

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.



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# New Blood Test Shows Great Promise in the Diagnosis of Alzheimer's Disease

*P-tau217 discriminated Alzheimer's from other conditions with high accuracy and detected the disease many years before symptoms develop*

LUND, SWEDEN AND PHOENIX, ARIZONA (July 28, 2020) — A new blood test demonstrated remarkable promise in discriminating between persons with and without Alzheimer's disease and in persons at known genetic risk may be able to detect the disease as early as 20 years before the onset of cognitive impairment, according to a large international study published today in the Journal of the American Medical Association (JAMA) and simultaneously presented at the Alzheimer's Association International Conference.

For many years, the diagnosis of Alzheimer's has been based on the characterization of amyloid plaques and tau tangles in the brain, typically after a person dies. An inexpensive and widely available blood test for the presence of plaques and tangles would have a profound impact on Alzheimer's research and care. According to the new study, measurements of phospho-tau217 (p-tau217), one of the tau proteins found in tangles, could provide a relatively sensitive and accurate indicator of both plaques and tangles—corresponding to the diagnosis of Alzheimer's—in living people.

“The p-tau217 blood test has great promise in the diagnosis, early detection, and study of Alzheimer's,” said Oskar Hansson, MD, PhD, Professor of Clinical Memory Research at Lund University, Sweden, who leads the Swedish BioFINDER Study and senior author on the study who spearheaded the international collaborative effort. “While more work is needed to optimize the assay and test it in other people before it becomes available in the clinic, the blood test might become especially useful to improve the recognition, diagnosis, and care of people in the primary care setting.”

Researchers evaluated a new p-tau217 blood test in 1,402 cognitively impaired and unimpaired research participants from well-known studies in Arizona, Sweden, and Colombia. The study, which was coordinated from Lund University in Sweden, included 81 Arizona participants in Banner Sun Health Research Institute's Brain Donation program who had clinical assessments and provided blood samples in their last years of life and then had neuropathological assessments after they died; 699 participants in the Swedish BioFINDER Study who had clinical, brain imaging, cerebrospinal fluid (CSF), and blood-based biomarker assessments; and 522 Colombian autosomal dominant Alzheimer's disease (ADAD)-causing mutation carriers and non-carriers from the world's largest ADAD cohort.

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- In the Arizona (Banner Sun Health Research Institute) Brain Donation Cohort, the plasma p-tau217 assay discriminated between Arizona Brain donors with and without the subsequent neuropathological diagnosis of “intermediate or high likelihood Alzheimer’s” (i.e., characterized by plaques, as well as tangles that have at least spread to temporal lobe memory areas or beyond) with 89% accuracy; it distinguished between those with and without a diagnosis of “high likelihood Alzheimer’s” with 98% accuracy; and higher ptau217 measurements were correlated with higher brain tangle counts only in those persons who also had amyloid plaques.
- In the Swedish BioFINDER Study, the assay discriminated between persons with the clinical diagnoses of Alzheimer’s and other neurodegenerative diseases with 96% accuracy, similar to tau PET scans and CSF biomarkers and better than several other blood tests and MRI measurements; and it distinguished between those with and without an abnormal tau PET scan with 93% accuracy.
- In the Colombia Cohort, the assay began to distinguish between mutation carriers and non-carriers 20 years before their estimated age at the onset of mild cognitive impairment.

In each of these analyses, p-tau217 (a major component of Alzheimer’s disease-related tau tangles) performed better than p-tau181 (another component of tau tangles and a blood test recently found to have promise in the diagnosis of Alzheimer’s) and several other studied blood tests.

Other study leaders include Jeffrey Dage, PhD, from Eli Lilly and Company, who developed the p-tau217 assay, co-first authors Sebastian Palmqvist, MD, PhD, and Shorena Janelidz, PhD, from Lund University, and Eric Reiman, MD, Banner Alzheimer’s Institute, who organized the analysis of Arizona and Colombian cohort data. In the last two years, researchers have made great progress in the development of amyloid blood tests, providing valuable information about one of the two cardinal features of Alzheimer’s. While more work is needed before the test is ready for use in the clinic, a p-tau217 blood test has the potential to provide information about both plaques and tangles, corresponding to the diagnosis of Alzheimer’s. It has the potential to advance the disease’s research and care in other important ways.



“Blood tests like p-tau217 have the potential to revolutionize Alzheimer’s research, treatment and prevention trials, and clinical care,” said Eric Reiman, MD, Executive Director of Banner Alzheimer’s Institute in Phoenix and a senior author on the study. “While there’s more work to do, I anticipate that their impact in both the research and clinical setting will become readily apparent within the next two years.”

Alzheimer’s is a debilitating and incurable disease that affects an estimated 5.8 million Americans age 65 and older. Without the discovery of successful prevention therapies, the number of U.S. cases is projected to reach nearly 14 million by 2050.



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# Covid-19 and Resources Available for Older Individuals

The Covid-19 pandemic has required unprecedented lifestyle changes to both home and work life. With outside resources and activities significantly reduced, there is additional stress for patients and caregivers. In addition, most individuals living with Alzheimer's disease are over the age of 65 (a risk factor), and most persons over 65 have at least one, and typically multiple, chronic illnesses (another risk factor). Therefore, we would like to provide you with some links to helpful resources available to you.

