

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 ADRD. 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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When Alzheimer's Disease Strikes Young: Spotlight on Early-Onset Alzheimer's Disease and LEADS (Longitudinal Early-Onset Alzheimer's Disease Study)

Early-onset Alzheimer's disease (EOAD) accounts for approximately 5% of all Alzheimer's disease (AD) cases, which represents around 250,000 individuals in the United States. Early-onset is defined as disease onset prior to age of 65. While the majority of EOAD cases have a memory-predominant presentation, a significant number of them might experience greater difficulty with language, visuospatial processing or executive functioning (decision making, problem solving) rather than memory, or have an atypical presentation. Because of their young age and the higher frequency of atypical presentations, an accurate diagnosis is often delayed or missed in EOAD individuals. This causes significant delays to treatment and services. Moreover, available services are often not tailored to this younger population.

The consequences of living with Alzheimer's are unique for someone who is under 65. For instance, many still have younger children who actively need them. The financial strains (e.g., loss of income and health benefits) are very different when Alzheimer's strikes early and specific planning needs to occur. Getting affairs in order is important because EOAD individuals often decline at a faster rate than people diagnosed later in life. This also underscores the importance of an accurate, timely diagnosis.

Much like late-onset AD (LOAD), many factors can contribute to the development of the disease. From a hereditary standpoint, most people diagnosed with early-onset AD have the non-familial type, which means the disease is not caused by a known inherited mutation in certain genes known to cause Alzheimer's. Still, research suggests that a high proportion of EOAD risk is genetically encoded which suggests novel, undiscovered genetic risk factors will emerge in this population.

Given the atypical presentation, frequency of missed or delayed diagnosis, aggressive course, age-specific challenges and genetic unknowns, EOAD research is sorely needed. Until recently, individuals with EOAD were often excluded from observational and therapeutic AD research studies due to their young age or atypical presentation. Yet these younger individuals are highly motivated to participate and have fewer age-related comorbidities, making them ideal candidates for research.

In the past two years, the Indiana University School of Medicine launched a national research program focused on EOAD called LEADS (Longitudinal Early-Onset Alzheimer's Disease Study). The study launched in 2018 and is supported by a \$44.7M National Institute on Aging grant. LEADS is a five-year observational study that will track changes in cognition, imaging, and fluid biomarker measures among participants ages 40-64 who have EOAD and age-matched cognitively

normal controls. This comprehensive study seeks to discover insights into EOAD and how it differs from late-onset AD in cognition, genetics, imaging, and other measures over time. LEADS will enroll 700 people at 18 sites nationwide.

Committed to EOAD research, LEADS was recently awarded additional funds from the NIH-NIA to add a neuropathology component to the main study, which will enable the researchers to study the actual changes in the brain after LEADS participants pass away. EOAD brain pathology has not been studied systematically. The LEADS neuropathology piece will address this research gap by examining post-mortem brain tissue to confirm the AD diagnosis, search for co-occurring conditions, and look for the underlying disease mechanisms. The knowledge gained from this investigation will inform and direct future research questions.

Dr. Apostolova and the LEADS team are dedicated to tackle the questions related to EOAD. This comprehensive, longitudinal study will help us better understand the disease and will set the stage for clinical trials in this unique patient population.

To learn more about LEADS, how you can enroll, and other ways you can contribute, please visit www.LEADS-study.org. ■



Dr. Liana Apostolova



Dr. Sophia Wang

Holiday Season Tips for Family Members and Caregivers for Loved Ones with Alzheimer’s Disease

With the holiday season in full swing, family members and caregivers of loved ones who suffer from Alzheimer’s disease and other dementias wonder what are the right decisions when making holiday plans.

Prioritizing your needs versus your wants can help you figure out how you should be spending your holidays. Consider making the “Eisenhower Square” to help yourself with this process, and then decide how to take action.

