



EARLY-ONSET ALZHEIMER'S DISEASE (EOAD) STUDY

GOAL OF THE EARLY-ONSET ALZHEIMER'S DISEASE FAMILY STUDY

The ultimate goal of the EOAD Family Study is to identify genetic factors that increase the risk of early-onset Alzheimer's disease and are possible targets for the development of therapeutic interventions. To be able to do so, the EOAD Family Study recruits, evaluates and follows families who have multiple members with early-onset Alzheimer's disease. To date, over 87 families across the U.S. are participating in this effort.

The Early-onset Alzheimer's Disease Family Study aims to foster a culture of greater cooperation and sharing of clinical and biological resources among researchers worldwide. Virtually every major genetic study of early-onset Alzheimer's disease will be able to utilize information, patients and controls from this dataset. Though many studies of Alzheimer's disease (AD) have identified genetic mutations linked to the disease, these mutations only explain ~10% of EOAD cases! With your participation, this study can lay the groundwork for identifying the genetic links to the remaining 90% of unexplained cases of early-onset Alzheimer's disease.

OUR PROGRESS RELIES ON THE FAMILIES PARTICIPATING IN THIS RESEARCH!

The families that participate in this study have the opportunity to become the foundation of a groundbreaking array of genetic discoveries about early-onset Alzheimer's disease. By studying the incidence of disease in families affected by EOAD, we can greatly improve 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 EOAD, for all those impacted by this devastating disease.

MOVING FORWARD...

While the discoveries that have been made about inheritance patterns associated with genetic mutations linked to AD risk are extremely exciting and incredibly important, much work remains to be done.

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Columbia University IRB



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What are the genetic factors underlying the many unexplained cases of familial early-onset Alzheimer's disease? 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 EOAD Family Study dataset to find a cure for this disease.

HOW CAN YOU HELP US FIND A CURE FOR THIS DISEASE?

If anyone in your family under the age of 65 is experiencing memory problems or dementia, they may be suffering from early-onset Alzheimer's disease. If you think your family meets these criteria and would like to participate in this research, please contact our study coordinator Penelope Baez (Tel: 212-305-1527). Also, if you know of others who may qualify, please have them contact us as well. 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 verbal and visual memory test 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 EOAD Family Study dataset will be a preeminent resource, both nationally and internationally, for scientists from academia and industry to continue to make headway into the genetic complexities of EOAD. 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
Columbia University

“Hopefully, somewhere along the way the cycle will be broken.”

– *Research Participant*



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