

Making Headway Toward 1,000 Family Goal

The AD Genetics Study is within reach of our goal! As of March 2006, researchers had identified **888** families for participation in the study. Of these, 622 families are actively enrolled in the study at the National Cell Repository for AD (NCRAD).

We anticipate hitting the 1,000-family mark this year. Even after we meet this goal, recruitment of new families will continue.

Many thanks to you and your family members for making this landmark study possible. Your participation is invaluable to the many researchers looking to find the genes that increase the risk of late-life AD.

Next Steps for Participating Families

Researchers hope to re-evaluate participating families every three years, to make sure family history and other information is up-to-date with any changes in health or memory. This summer, study sites will begin follow-up evaluations that will include:

- 1) an update of family history information;
- 2) cognitive tests and other questionnaires;
- 3) a neurological evaluation; and
- 4) a repeat blood draw (if necessary).

If we are not able to see family members in person, we would like to check in and conduct some questionnaires over the phone.

Please let your study site coordinator know if your contact information changes. ☺

Study Contact Information

For further information on these or any other issues related to the AD Genetics Study, contact:

STUDY SITE COORDINATOR

[NAME]
[PHONE]
[E-MAIL]

More Families Needed

We need your help! If you know families who may meet the eligibility criteria for this study, please encourage them to contact NCRAD at **1-800-526-2839** or e-mail alzstudy@iupui.edu for more information.

Eligible families: must have at least 2 living siblings (brothers/sisters) who developed AD after age 60 **and** 1 other living family member age 50 or older who may have memory loss **or** age 60 or older with no memory loss.

Controls: The study is also seeking volunteers to serve as "controls" - spouses, friends, and other interested people age 60 or older without memory impairment who are *not* biologically related to participating family members. For information, contact your study site coordinator.

What Happens Next?

How Researchers Assess and Use Your Blood Samples and Family History

The first step to isolating and identifying genes associated with Alzheimer's disease is finding families and gathering family histories, blood samples, and other data. The second step is taking the samples into the laboratory for "genotyping," the process of identifying the DNA (genetic information) contained in the blood cells. We are very excited to have started this second step. Samples from 362 families in the project have been sent to the Center for Inherited Disease Research (CIDR) at NIH for genotyping.

The genotype data provides information about different genetic markers throughout the entire human genome (the complete set of DNA). These markers, in combination with the family history information and other data, will help us narrow down specific regions in the genome that may contain genes associated with AD. It is important to have complete information from all participating families for the analysis of this new

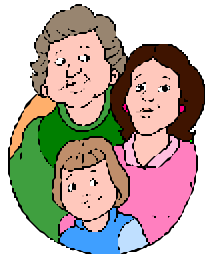
data. Follow-up evaluations will ensure that researchers are analyzing the most up-to-date information.

The genotype data, biological samples, and information collected from families will be available for all qualified researchers studying AD. The samples and data are coded and all personal identification removed to protect the privacy of study participants.

Already, researchers from numerous institutions have requested to use AD Genetics study data and biological samples to investigate potential candidate genes for Alzheimer's disease. Recent requestors include: the University of Wisconsin, Albert Einstein College of Medicine (New York), and New York University School of Medicine.

Having access to this large, well-established bank of genetic information and samples means that researchers can move ahead quickly in their studies, rather than having to gather their own samples and data.

NCRAD and AD researchers worldwide greatly appreciate your support and participation. ☞



The Importance of Autopsy

An accurate diagnosis of a memory disorder is only possible by examining brain tissue at death. Our ability to understand how AD affects the brain and causes memory loss, confusion, and other symptoms is dependent upon studying brain tissue. Having a confirmed autopsy diagnosis is a valuable addition to our genetic research studies in families, and gives families important information about their medical histories. Alzheimer's Disease Centers (ADCs) throughout the country perform this essential research procedure to learn about memory disorders.

Participants in the AD Genetics Study can make an additional contribution to furthering AD research by making arrangements to donate their brains. For more information, contact your study site coordinator. ☞

NEW! Easy-to-Read AD Materials

Two new booklets, *Understanding Memory Loss* and *Understanding Alzheimer's Disease* are now available FREE from the National Institute on Aging's Alzheimer's Disease Education and Referral (ADEAR) Center. The booklets offer a brief, easy-to-read introduction to AD and memory loss issues. To order, call the ADEAR Center at 1-800-438-4380 or view online at: www.alzheimers.nia.nih.gov. ☞

Free Resources

Looking for more information on Alzheimer's disease, caring for someone with AD, finding a support group, or keeping your brain and body healthy as you age?

For free resources, contact:

- **National Institute on Aging's Alzheimer's Disease Education and Referral (ADEAR) Center**
Phone: 1-800-438-4380
Web: www.alzheimers.nia.nih.gov
- **Alzheimer's Association**
Phone: 1-800-272-3900
Web: www.alz.org

The *National Institute on Aging*, the *Alzheimer's Association*, and *Alzheimer's Disease Centers (ADCs)*, coordinated by the *Columbia University ADC*, are working together to conduct the AD Genetics Study.

For more information, contact the National Cell Repository for Alzheimer's Disease (NCRAD) at 1-800-526-2839, e-mail alzstudy@iupui.edu, or visit the Web site at www.ncrad.org

