

## The National Centralized Repository for Alzheimer's Disease and Related Dementias (NCRAD)

is a data and specimen collection source for families with Alzheimer's disease (AD) or serious memory loss. Families having two or more living individuals with memory loss are encouraged to participate. We would like to thank the hundreds of families nationwide who are already participating in the National Centralized Repository for AD. Many family members have provided blood samples, which researchers use to study AD and other related diseases. Our hope is that through the efforts of our participants, we will one day unravel the mystery of devastating diseases like AD. We are always eager to accept new families to help us move toward this goal.



## INDIANA UNIVERSITY

SCHOOL OF MEDICINE

## National Centralized Repository for Alzheimer's Disease and Related Dementias

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# NCRAD

# Update

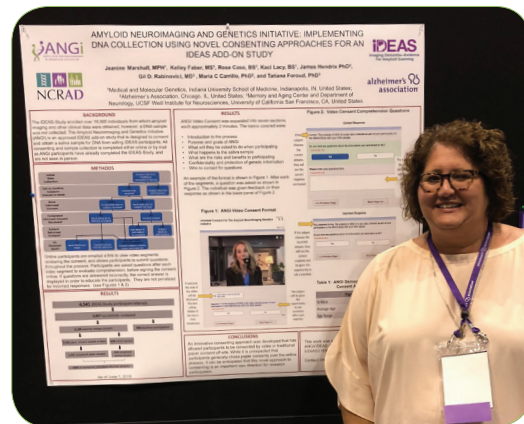
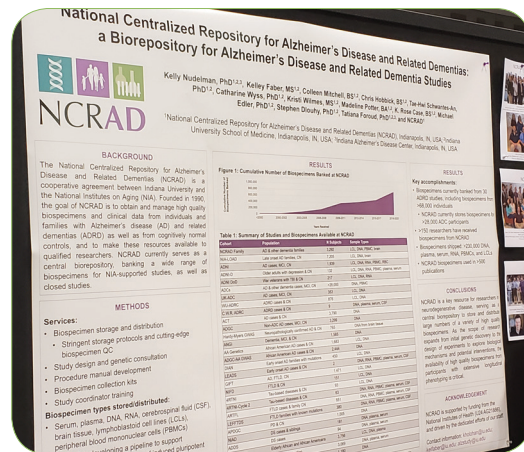
Newsletter of the National Centralized Repository for Alzheimer's Disease and Related Dementias  
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In July 2018, NCRAD attended the Alzheimer's Association International Conference (AAIC) in Chicago, IL. AAIC is the largest international meeting dedicated to advancing dementia research. Each year, the conference brings together laboratory and clinical researchers, clinicians, and the care research community from both academic and commercial institutions to share advances in dementia research. Key topics from the meeting included new studies that have explored differences diagnosing dementia in men and women, how blood pressure affects dementia, improving measures for early disease detection, and some early drug trial results.

NCRAD team members attended research sessions, and presented scientific posters describing the NCRAD biorepository and a new NCRAD study called ANGI (Amyloid Neuroimaging and Genetics Initiative). We also hosted a booth in the exhibition hall where we spoke with numerous academic and commercial researchers from around the world. Investigators we met are interested in both banking samples with NCRAD and also requesting samples from NCRAD to support their research. This was a great opportunity to raise awareness in the dementia research community about the studies and samples stored at NCRAD, and how they can be used to advance research for Alzheimer's disease and related dementias. ■

News highlights from the conference can be found at:

[https://www.alz.org/aaic/2018\\_media\\_coverage.asp](https://www.alz.org/aaic/2018_media_coverage.asp)



# NIH Funds Major Biobank Expansion at IU School of Medicine to Support Alzheimer's Disease Research

*Emily McKnight* July 19, 2018

With a grant from the National Institute of Health's National Institute on Aging, Indiana University School of Medicine will dramatically increase the size and scope of the biobank that stores DNA and other biological samples used by researchers globally to better understand, treat and hopefully cure Alzheimer's disease. The grant is expected to last three years and total \$12 million pending the availability of funds.

"Anticipating increased need for a central national biobank resource, this award aims to boost the capacity of our national biobank so it can continue to facilitate both withdrawals and deposits, provide cutting edge centralized resources with efficient processes for reviewing requests and assure that precious research resources are used wisely," said Nina Silverberg, PhD, director of the Alzheimer's Disease Centers Program at the NIA.