Sample Eisenhower Square

	URGENT Need to finish within 2 weeks	NOT URGENT More than 2 weeks
IMPORTANT (serious, adverse consequences)	Part-time job Sleep 6 hours a night <u>(NO MORE THAN 3 ITEMS)</u>	Finding an eldercare attorney Visiting assisted living facilities <u>(NO MORE THAN 3 ITEMS)</u>
NOT IMPORTANT (would not be good but no permanent consequences)	Grocery shopping (set up online Amazon delivery) Mowing the lawn (pay the neighbor’s kid)	Watching TV Posting Facebook pictures

What to Do with Each Square

	URGENT Need to finish within 2 weeks	NOT URGENT More than 2 weeks
IMPORTANT (serious, adverse consequences)	DO Tasks you will do immediately	DECIDE Tasks you will schedule to do later
NOT IMPORTANT (would not be good but no permanent consequences)	DELEGATE Tasks you will delegate or cut back on (whenever possible)	DELETE Tasks that you will eliminate or say no to

Tips for Enjoying Your Holidays

1. Know your values. Know yourself. Deciding how you and your family should spend time around the holidays should reflect your personal values and your values as a caregiver. You should not feel pressured by other family members or friends into making holiday plans that do not reflect these values.
2. If you are feeling overwhelmed, it is time to simplify. As your holiday plans start to pile up, it is important to cut back on other activities or delegate certain activities to others. For example, “Can you help me watch your dad for 4 hours a week while I go shopping to prepare for the holidays?”
3. If you are not sure what do for your holiday plans, make a Plan A, a Plan B, and a Plan C. Then decide which one works best for you. “Plan A: Fly 6 hours to visit our children for 3 days on Thanksgiving. Plan B: Celebrate Thanksgiving with our neighbors. Plan C: Buy dinner, sleep in, and watch TV at home.” Even if you still end up going with Plan A, going through this process will give you perspective.
4. Changes in routine can sometimes cause stress and confusion for your loved one. Pace accordingly. If possible, take your loved one to visit a familiar place. Stick to familiar routines and bring familiar items and favorite foods.
5. If you decide to travel, consider having family, friends, or hired helpers assist you.
6. If you decide to fly, sign up for TSA pre-check for shorter lines and to minimize removal of shoes, laptops, liquids, belts, and light jackets.
7. If you are flying long distances, consider stopping for one day at the halfway point to help with the jet lag.
8. If you are flying, stay well-hydrated with plain water to minimize the effects of jet lag.
9. If your loved one has incontinence, place chux pads on the mattress (and the seat of the airplane or car).
10. If you are staying in a hotel or you are a guest at someone’s home, consider childproofing the door knob or bringing a portable door alarm to prevent wandering.
11. If you are hosting, ask the family to help with preparations ahead of time. If you agree to host, you should not feel pressured to do it all by yourself. Ask family and friends to help bring food and clean up. Be clear about what time people need to get home.
12. If you are visiting someone’s home, talk to your host or hostess about accommodations beforehand. See if there can be a quiet room so your loved one can get a breather. Bring photos of familiar people and activities to keep your loved one occupied and calm. Consider brunch or lunch instead of dinner to avoid sundowning.
13. Provide education to all generations of family about Alzheimer’s disease. Encourage parents to read the kids-teens section of the Alzheimer's Association website with their children so they can learn more about what is happening to your loved one.
<https://www.alz.org/help-support/resources/kids-teens>
14. Spend time enjoying the holiday and simply watching the snowflakes fall. Amidst all the holiday rush, make sure you schedule quality time for yourself and get a respite from caregiving. Consider asking for time off from your family members as your holiday present.
15. Listen to others’ advice, but trust yourself. At the end of the day, you know what you and your loved one can handle. Prioritize your safety and well-being during the holiday season. ■

Check out more travel tips at these websites:

<https://www.alz.org/help-support/caregiving/safety/traveling>

<https://dailycaring.com/6-simple-auto-aids-for-seniors-make-car-travel-easier/>

<https://purpletables.us/> (list of dementia friendly restaurants)

<https://www.alz.org/help-support/resources/kids-teens>

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

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>



Longitudinal Early-Onset Alzheimer's Disease Study (LEADS)

- Purpose: To study the associations of longitudinal clinical and cognitive assessments with multimodal imaging and biofluid markers that capture different elements of AD pathophysiological cascade.
- Eligibility: Men and women ages 40 – 64 years of age, diagnosed with MCI due to AD dementia or have no significant memory impairment.
- Locations: USA – AZ, CA, FL, GA, IL, IN, MD, MA, MO, MN, NY, PA, RI, TX
- Contact:
PH: 317-963-7436 or
EMAIL: iuLEADS@iupui.edu
webpage: <https://leads-study.medicine.iu.edu/>



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

■ Website: 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

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://cjdfoundation.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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