



# NCRAD Notes

Newsletter of the National Centralized Repository for Alzheimer’s Disease and Related Dementias • Fall 2021 • Issue 29

## IU School of Medicine receives \$30 million NIA grant for Alzheimer's, related dementia research

**National Centralized Repository for Alzheimer’s Disease and Related Dementias (NCRAD) located at IU School of Medicine has been continuously funded since 1990.**

The burden of Alzheimer’s disease and related dementias in the United States is projected to grow to 13.9 million individuals in 2060, which represents nearly 3.3% of the population. The National Centralized Repository for Alzheimer’s Disease and Related Dementias (NCRAD) is one of a range of research resources the National Institute on Health/National Institute on Aging has funded as part of its ambitious goal of developing effective prevention strategies and treatments for Alzheimer’s disease and related dementias by 2025. In 2018, the NCRAD program changed its name to include “Related Dementias”. NCRAD serves as the biospecimen repository for NIA’s dementia programs, including large groups focused on Alzheimer’s disease, frontotemporal lobar dementia, REM sleep behavior disorder, Parkinson’s disease, longevity/aging and Down syndrome.

In June 2021, NCRAD was renewed for another five years with funding expected to total \$30 million from the National Institute on Aging. NCRAD is led by Tatiana Foroud, PhD, chair for the Department of Medical and Molecular Genetics at Indiana University School of Medicine. Co-investigators include: Michael Edler, PhD, Kelly Nudelman, PhD, Jason Meyer, PhD, Stephane Pelletier, PhD, all from the Department of Medical and Molecular Genetics as well as Adrian Oblak, PhD in the Department of Radiology and Imaging Sciences and Jared Brosch, MD and Jeffrey Dage, PhD from the Department of Neurology.

“The National Centralized Repository for Alzheimer’s Disease and Related Dementias serves as the primary resource for samples for all NIA-funded dementia studies,” said Foroud. “In the next five years, our recruitment efforts will focus on engaging diverse communities to obtain a broad range of samples from individuals that represent the diversity of populations that make up our nation and our world.”

NCRAD is home to more than a million biological samples, including DNA, plasma, brain tissue and cell lines. These samples assist scientists in conducting a variety of research to understand the causes and early detection of Alzheimer’s disease and related dementias. Since its inception in 1990, NCRAD has distributed more than 300,000 samples to researchers all over the world, leading to more than 600 publications in scientific journals. Scientists have banked samples for dozens of studies with NCRAD, which also keeps samples of healthy controls. “It has been incredible to see NCRAD grow over the last several years, even during the COVID-19 pandemic,” said Foroud. “I am proud to work with researchers all around the world to further the effort to help prevent and treat this dreaded disease.”

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# NCRAD Staff Kelly Horner



Many of our study participants will recognize her name on an email or her voice from a call. But most may not realize that Kelly has been a constant presence for 20 years for the NCRAD Family and LOAD Family studies. It is not often that someone reaches such a significant milestone in their career. We are excited to acknowledge Kelly's achievement.

Kelly Horner is celebrating 30 years with the Indiana University School of Medicine, Department of Medical and Molecular Genetics. She started with NCRAD in 2002 with the NCRAD Family and LOAD Family studies. Her primary responsibilities include screening and recruiting eligible research participants, conducting cognitive testing by telephone, and planning and managing brain donations and autopsy for enrolled study participants and their families.

It is Kelly's engagement and relationships with study participants that is her greatest strength. When asked about the most rewarding thing about working on the NCRAD Family and LOAD Family studies, Kelly said,

"I am amazed at how some families are very comfortable with planning their loved one's brain donation to research. It is a wonderful gesture that they are providing the study and I make sure they know how appreciative we are for that. I have even had families write me personal thank you notes for helping make the donation happen and it warms my heart that I was able to achieve this for them."

Kelly began her career with Indiana University, School of Medicine in 1990. She started as the department receptionist, supporting the critical department operations. As the Department of Medical and Molecular Genetics grew, so did Kelly's roles. She has experience working in the DNA laboratory, as well as clinical trials including Huntington's disease, Spinal Muscular Atrophy, Familial Intracranial Aneurysm, and the Multi-Institutional Research in Alzheimer's Genetic Epidemiology studies. Kelley Faber, NCRAD project manager and longtime co-worker said, "Kelly is an incredibly valuable asset to the NCRAD team and study. Her compassion towards the families involved and her passion for Alzheimer's disease research are inspiring. I really admire and appreciate the time Kelly has dedicated to this work and cannot imagine NCRAD without her!"

When asked to reflect on her 30-year career with Indiana University and what it has meant to her, Kelly said, "Wow, this is probably the hardest question."

"The NCRAD and LOAD families feel like my own family at times. I feel blessed that they trust that I am taking care of their needs."