The expanded IU biobank – the National Centralized Repository for Alzheimer's Disease and Related Dementias – will play a central role in the effort to reach the national goal of developing effective prevention and treatments for Alzheimer's disease and related dementias by 2025. It's estimated that there will be 8.4 million Americans aged 65 and over with Alzheimer's disease by 2030, up from about 5.5 million now.

"We're centralizing resources at Indiana University to make it easier for scientists from around the world to share and to access these critically important biological samples for ongoing and new research," said Tatiana Foroud, PhD, director of the repository and chair of the Department of Medical and Molecular Genetics at IU School of Medicine.

The expansion of the National Centralized Repository for Alzheimer's Disease and Related Dementias is meant to support the growth in Alzheimer's disease research resulting from a dramatic increase in funding at the National Institute on Aging. Funds for research into Alzheimer's disease and related dementias more than doubled from 2015 to 2018, reaching more than \$1.5 billion. Scientists supported by that additional funding will be producing – and needing access to – many kinds of biological samples, including DNA, cerebrospinal fluid, brain tissue and other biospecimens that are the tools of laboratory research in Alzheimer's disease.

The expansion also will create an NIA-funded centralized repository that will collect and distribute induced pluripotent stem cell lines created by scientists to study

Alzheimer's disease and related dementias. Induced pluripotent stem cells are created by taking cells from adults – frequently skin cells or blood cells – and activating genes that return the cells to a stem cell state. At that point, the cells are "pluripotent," meaning they can be coaxed by scientists to differentiate into many types of cells, such as various neurons found in the brain. Jason S. Meyer, PhD, an associate professor of biology in the IUPUI School of Science, will serve as a co-investigator who is leading work related to induced pluripotent stem cells.

To accommodate the expansion, the National Centralized Repository for Alzheimer's Disease and Related Dementias will move into larger, newly renovated facilities in Indianapolis.

Since its creation in the early 1990s, the repository has collected more than 500,000 samples. With the additional Alzheimer's disease research funding, it is expected that the biobank will receive 300,000 additional specimens in just three years, said Foroud, the Joe C. Christian Professor of Medical and Molecular Genetics.

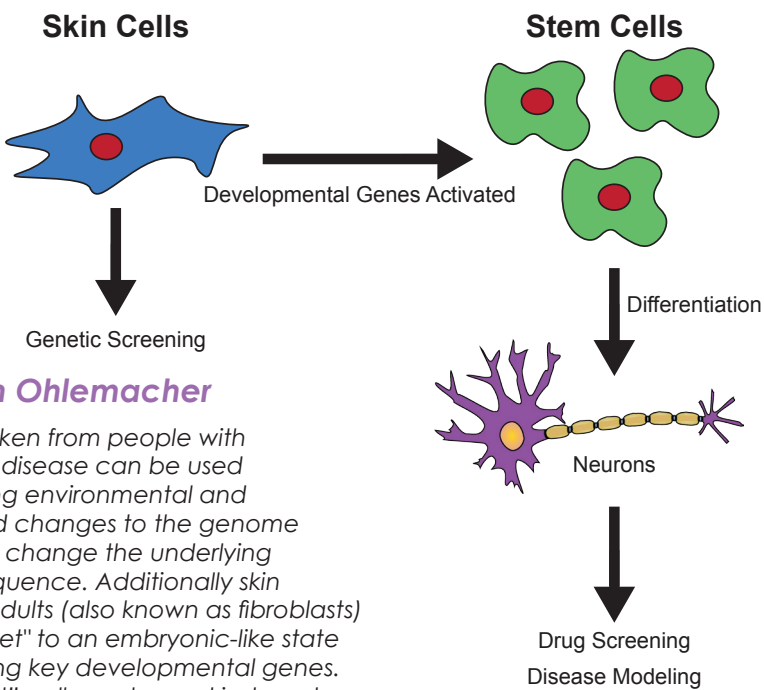
One of the primary goals of research using the repository's resources is to identify diagnostic signals – called biomarkers – for Alzheimer's disease. The Alzheimer's disease process begins years before symptoms appear, so scientists hope to develop convenient and inexpensive biomarker tests that would identify problems early. Current experimental methods for early detection, such as PET scans and tests using cerebrospinal fluid, are expensive and invasive.

"What we really want to develop is a blood-based test. You would simply draw a sample of blood and run tests that predict whether an individual is at increased risk for Alzheimer's disease or a related dementia, or that would tell you that symptoms are developing," said Foroud.

