

VOLUNTEERS NEEDED FOR RESEARCH ON CADASIL

Invitation to Participate

Researchers at the Centre for Healthy Brain Ageing (CHeBA), UNSW Sydney are inviting individuals to join **AusCADASIL**, a study that will look at clinical and genetic features of CADASIL. We will recruit individuals who have a diagnosis of CADASIL, are suspect for CADASIL, are a relative of someone with CADASIL and had previous genetic testing themselves, or a healthy control volunteer with no family history of CADASIL.

What is CADASIL?

Cerebral Autosomal Dominant Arteriopathy with Subcortical Infarcts and Leukoencephalopathy, or CADASIL, is genetic condition which causes strokes, and often migraines, and changes to cognition and mood.

We will use MRI, cognitive tests, retinal imaging, and blood markers to study the impacts of CADASIL.

This study might be a good fit for you if you are:

- Aged 18 and over
- Able to provide written consent
- Able to attend a study site in-person

This study might not be suitable for you if you:

- Are unable to participate voluntarily
- Have confounding comorbidities such as HIV/AIDS, multiple sclerosis, metastatic cancer, active autoimmune disease, and sarcoidosis.

If you participate, you will need to:

- Receive a screening phone call to confirm eligibility (10 minutes)
- Have a physical examination (30 minutes, optional)
- Have an MRI scan (1 hour, optional)
- Provide a blood sample (15 minutes)
- Complete some tasks (online and in-person) on thinking and mood (20 minute; or up to 2 hours optional)
- Complete a survey about your basic medical and health history (25 minutes)
- Have an eye test (Only available at Sydney and Melbourne sites, 90 minutes, optional)
- Have genetic counselling (as appropriate; approximately 1 hour)
- Return for annual follow up of medical history and tasks of thinking and mood (1 hour, optional).
- Return after 3 years for a repeat MRI brain scan, eye test, and blood sample (3 hours, optional)

Tests can be completed over multiple days at your convenience. **There are no costs associated with participating, nor will you be paid to take part. The study can assist with transport costs from a CBD railway station or parking costs on-site.**



This study looks at clinical and genetic features of CADASIL to better understand its progression and management.

To express interest in participating or to learn more about this study, please contact Dr Danit Saks.

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