by starting with a cohort of individuals of Chinese, Korean, and Vietnamese ancestry, and later extending to other major Asian populations in both countries.

Alzheimer’s disease (AD) affects 5.8 million people in the United States and 700,000 people in Canada and impacts the economy, patients, and caregivers. Genetic studies on large numbers of participants have successfully led to dozens of genetic findings associated with AD risk and promises for understanding the cause of the disease and strategies for treatment. Most of these



ACAD study team at a Chinese community health fair



ACAD study team in Oakland, CA

findings are made on participants with European ancestry. Knowledge about AD genetics among Asian Americans is especially limited due to lack of participants. Comprising 6% of the US populace, Asian Americans are under-sampled and deserve more scientific investment.

ACAD is the first large AD genetics cohort for Asians in the United States and Canada. We have assembled a team of scientists, clinicians, and community partners with a collaborative history and expertise in AD research, human genetics, and Asian community outreach. ACAD will recruit

participants, collect data using translated data forms and clinical/diagnostic protocols, and collect blood to study chemical changes or abnormal protein levels. We are learning how sex, genetics, and lifestyle risk factors, such as diet, differ between Asians and Caucasians and will further explore how this impacts our risk for getting AD when we are older. The ultimate goal of ACAD is to develop more reliable AD diagnostics, more accurate risk predictions and more effective treatments and health delivery for the Asian American and Canadian populations.



ACAD study team at the 2022 San Diego Lunar Tét Festival

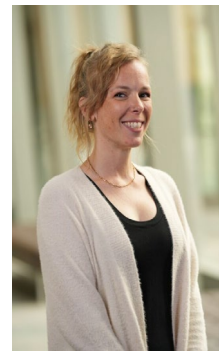
Enrollment in ACAD involves a demographic questionnaire, cognitive testing, and saliva and/or blood sample for genetic analysis. These data will be used to determine the impact of lifestyle and genetic factors on AD risk. Participants are contacted by ACAD outreach staff or can contact ACAD directly. A pre-screening phone call determines participant eligibility. To learn more about the ACAD study or to participate, visit their website at www.acadstudy.org.

NCRAD Attends AAIC 2023 Alzheimer’s Association International Conference

This year seven members of the National Centralized Repository for Alzheimer’s Disease and Related Dementias (NCRAD) team attended the 2023 Alzheimer’s Association International Conference (AAIC) in Amsterdam, Netherlands! AAIC provides a unique opportunity for laboratory and clinical researchers, clinicians, and others from the research community, from both academic and commercial institutions, to come together to share new and exciting advancements in Alzheimer’s and dementia research.



*Kaci Lacy, MPH,
CCRP*



*Casey Snoddy, BS,
CCRP*

Kaci and Casey were excited to share booth space at AAIC with other NIA-affiliated groups including our close partners NIAGADS (The National Institute on Aging Genetics of Alzheimer’s Disease Data Storage Site) and NACC (The National Alzheimer’s Coordinating Center). They greeted colleagues at the NCRAD booth where they were able to discuss the new NCRAD Biomarker Assay Lab and the large variety of samples banked at NCRAD that are available for request. The pair handed out flyers and other fun items while they discussed both sample banking and distribution opportunities with hundreds of investigators. They were fortunate to meet with researchers from all over the world and provide them with information on NCRAD’s ongoing diversity initiatives along with the many services NCRAD provides.

NCRAD was also represented by several posters that were on display during the conference by NCRAD co-investigators: Dr. Michael Edler, “Implementing New Technologies of Enhance Specimen Quality and Researcher Value at the National Centralized Repository for Alzheimer’s Disease and Related Dementias (NCRAD)”; Dr. Kelly Nudelman, “Genetic ancestry of human induced Pluripotent Stem Cells (iPSCs) banked for neurodegeneration research”; and Dr. Kristen Russ, “High Precision β -amyloid, 1-42, and p-Tau 181 Plasma Assay Performance in NCRAD Biomarker Assay Laboratory”. These posters highlighted various technologies, sample types and exciting genetic ancestry and biomarker research that is being done using NCRAD resources.