The National Institute on Aging renewed its support for the National Centralized Repository for Alzheimer's Disease and Related Dementias in 2016 with an expected five-year grant for \$1.3 million annually. In addition to expanding facilities and biobanking systems, the new \$4 million grant annually will mean the addition of 10 to 15 people to the repository's staff. The National Centralized Repository for Alzheimer's Disease and Related Dementias and other biobanking facilities at IU School of Medicine currently employ about 90 people.

The grant number is U24AG021886. ■





### Dr. Sarah Ohlemacher

Skin cells taken from people with Alzheimer's disease can be used for screening environmental and age-related changes to the genome that do not change the underlying genetic sequence. Additionally skin cells from adults (also known as fibroblasts) can be "reset" to an embryonic-like state by activating key developmental genes. These "reset" cells are termed induced pluripotent stem cells (or iPSCs). The person's unique DNA is retained in these stem cells and can be programmed to turn into any cell type of the body, including specialized brain cells, called neurons. The development of neurons can be observed in the lab and used to study Alzheimer's disease. Importantly, induced pluripotent stem cells can also be used to test potential medications that might be used in the future to treat or prevent Alzheimer's disease and other types of dementia. This can serve as a complement to the use of traditional animal models of disease.

**NCRAD**  
is now on  
Twitter!



Want to keep up with  
NCRAD?

Check out @Alzheimers\_NIH  
on Twitter for more  
information on  
everything our team  
has to offer!

**@Alzheimers\_NIH**  
**#NCRAD**

# Expansion of Alzheimer's Disease Biospecimens Repository Prompts Name Change

**Emily McKnight** July 19, 2018

Indiana University School of Medicine's repository for biological samples used by the nation's Alzheimer's disease researchers is changing its name to the National Centralized Repository for Alzheimer's Disease and Related Dementias.

"The new name reflects the significant expansion of the repository's scope and activities since its creation in 1990," said Tatiana Foroud, PhD, director of the repository and chair of the Department of Medical and Molecular Genetics at IU School of Medicine.

Formerly called the National Cell Repository for Alzheimer's Disease (NCRAD), the repository collects, maintains and provides scientists access to more than 500,000 biological samples, including DNA, cerebrospinal fluid, brain tissue and other biospecimens.

The repository's resources have been used by more than 150 scientists and resulted in more than 500 scientific publications.

The National Centralized Repository for Alzheimer's Disease and Related Dementias is supported by grants from the National Institutes of Health's National Institute on Aging. ■



Tatiana Foroud, PhD, Chair,  
Medical and Molecular  
Genetics, Joe C. Christian  
Professor of Medical and  
Molecular Genetics,  
Distinguished Professor,  
Chancellor's Professor, IUPUI

## Research Opportunities:

### 4 Repeat Tauopathy Neuroimaging Initiative (4RTNI-2)

- Purpose: To identify the best methods of analysis for tracking PSP and CBD over time. The results from this study may be used in the future to calculate power for clinical drug trials as this study aims to identify the most reliable outcome measures.
- Eligibility: Men and women ages 40 to 80, diagnosis of Progressive Supranuclear Palsy or Corticobasal Degeneration (CBD)
- Locations: UCSF, Mass Gen Hosp, UCSD, UPenn, U of Toronto, Mayo Rochester, Johns Hopkins
- Contact: PH: 415-476-9578 or 4RTNI2 webpage: <http://memory.ucsf.edu/research/studies/4rtni2>

### Dominantly Inherited Alzheimer Network (DIAN)

- Purpose: To study brain changes in people who carry an Alzheimer's disease mutation in order to determine how the disease process develops before the onset of symptoms.
- Eligibility: Men and women ages 55 to 80 years, diagnosis of mild to moderate Alzheimer's disease, good general health and medically able to undergo neurosurgery.
- Locations: USA - CA, IN, MA, MO, NY, RI; United Kingdom; Australia
- Contact: PH: 314-286-2683 or DIAN webpage: <http://www.dian-info.org>