*On behalf of the NCRAD team, we would like to congratulate Kelly on this exceptional achievement and to thank her for her dedication and hard work!*

# Study Spotlight



## National Institute on Aging Late Onset Alzheimer's Disease (LOAD) Family Study

The National Institute on Aging Late Onset Alzheimer's disease (LOAD) Family study was established in 2003 with the goal of recruiting families having multiple members with dementia to support genetic research. Since that time, the LOAD Family study has recruited and followed 1,353 families, with more than 8,810 assessed family members, as well as 1,030 unrelated, non-demented elderly, including non-Hispanic whites, African Americans, and Caribbean Hispanics. Today, it is widely considered the most utilized Alzheimer's disease (AD) genetics dataset in the world, with genome-wide single nucleotide polymorphism (SNP) arrays in 5,428 individuals, whole exome sequencing in 1,484, whole genome sequencing in 928 family members and controls, and counting.

Fourteen years after the initial recruitment of these multiplex families, the focus of LOAD Family study has turned to the offspring (adult children) of the initial participants. The adult children are now entering the age of greatest risk of Alzheimer's disease and can now help us better understand why some members of these families develop Alzheimer's disease and others do not. The enrollment of the 'next generation' is critical to help us address these critical research questions.

Since most of the LOAD Family study participants are of European ancestry, a significant effort has been made to extend this genetic research to ethnically diverse families. The recruitment of African Americans, Mexican Americans, and Central and South Americans residing in the United States is ongoing. We hope to better understand the genetics of Alzheimer's disease in all Americans.

We have learned over the years that researchers need to perform a wide range of studies in order to better understand the causes of Alzheimer's disease. To help these research studies, the LOAD Family study is collecting blood samples not only to obtain DNA but also to obtain plasma and cells in the blood. In addition, the study of brain tissue following death is still very important to confirm whether the individual did indeed have Alzheimer's disease or another type of related dementia.

## Indiana University and NCRAD are actively recruiting new participants for this study.

Eligible participants include:

- A person, age 60 or older, with a diagnosis of Alzheimer's disease or related dementia, **AND**
- A sibling, age 60 or older, with a dementia diagnosis, **AND**
- A third related family member, age 50 or older, with or without a dementia diagnosis.

**For more information and screening, please visit:**

[https://ncrad.iu.edu/load\\_informed\\_consent.html](https://ncrad.iu.edu/load_informed_consent.html) or call 1-800-526-2839



## 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](mailto:alzstudy@iu.edu).

You can explore each study for more information, visit:

<https://ncrad.org/participate.html>



## 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/>

**We are also on Twitter! Follow us at @NCRAD\_ADRD**



\*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](http://www.alz.org)

Tel: 800-272-3900

### **Alzheimer's Disease Education and Referral Center (ADEAR)**

[www.nia.nih.gov/Alzheimers](http://www.nia.nih.gov/Alzheimers)

Tel: 800-438-4380

### **Association for Frontotemporal Dementias (AFTD)**

[www.theaftd.org](http://www.theaftd.org)

Tel: 866-507-7222

### **Center for Disease Control and Prevention (CDCP)**

[www.cdc.gov](http://www.cdc.gov)

Tel: 800-311-3435

### **Creutzfeldt- Jakob Foundation Inc. (CJD)**

[cjd.foundation.org](http://cjd.foundation.org)

Tel: 305-891-7579

### **National Organization for Rare Disorders (NORD)**

[www.rarediseases.org](http://www.rarediseases.org)

Tel: 800-999-NORD (6673)

### **National Parkinson Foundation**

[www.parkinson.org/](http://www.parkinson.org/)

Tel: 800-327-4545

### **Parkinson's Disease Foundation (PDF)**

[www.pdf.org](http://www.pdf.org)

Tel: 800-457-6676

## Caregiver Resources

### **Alzheimer's Disease Education and Referral Center (ADEAR)**

[www.nia.nih.gov/Alzheimers](http://www.nia.nih.gov/Alzheimers)

Tel: 800-438-4380

### **Assisted Living, Nursing Facilities & Hospice Care**

[www.medicare.gov/](http://www.medicare.gov/)

### **Family Caregiver Alliance**

[www.caregiver.org](http://www.caregiver.org)

Tel: 800-445-8106

### **National Institute on Aging- Alzheimer's Caregiving**

[https://www.nia.nih.gov/health/getting-help-alzheimers-](https://www.nia.nih.gov/health/getting-help-alzheimers-caregiving)

[caregiving](https://www.nia.nih.gov/health/getting-help-alzheimers-caregiving)

### **US Department of Health and Human Services**

[https://www.alzheimers.gov/life-](https://www.alzheimers.gov/life-with-dementia/resources-caregivers)

[with-dementia/resources-](https://www.alzheimers.gov/life-with-dementia/resources-caregivers)

[caregivers](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/](http://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](http://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-](http://www.alz.org/alzheimers-dementia/research_progress/clinical-trials/trialmatch)  
[dementia/research\\_progress/cli-](http://www.alz.org/alzheimers-dementia/research_progress/clinical-trials/trialmatch)  
[nical-trials/trialmatch](http://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](mailto:alzstudy@iu.edu)

[www.ncrad.org](http://www.ncrad.org)



**INDIANA UNIVERSITY**

SCHOOL OF MEDICINE

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