Participating in Research with NCRAD

The National Centralized Repository for Alzheimer's Disease and Related Dementias (NCRAD) collaborates closely with research studies and institutions around the world. We have compiled a listing of studies currently enrolling participants and banking samples with NCRAD. A NCRAD staff member can help connect you to these programs at 800-526-2839 or by email alzstudy@iu.edu. You can explore each study for more information, visit: <https://ncrad.org/participate.html>

Indiana University and NCRAD are actively recruiting new study participants.

Alzheimer's Disease- Family Based Study eligible participants include:

- A person, with a diagnosis of Alzheimer's disease or related dementia, **AND**
- A living sibling, with a dementia diagnosis, **AND**
- A third related family member, age 50 or older, with or without a dementia diagnosis.

Participation activities include:

Annual telephone survey, possible blood sample collection and optional brain autopsy program.

For more information and screening, please visit:

https://ncrad.iu.edu/load_informed_consent.html or call 1-800-526-2839



NCRAD Researcher & Professional Staff Mailing List

Researchers registered with the mailing list will receive updates on new initiatives and important activities happening at NCRAD. NCRAD, supported by the National Institutes on Aging (NIA), is a national resource where clinical information and biological materials, such as DNA, plasma, serum, RNA, CSF, cell lines and brain tissue can be stored for NIA funded studies. Additionally, NCRAD distributes samples to researchers to help facilitate new innovations and discoveries in Alzheimer's disease and related dementias.

Join here to connect with NCRAD today!

<https://ncrad.org/dissemination-list/>

*Your contact information will not be shared with other parties. NCRAD is approved by the Indiana University Institutional Review Board (IRB) # 1011003300, PI: Tatiana Foroud, PhD.

Additional Information and Resources

Alzheimer's Disease and Related Dementias Resources

Alzheimer's Association

www.alz.org

Tel: 800-272-3900

Alzheimer's Disease Education and Referral Center (ADEAR)

www.nia.nih.gov/Alzheimers

Tel: 800-438-4380

Association for Frontotemporal Dementias (AFTD)

www.theaftd.org

Tel: 866-507-7222

Center for Disease Control and Prevention (CDCP)

www.cdc.gov

Tel: 800-311-3435

Creutzfeldt- Jakob Foundation Inc. (CJD)

cjd.foundation.org

Tel: 305-891-7579

National Organization for Rare Disorders (NORD)

www.rarediseases.org

Tel: 800-999-NORD (6673)

National Parkinson Foundation

www.parkinson.org/

Tel: 800-327-4545

Parkinson's Disease Foundation (PDF)

www.pdf.org

Tel: 800-457-6676

Caregiver Resources

Alzheimer's Disease Education and Referral Center (ADEAR)

www.nia.nih.gov/Alzheimers

Tel: 800-438-4380

Assisted Living, Nursing Facilities & Hospice Care

www.medicare.gov/

Family Caregiver Alliance

www.caregiver.org

Tel: 800-445-8106

National Institute on Aging- Alzheimer's Caregiving

<https://www.nia.nih.gov/health/getting-help-alzheimers-caregiving>

US Department of Health and Human Services

<https://www.alzheimers.gov/life-with-dementia/resources-caregivers>

Clinical Research Resources

ClinicalTrials.gov is a resource provided by the U.S. National Library of Medicine. It contains information about research trials, who may participate, locations, and phone numbers for more details.

www.clinicaltrials.gov/

Research Match is supported in part by the National Institutes of Health (NIH) Clinical and Translational Science Award (CTSA) program. It is a free service that pairs volunteers, including healthy participants, with research opportunities.

www.researchmatch.org

Trial Match is supported by the Alzheimer's Association, and connects individuals with Alzheimer's, caregivers and healthy volunteers to clinical trials that may advance Alzheimer's research.

www.alz.org/alzheimers-dementia/research_progress/clinical-trials/trialmatch



NCRAD

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The National Centralized Repository for Alzheimer's Disease and Related Dementias, NCRAD, is a National Institutes on Aging (NIA) funded biorepository for clinical information and biological materials to support research focused on the etiology, early detection, and therapeutic development for Alzheimer's disease and related dementias. Started in 1990, NCRAD continues to expand our sample collections, including: DNA, plasma, serum, RNA, CSF, PBMCs, iPSCs and other types of cell lines as well as brain tissue can be stored and requested. NCRAD currently maintains samples from individuals with Alzheimer's disease and/or related dementias as well as healthy controls.

1-800-526-2839

alzstudy@iu.edu

www.ncrad.org



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