

## Longitudinal Early-onset Alzheimer's Disease Study (LEADS) Cognitively Impaired Participants

### ABOUT THIS RESEARCH

You are being asked to participate in a research study. This consent form will give you information about the study to help you decide whether you want to participate. Please read this form and ask any questions you have before agreeing to be in the study.






Early-onset Alzheimer's disease (EOAD) is a devastating, but often overlooked, disease that affects about 5% of individuals with Alzheimer's disease (AD) (~200,000-300,000 cases in the United States). The Longitudinal Early-Onset Alzheimer's Disease Study (LEADS) explores the development of EOAD and how it compares to the more common late-onset form of AD. To successfully move toward effective treatments, researchers need to understand the genetic, biological and clinical processes involved in EOAD. Your participation in LEADS could contribute to future medical advances to help all those affected by AD.

### TAKING PART IN THIS RESEARCH STUDY IS VOLUNTARY

You may choose not to take part in the study or may choose to leave the study at any time. Deciding not to participate or deciding to leave the study later will not result in any penalty or loss of benefits to which you are entitled and will not affect your relationship with [REDACTED]

### STUDY SUMMARY

If you agree to participate in the study, you will attend up to three yearly visits with the study team that can be split over multiple days. The following things will happen during the study:

	Research procedures	Potential risks
	Blood draws Lumbar puncture (optional)	You might experience anxiety, pain and/or bruising from the needle stick. You might experience temporary back pain and a headache (lumbar puncture).
	MRI scans PET scans	You might experience anxiety from being in a small space, or displeasure from hearing loud noises (MRI scans). You will be exposed to radiation (PET scans).
	Experimental dye, used in the PET scan to help us see your brain	The most common, usually mild, side effects include diarrhea, headache, and a weird taste in your mouth.
	Learn the result of your PET scan	Learning the results of your scan may be upsetting to you, whether it is positive or negative.
	Questionnaires, cognitive testing and genetic testing	Anxiety, frustration, stress or boredom during testing. Learning your genetic result may upset you.

### STUDY DETAILS

Please review the rest of this document for more details about the study and the things you should know before making a decision about whether to participate in this study.