

Alzheimer's Disease Genetics Study **UPDATE**

Winter/Spring 2004

Dear AD Genetics Study Family Members;

Thank you very much for participating in this important research study. Truly, without your help, the AD Genetics Study would not be possible. Your willingness to step forward both inspires and motivates us as researchers looking to unravel the mysteries of Alzheimer's disease.

Many of you requested updates on the study as it moves forward. We hope this twice-yearly newsletter will give you a glimpse of our progress and a sense of the community of people – families and researchers – involved in this groundbreaking cooperative effort.

Sincerely,



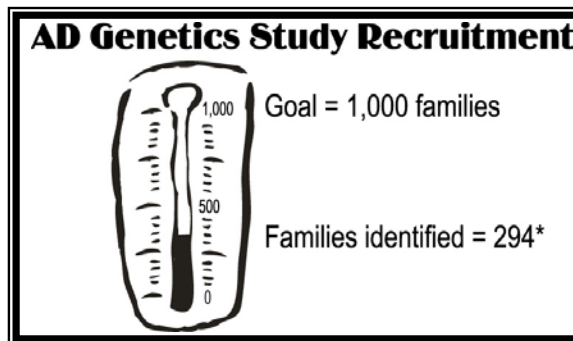
Richard J. Hodes, MD
Director, National Institute on Aging

Hundreds Respond to Call for Volunteers

The outpouring of response has been amazing. Since the official launch of the AD Genetics Study last July, more than 1,000 calls and e-mails from interested families have streamed into the National Cell Repository for Alzheimer's Disease (NCRAD) at Indiana University. From these contacts, NCRAD has identified nearly **300** eligible families, putting us almost one-third of the way toward our goal of 1,000 families.

The surge in interest has had a positive spillover for other research. A number of families who contacted NCRAD who did not meet specific eligibility requirements for the AD Genetics Study were able to enroll in other AD research at study sites around the country.

We still have a significant way to go to reach our recruitment target. 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.



* as of 2/04

Eligible families must have at least 3 living members who can donate blood, including:

- 2 siblings (brothers/sisters) who developed AD after age 60 **and**
- 1 other family member age 50 or older who may have memory loss **or** age 60 or older with no memory loss.

Strength in Numbers: Large Family Enthusiastically Volunteers

"Their enthusiasm is just incredible," says Karen Kuntz, study coordinator at the Mayo Clinic in Rochester, Minnesota, describing her experience enrolling several large families in the AD Genetics Study. "They are so dedicated to AD research."

With 9 brothers and sisters enrolled in the study and scores of children, nieces, and nephews volunteering to participate in research, one Rochester-area family exemplifies this support and dedication. "We're proud of what we're doing as a family," says Mrs. H, who initiated her family's participation.

The 71-year old Mrs. H is the 8th child of 11 in her generation, 10 living, several with AD. Both her mother and oldest sister died of Alzheimer's. At an annual check-up with her family doctor at the Mayo clinic, she mentioned her concerns about AD and its incidence in her family. "The chances of my getting it are up there," she notes.

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Mrs. H was referred to a neurologist at Mayo for testing, and he suggested the Genetics Study. Eventually, the siblings who had agreed to participate all came in together to be assessed and enrolled in the study. The one-time visit made it easy, and was “like a family reunion at the clinic,” recalls Kuntz.

Mrs. H is passing the word on to the 43 kids in the next generation as well, and they are doing their part. “It’s very humbling,” she says. “I don’t know if we can do a whole lot for us in my generation. But it’s the kids.”

Brain Donation: A Gift to Research and Future Generations

Have you considered brain donation -- giving permission for a brain autopsy after death? As participants in AD research, you and your family have already given a gift to research. Taking the additional step of brain donation offers scientists the chance to gather further in-depth information. For example, examining the brains of research patients gives insight into how the disease progresses, how healthy brains can be protected, and can confirm diagnoses. And, future generations of your family would have more information about their genetic history.

For more information about brain donation, talk to your study site coordinator.

AD Genetics in the News

Researchers are on the trail of new genetic clues to AD. In November, researchers at Duke University announced findings about several AD-related genes they had identified through a novel approach. Instead of looking for the genes that determine whether a person might get AD, they looked for the genes linked to age at onset of the disease. The Duke group found a gene on chromosome 10, called “GSTO1,” significantly associated with late-life onset of both Alzheimer’s and Parkinson’s diseases. The same lab also identified two chromosomes not previously linked to AD: a region on chromosome 2 strongly associated with early onset AD and another on chromosome 15 with very late onset AD.

Further study of the GSTO1 and how it works could open up new avenues of research for delaying the onset of Alzheimer’s and Parkinson’s diseases. Delaying the onset of symptoms of AD by even 5 years could greatly reduce the numbers of people who will get the disease.

The genetic information gathered from families like yours will help speed this sort of AD genetics research forward, helping scientists to identify new strategies for delaying, preventing, or treating the disease.

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.org
- **Alzheimer’s Association**
Phone: 1-800-272-3900
Web: www.alz.org

The *National Institute on Aging*, the *Alzheimer’s Association*, and 18 *Alzheimer’s Disease Centers*, 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.

