Dominantly Inherited Alzheimer’s Network (DIAN)

Purpose
DIAN stands for the Dominantly Inherited Alzheimer’s Network. This international network has been established to bring together researchers who study genetic forms of Alzheimer’s disease. Research suggests that brain changes may occur years before actual symptoms are detected. The major goal of DIAN is to study these changes in people who carry a genetic mutation that causes Alzheimer’s disease before symptoms are evident. Ultimately, knowledge gained from DIAN may lead to tests which can detect people who are at a very high risk of developing dementia caused by Alzheimer’s disease.

What is being investigated?
Individuals volunteering for the DIAN study will be members of families in which Alzheimer’s disease is dominantly inherited, meaning that approximately 50% of the individuals in each generation of the family will develop Alzheimer’s disease, generally before age 60. This rare form of Alzheimer’s disease is caused by a mutation in one of 3 genes and participants need to be from families known to carry a mutation.

Each child of an affected parent has a 50% chance of inheriting the mutation. If they do, they will develop dementia of the Alzheimer’s type at about the same age as their affected parent. Siblings who do not have the mutation have no greater risk of developing Alzheimer’s disease than someone without a family history, but can participate in DIAN as part of a comparison group for their mutation-carrying siblings.

Participation in the DIAN study involves investigation into physical and mental changes that may predict a person’s future development of Alzheimer’s disease.

What will be required of the participants?
The following investigations are carried out at an initial assessment and then at follow-up intervals which will vary depending on the age of the participant:

- Clinical interviews
- Mental status testing
- Brain scans, including magnetic resonance imaging (MRI) and positron emission tomography (PET)
- Blood tests, including genetic studies
- Assays of cerebrospinal fluid (CSF), obtained by a lumbar puncture

Research volunteers travel to the sites for the investigations. It is expected that each round of DIAN investigations will take three days to complete.

Reasonable costs of travel to a study site, accommodation and meals during study participation may be also covered by DIAN.
Who can participate in the study?
DIAN participants need to:

- Have a biological parent or sibling with Alzheimer’s Disease caused by a known genetic mutation.
- Be at least 18 years of age
- Speak and read English
- Have someone who knows them well and be willing to answer questions about their memory and thinking

How large is the study?
There are 10 DIAN study sites: 3 in Australia, 6 in the US, and 1 in England. Together they aim to recruit 400 participants worldwide.

What are the Australian Study sites?

**Melbourne:**
Mental Health Research Institute, Melbourne

**Sydney:**
Neuroscience Research Australia, Sydney

**Perth:**
Sir James McCusker Alzheimer’s Disease Research Unit
Edith Cowan University, Perth

Where can I get more information?
For more information please contact:

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Dates
We are currently recruiting and are in the 2\textsuperscript{nd} year of this 6 year study.