NATIONAL INSTITUTE ON AGING LATE ONSET ALZHEIMER DISEASE (NIA-LOAD) STUDY

GOAL OF THE NIA-LOAD FAMILY STUDY

The ultimate goal of the NIA-LOAD Family Study is to identify genetic factors that increase the risk of Alzheimer's disease and are possible targets for the development of therapeutic interventions. To be able to do so, the NIA-LOAD Family Study recruits, evaluates and follows families who have multiple members with Alzheimer's disease. To date, over 1,032 families across the U.S. are participating in this effort.

The inception of the National Institute of Aging Late Onset Alzheimer's Disease (NIA-LOAD) Family Study in 2002 started a trend of greater cooperation and sharing of clinical and biological resources among researchers worldwide. Virtually every major genetic study of Alzheimer's disease (AD) has included patients and controls from this dataset. It is arguably the most widely used AD genetics dataset in the world, with over a hundred research publications, to date, and counting! A complete list of these publications can be found here: http://taubinstitute.org/res-normal.html#nia. Over 25 susceptibility genes have now been identified for Alzheimer's disease.

ACHIEVEMENTS TO DATE

Here are just a few of the ways in which your participation can help further progress in the field of Alzheimer's disease genetic research:

- The NIA-LOAD/NCRAD cohort is the most frequently used data set for Alzheimer's disease genetics research IN THE WORLD!
- Through the care and generosity of NIA-LOAD families and our brain donation program, researchers around the world have the vital ability to study a large collection of familial LOAD brain tissue.
- The NIA-LOAD Family Study has resulted in at least 100 new research publications and counting! With each new discovery, we come one step closer to identifying more effective therapeutic targets.

IT IS ALL DUE TO THE FAMILIES PARTICIPATING IN THIS RESEARCH!

The families of NIA-LOAD are the foundation of this extraordinary array of Alzheimer's disease genetic discoveries. By studying incidence of disease in families with Alzheimer's disease, we are greatly improving our understanding of the various genes, genetic variants (subtle, individual differences in DNA), and related genetic pathways leading to disease. We are also sharing this information (in a de-identified manner) with scientists worldwide to encourage more rapid progress in terms of identifying, treating, and even preventing AD, for all those impacted by this devastating disorder.

MOVING FORWARD…

While the discoveries we have made in both common and rare genetic variants associated with LOAD risk are extremely exciting and incredibly important, much work remains to be done. What are the genetic factors underlying AD in the ethnic groups not yet studied? What additional genetic factors are involved in the development of AD? What is the impact on disease risk of inheriting one or more of the identified variants? What is the impact of the identified genetic variants in disease in offspring of families with multiple affected individuals? Why do certain individuals who carry high risk genetic variations seem to escape disease—what is protecting them? These are just a few of the questions researchers around the world can investigate with the NIA-LOAD dataset to find a cure for this disease.

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WHY WE ARE NOW SPECIFICALLY ASKING AFRICAN AMERICAN FAMILIES TO JOIN THE STUDY?

It is clear that genetic risk factors vary between ethnic groups. Although African Americans have a substantially higher risk of Alzheimer's disease compared to non-Hispanic Whites, they are significantly underrepresented in current research efforts. Therefore, we are now specifically recruiting African American families with two or more individuals with late-onset Alzheimer's disease or memory problems. **If your family meets these criteria and would like to participate in this research, please contact our study coordinator Izri Martinez (Tel: 212-305-2349). Also, if you know of others who may qualify, please have them contact us.** Study participation can be completed over the phone or in person. The evaluation will take about 1 to 1½ hours per person and includes:

1. **Blood Sample (2 tbsps.):** This sample is used to create de-identified cell lines that will be banked at our blood bank here at Columbia University Medical Center. (Blood kits will be made available to over the phone participants.)

2. **Brief Neuropsychological Assessment:** This is a verbal and visual memory test that will take approximately 45 minutes to one hour.

3. **Medical History:** A research physician will collect basic medical information on you and your family. We may also request that you and your family members authorize the release of medical records to our research team, from any physician(s) seen for memory problems.

If you and your family decide to participate, we hope that you will take great pride in the fact that the NIA-LOAD Family Study dataset is the preeminent resource, both nationally and internationally, for scientists from academia and industry to continue to make headway into the genetic complexities of AD. Indeed, the tremendous contribution you and your family members will make to the field of Alzheimer's disease research cannot be understated.

We thank you!

Christiane Reitz, MD, PhD
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"Hopefully, somewhere along the way the cycle will be broken."

– LOAD Research Participant