

**What is DIAN?**

DIAN stands for the Dominantly Inherited Alzheimer's Network. This international Network has been established by the National Institute on Aging of the National Institutes of Health (US) to bring together researchers who study genetic forms of Alzheimer's disease (AD). The DIAN research volunteers are members of families in which AD is dominantly inherited, meaning that about 50% of the individuals in each generation of a family develop AD, generally before age 60. These rare forms of AD are caused by a mutation in one of 3 genes. Each child of an affected parent has a 50% chance of inheriting the mutation. If they do, they will develop the dementia of AD at about the same age as their parent. Siblings who do not have the mutation have no greater risk of developing AD than someone without a family history of AD and will participate in DIAN as part of a comparison group for their mutation-carrying siblings.

NOTE: INDIVIDUALS PARTICIPATING IN DIAN ARE NOT REQUIRED TO KNOW WHETHER OR NOT THEY CARRY A MUTATION. Should they wish to learn their mutation status through genetic testing following genetic counseling, DIAN can assist with this process.

**What is DIAN's goal?**

Research suggests that brain changes may occur years before actual Alzheimer's symptoms are detected. The major goal of DIAN is to study these changes in people who carry an AD mutation to determine how the disease process develops before there are any symptoms. Ultimately, knowledge gained from DIAN may lead to tests that detect people who still are normal but are at very high risk of developing dementia caused by AD. All DIAN participants will be members of families with dominantly inherited AD caused by a known mutation and may be ideal candidates to participate in future studies of drugs that have the potential to halt the AD process and prevent dementia.

**How will DIAN accomplish this goal?**

People from families with a known mutation causing AD are eligible to participate in DIAN and its studies of physical and mental changes that may predict future AD. These studies include:

- clinical interviews
- mental status testing
- brain scans, including magnetic resonance imaging (MRI) and positron emission tomography (PET)
- blood assays, including genetic studies
- assays of cerebrospinal fluid (CSF), obtained by lumbar puncture (spinal tap)

Presently, there are 10 DIAN study sites: 6 in the US, 1 in England, and 3 in Australia. Research volunteers travel to one of the sites for the studies, which are repeated every few years. It is expected that each round of DIAN studies will take about 3 days to complete.

### **Are there any costs to participate?**

All DIAN assessments are for research purposes and are supported by DIAN. Reasonable costs of travel to a study site, accommodations and meals during study participation may also be covered by DIAN. Volunteers may receive payment for some study procedures; whether payment is offered and the amount are determined by the individual study site.

### **Can I be a part of DIAN?**

DIAN participants need to:

- have a biological parent or sibling with AD caused by a known mutation
- be at least 18 years of age
- speak and read English
- have someone who knows them well be willing answer questions about their memory and thinking

### **United States DIAN Sites:**

Brown/Butler Hospital	Providence, RI
Columbia University	New York, NY
Harvard/Brigham and Women's Hospital	Boston, MA
Indiana University	Indianapolis, IN
Washington University	St. Louis, MO
University of California, Los Angeles	Los Angeles, CA

### **United Kingdom DIAN Site:**

Institute of Neurology, University College London	London
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### **Australian DIAN Sites:**

Sir James McCusker Alzheimer's Disease Research Unit, Edith Cowan University	Perth
Prince of Wales Medical Research Institute	Sydney
Mental Health Research Institute, University of Melbourne	Melbourne

### **The Challenge:**

Eligible individuals who volunteer to enroll in DIAN's studies will contribute to this unique international effort to discover the basic causes of AD. At the same time, they must be highly committed because DIAN asks much from these volunteers in terms of time and testing. It is anticipated that the improved understanding of the AD process will result in better tests to detect AD and eventually lead to therapies to treat or even prevent the illness. However, there can be no guarantees of success in these areas, and almost certainly not within the next few years. DIAN volunteers who donate their valuable time to DIAN may not directly benefit themselves but hopefully will greatly help their children and grandchildren.

### **Where can I get more information about DIAN?**

Information about DIAN can be found at: [www.dian-info.org](http://www.dian-info.org)

## THE CHALLENGE:

Eligible individuals from families with inherited forms of Alzheimer's disease who volunteer to enroll in DIAN's studies will contribute to this unique international effort to discover the basic causes of this illness. At the same time, they must be highly committed because DIAN asks much from these volunteers in terms of time and testing. It is anticipated that the improved understanding of the Alzheimer's disease process will result in better tests to detect Alzheimer's disease and eventually lead to therapies to treat or even prevent the illness. However, there can be no guarantees of success in these areas, and almost certainly not within the next few years. DIAN volunteers who donate their valuable time to DIAN may not directly benefit themselves but hopefully will greatly help their children and grandchildren.

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## DIAN SITES

### UNITED STATES:

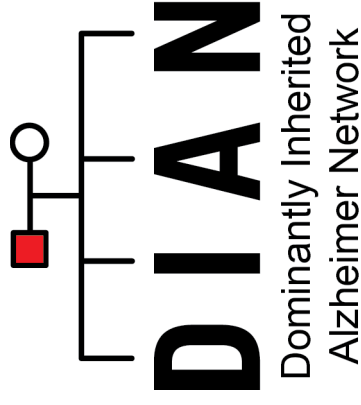
Brown University/Butler Hospital	Providence, RI
Columbia University	New York, NY
Indiana University	Indianapolis, IN
Massachusetts General Hospital/Brigham and Women's Hospital/Harvard University	Boston, MA
University of California, Los Angeles	Los Angeles, CA
University of Pittsburgh (Planned for 2011)	Pittsburgh, PA
Washington University	St. Louis, MO

### UNITED KINGDOM:

Institute of Neurology, University College London	London
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### AUSTRALIA:

Mental Health Research Institute, University of Melbourne	Melbourne
Neuroscience Research Australia	Sydney
Sir James McCusker Alzheimer's Disease Research Unit, Edith Cowan University	Perth



**Dominantly inherited Alzheimer's disease is a rare form of AD caused by genetic mutation.**



**DIAN COORDINATING CENTER**

**WASHINGTON UNIVERSITY**

**GLOBAL CLINICAL COORDINATOR:**

**(314) 286-2683**

**[www.dian-info.org](http://www.dian-info.org)**



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## WHAT IS DIAN'S GOAL?

Research suggests that brain changes may occur years before actual Alzheimer's symptoms are detected. The major goal of DIAN is to study these

changes in people who carry an Alzheimer's disease mutation to determine how the disease process develops before there are any symptoms. Ultimately, knowledge gained from DIAN may lead to tests that detect people who still are normal but are at very high risk of developing dementia caused by Alzheimer's disease. All DIAN participants will be members of families with dominantly inherited Alzheimer's disease caused by a known mutation. These individuals may be ideal candidates to participate in future studies of drugs that have the potential to halt the Alzheimer's disease process and prevent dementia, although these studies are not currently part of DIAN.

## HOW WILL DIAN ACCOMPLISH THIS GOAL?

People from families with a known mutation causing Alzheimer's disease are eligible to participate in DIAN and its studies of physical and mental changes that may predict future Alzheimer's disease. These studies include the following at initial assessment and then at follow-up times (which may 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 assays, including genetic studies
- Assays of cerebrospinal fluid (CSF), obtained by lumbar puncture (spinal tap)

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## FOR MORE INFORMATION ABOUT DIAN CONTACT:

➤ [www.dian-info.org](http://www.dian-info.org)

OR

➤ **The DIAN Global Coordinator,  
at 314-286-2683**