### Advancing Research and Treatment for Frontotemporal Lobar Degeneration (ARTFL)

- Purpose: "New therapies targeting some of the molecular causes of FTLT are rapidly becoming available for testing in human clinical trials. The ARTFL's goal is to prepare for clinical trials of these new therapies by evaluating people who might eventually be candidates for participation in clinical trials and by developing new diagnostic technologies to evaluate the effectiveness of new treatments for FTLT."  
(Citation: <https://www.rarediseasesnetwork.org/ARTFL/index.htm>)
- Locations: Columbia University, University of California in Los Angeles, University of California in San Diego, University of California in San Francisco, Harvard/Massachusetts General Hospital, Johns Hopkins University, University of North Carolina, Mayo Clinic in Rochester, Mayo Clinic in Jacksonville, University of Pennsylvania, Northwestern University, University of Toronto, University of British Columbia, and Washington University.
- See this website for more information: <https://www.rarediseasesnetwork.org/ARTFL/index.htm>

### Longitudinal Evaluation of Familial Frontotemporal Dementia Subjects (LEFFTDS)

- Purpose: To model the rates of decline in clinical function of those suffering from Frontotemporal Lobar Degeneration (FTLD) and identify genetic and biofluid factors that modify these rates.
- Eligibility: Must be a member of a family with a known mutation, have a reliable informant who personally speaks with or sees that subject weekly, the subject and informant must be fluent in English, the subject must be willing to undergo yearly evaluations for a period of three years, and the subject must be willing to undergo neuropsychological testing and MRI imaging.
- Locations: Mayo Clinic, Rochester, MN, University of California, San Francisco, University of Pennsylvania, Mayo Clinic, Jacksonville, FL, University of British Columbia, Washington University, Columbia University, Harvard University
- Contact:  
Mayo Clinic Rochester  
Alzheimer's Disease Research Center  
507-284-1324

### NCRAD Welcomes Your Ideas and Suggestions

We hope that you and your family find the NCRAD newsletter informative. We would welcome suggestions on future topics for articles, questions you would like to ask the NCRAD doctors, or anything you would like shared with our readers about your family's experience with Alzheimer's Disease. Please send us your ideas by email or by phone.

■ Phone: 1-800-526-2839

■ Email: [alzstudy@iu.edu](mailto:alzstudy@iu.edu)

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

## Sources for Information and Support

### Alzheimer's Association

<http://www.alz.org>

Tel: 312-335-8700 or 800-272-3900

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

<http://www.nia.nih.gov/Alzheimers>

Tel: 301-495-3311 or 800-438-4380

\*\* ADEAR lists all 29 Alzheimer Disease Centers (ADCs) and their contact information.

### Assisted Living Directory, Assisted Living Facilities Information & Senior Care

<http://www.assisted-living-directory.com/>

### The Association for Frontotemporal Dementias (AFTD)

<http://www.theaftd.org>

Tel: 267-514-7221 or 866-507-7222

### Family Caregiver Alliance

<http://www.caregiver.org>

Tel: 415-434-3388 or 800-445-8106

### National Parkinson Foundation

<http://www.parkinson.org/>

Tel: 305-547-6666 or 800-327-4545

### Parkinson's Disease Foundation (PDF)

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

Tel: 212-923-4700 or 800-457-6676

### Society for Progressive Supranuclear Palsy

<http://www.psp.org>

Tel: 410-486-3330 or 800-457-4777

### National Organization for Rare Disorders (NORD)

<http://www.rarediseases.org>

Tel: 203-746-6518 or 800-999-NORD (6673)

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

<http://www.cdc.gov>

Tel: 800-311-3435

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

<http://cjd.foundation.org>

Tel: 954-704-0519 or 305-891-7579

**ClinicalTrials.gov** is a registry of federally and privately supported clinical trials conducted in the United States and around the world. ClinicalTrials.gov gives you information about a trial's purpose, who may participate, locations, and phone numbers for more details. This information should be used in conjunction with advice from health care professionals.

<http://www.clinicaltrials.gov/>

**Research Match** is a free service that pairs volunteers interested in participating in research opportunities from surveys to clinical trials with researchers. Open to all, including healthy volunteers.

<http://www.researchmatch.org>

### National Society of Genetic Counselors

<http://www.nsgc.org/>

Tel: 312-321-6834

## 10 Signs of AD

1. Memory loss
2. Difficulty performing familiar tasks
3. Problems with language
4. Disorientation to time and place
5. Poor or decreased judgment
6. Problems with abstract thinking
7. Misplacing things
8. Changes in mood or behavior
9. Changes in personality
10. Loss of initiative

**For more information, call the Alzheimer's Association at (800) 272-3900**

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