Alzheimer's Disease Research Center

The purpose of the study is to collect large amounts of information from various tests of brain function over time with the goal of improving early detection and clinical care for patients with dementia.

What will I do at the visit?

A basic visit includes:

- Reviewing and signing consent
- Blood draw for research purposes
- Tests of memory and thinking
- Study partner interview
- Neurological exam

During the visit we will discuss further optional testing with you, including additional memory and thinking tests, MRI and lumbar puncture.

What is the purpose of the blood draw?

Through the blood draw we collect genetic results that are pooled to better understand possible genetic links to dementias. The great majority of genetic results is not available to individuals, but is to be used for group analyses to help better understand the meaning of human genetic variation.

In rare circumstances, we might discover genetic information that may be clinically relevant to an individual. During your visit we will discuss options for disclosure of genetic information, and you can decide if you do or do not want to know the results, if any. The results from the blood draw are considered research and are used for research purposes only.

In all circumstances, the ADRC maintains discretion on the type of genetic results that will be disclosed. This is further outlined in Section 2.

STUDY TITLE: New Approaches to Dementia Heterogeneity

The Alzheimer's Disease Research Center (ADRC) is:

- Part of a national program with 31 centers around the country
- Dr. Bruce Miller is the director of this center
- UCSF is the largest center with over 400 people enrolled

You were asked to participate because you are a healthy volunteer, have complaints about your memory or thinking abilities, or a have a diagnosis of a neurological condition affecting your memory or thinking

Please contact Harli Grant if you have any questions, at 415.476.3722 or adrc@memory.ucsf.edu

Thank you very much for being a part of the ADRC!

How will my information be used?

Your information will be used to help health professionals better understand normal brain aging and dementia and will contribute to the development of treatments for different variants of dementia. Information collected as part of this study will be used for research purposes only.

What are the benefits and associated costs?

There are no direct benefits to you, including payment. There is no cost to you.

What are the risks?

The risks are carefully described in the consent process. Some risks include mild discomfort during some procedures and possible loss of confidentiality. There are risks inherent with any medical procedure, but we make every effort to minimize any risks to you.

Who may see my records?

If you are a UCSF Memory and Aging Center clinic patient, we will share your information with your neurologist. In some circumstances, researchers may be able to share some information and test results collected during the study with your health care provider. If you are not a patient at the UCSF Memory and Aging Center, you may sign a release of information form for information to be shared with your physician. Only those listed on the release of information will be able see your records, and you can remove someone at any time.

What about privacy?

Researchers are taking significant steps to protect information about you to maintain confidentiality. Any data linked to you will be de-identified and associated with a study number.

Under rare circumstances we may have to report you to the appropriate officials if you or someone else's safety is at risk. This may include the Department of Motor Vehicles, for example.

UCSF Weill Institute for Neurosciences

Memory and Aging Center