- Please visit the government's Covid-19 resources for older adults page: <https://www.nia.nih.gov/health/government-covid-19-resources-older-adults> to find information about Federal resources available for caregiving, financial and housing resources, as well as general healthcare information.
- For tips and resources related to managing daily care at home, health, safety, and services for adults with dementia and their families and caregivers, please visit this page with resources assembled by ADORE (Alzheimer's & Dementia Outreach, Recruitment & Engagement Resources): [https://www.nia.nih.gov/research/alzheimers-dementia-outreach-recruitment-engagement-resources-adore-resources-search?combine=COVID-19&items\\_per\\_page=10](https://www.nia.nih.gov/research/alzheimers-dementia-outreach-recruitment-engagement-resources-adore-resources-search?combine=COVID-19&items_per_page=10).
- The Alzheimer's Association also provides resources for caregivers and protecting individuals in long-term care facilities: <https://www.alz.org/alzheimers-dementia/coronavirus-covid-19>

It is important to take care of your body to help cope with the stress of the pandemic. Eating healthy meals, getting plenty of sleep, and exercising regularly can help. The deputy director of the National Institute on Aging (NIA), Dr. Marie Bernard, presents a live exercise demonstration to encourage remaining active and staying healthy while staying at home: <https://www.nia.nih.gov/news/nia-deputy-director-present-live-exercise-demonstration-nih-coping-covid-19-series>.

Finally, the National Institute of Allergy and Infectious Diseases (NIAID), provides an overview of the Coronavirus on its "Diseases and Conditions" page: <https://www.niaid.nih.gov/diseases-conditions/coronaviruses>.

All of these websites provide further links to additional pages, helpful videos and resources. There is a lot of information out there designed specifically to help older adults with dementia and their caregivers during this difficult time.

## 10 Tips for Caregivers

(From Alzheimer's Association's article Coronavirus (Covid-19): Tips for Dementia Caregivers):

- Consider placing signs in the bathroom and elsewhere to remind people with dementia to wash their hands with soap for 20 seconds.
- Ask your pharmacist or doctor about filling prescriptions for a greater number of days to reduce trips to the pharmacy.
- If you are giving care in your home: Think ahead and make alternative plans for care management if the primary caregiver should become sick.
- If your loved one is in a long-term care facility: Check with the facility regarding their procedures for managing COVID-19 risk. Ensure they have your emergency contact information and the information of another friend or family member as a backup.
- Ask health care professionals providing home based services to wear a mask.
- If you go to visit a long-term care facility or hospital, bring your own mask and wear it at all times.
- Do not visit your family member or allow visitors (i.e. home health care providers or other family members) in your home if you or the visitor have any signs of illness.
- Consider alternative ways to connect with loved ones outside the home when possible, such as video or phone calls.
- Consider programs that offer virtual activities to encourage social engagement.
- If you think you have COVID-19, call your health care provider. They can determine whether or not a COVID-19 test is needed.

## Research Opportunities:

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

- 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 45 to 90 years, diagnosis of Progressive Supranuclear Palsy or Corticobasal Degeneration (CBD)
- Locations: CA
- Contact: PH: 415-476-9578 or 4RTNI webpage: <https://memory.ucsf.edu/research-trials/research/4rtni-2>



### 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>



### ARTFL-LEFFTDS Longitudinal Frontotemporal Lobar Degeneration (ALLFTD)

- Purpose: The goal of the ALLFTD study is to understand the changes in brain function that occur as a result of disease progression, and how changes differ from normal aging. We track changes in clinical features (symptoms, neurologic examination) and biomarkers (neuropsychological tests, blood proteins, MRI, CSF proteins) over several years. Our prediction is that there are changes in biomarkers that precede clinical changes by years or even decades.
- Eligibility: Members of families in whom at least one member has a known disease-associated mutation in one of the major genes that cause f-FTLD: MAPT, GRN, C9orf72 (or other rare genes); autosomal dominant family history of a FTLD syndrome (without a known gene) verified by medical record review or well-documented family history including family members with a medical history consistent with FTLD or a related disorder.
- Locations: University of Alabama Birmingham, University of CA, Los Angeles, University of CA San Diego, University of CA San Francisco, Mayo Clinic Florida, Northwestern University Illinois, John Hopkins University Maryland, Massachusetts General Hospital, Mayo Clinic Rochester Minnesota, Washington University St. Louis Missouri, Cleveland Clinic Lou Ruvo Ctr for Brain Health Nevada, Columbia University New York, University of North Carolina Chapel Hill, Case Western Reserve Med Ctr Ohio, University of Pennsylvania in Philadelphia, Nantz National Alzheimer Center Houston Texas, University of Washington in Seattle, University of British Columbia in Canada, University of Toronto in Canada
- Contact: Visit <https://www.allftd.org/> for more information

### 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

### National Society of Genetic Counselors

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

Tel: 312-321-6834

**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>

## 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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