NIA and Alzheimer’s Association Join Forces  
Promoting Major AD Genetics Initiative

Searching for Families with Multiple Members with AD

The National Institute on Aging (NIA) is greatly advancing the search for genes involved in Alzheimer’s disease (AD) with acceleration of the AD Genetics Initiative. Joined by the Alzheimer’s Association, the NIA is stepping up the Initiative to create a large bank of genetic material, cell lines, and data from families with multiple members with late-onset AD. Scientists will use the data bank in their quest to discover the risk factor genes that contribute to late-onset AD, the most common form of the disease. Discovery of risk factor genes will help illuminate the underlying disease processes of AD, open up novel areas of research, and identify new targets for drug therapy.

NIA-supported researchers across the U.S. and the Association’s network of local chapters will work with families having multiple members diagnosed with late-onset AD in an effort to enlist 1,000 of those families over 3 years. The NIA, in consultation with the Association, is currently developing information materials to aid local Association chapters and NIA-supported Alzheimer’s Disease Centers in recruitment and to provide detailed information on the project. These materials will be distributed to chapters and centers in the fall.

“We are so pleased to be working hand-in-hand with the Association and its chapter network across the country on such an important effort,” says Marcelle Morrison-Bogorad, Ph.D., Associate Director, Neuroscience and Neuropsychology of Aging Program at the NIA. “The Association’s commitment to research, coupled with the depth of its efforts in the community, makes this a crucial alliance for moving this research forward.”

William Thies, Ph.D., Alzheimer’s Association Vice-President for Medical and Scientific Affairs, notes that the study is one way that families with AD can make a major difference in the pace of research. “Discovery of risk factor genes is essential for understanding the causes of late-onset AD and for developing effective treatments and prevention strategies. We welcome the opportunity to mobilize the Alzheimer’s community toward this end,” he says.

For a family to participate, there must be at least one affected pair of siblings and at least one other affected relative or unaffected relative for whom biological samples from blood or tissue are available. A participating family could include, at a minimum, a pair of siblings diagnosed with AD at age 60 or older and a third relative age 50 or older at onset of AD or age 60 or greater if unaffected. Participation involves a neurological examination or collection of medical records and the donation of a blood sample, which will be made into a cell line (a family of cells grown in the laboratory) that will enable the participant’s DNA to be available to qualified scientists over many years. Samples gathered at autopsy from deceased family members may also be used to provide DNA. Medical, demographic, and family history information also will be collected. Unaffected family members also may be asked to participate.
The cell lines and DNA will be stored at a centralized repository at Indiana University – the National Cell Repository for AD (NCRAD) – which is to serve as the first point of contact for people interested in participating in the Initiative.

There is no cost for those who join the study. To ensure broad participation, study coordinators will make alternative arrangements for participation if people eligible to take part are not located near a designated study site.

An important part of the study is the confidential treatment of the genetic information collected from participants. Researchers will not be able to identify samples on an individual level. While clinical, demographic and family history information about the participants will be available to researchers, this information will also be free of unique identifiers. Coded data on the blood sample will be stored in a secure computer at the NCRAD. Detailed discussion of informed consent documents will outline for participants how the study will be conducted and how data will be protected at each site and at the cell repository.

The Genetics Initiative Study Coordinator is Richard Mayeux, M.D., co-director of the Columbia University Alzheimer’s Center in New York City, a senior researcher who has investigated AD genetic risk in specific populations in New York and the Caribbean. Twelve Alzheimer’s Disease Centers (ADCs) have been provided with supplemental funding from NIA to recruit new individuals for genetics research and to deposit participants’ blood samples with NCRAD. NCRAD, under the direction of P. Michael Conneally, Ph.D., was established in 1989 to store DNA and cells, collect data on participants and their families, and distribute data and biological materials free of charge to qualified investigators.

To participate in the study, families should contact NCRAD toll-free at 1-800-526-2839 or 317-274-7360 or, by e-mail, Jamalynne Stuck, Research Coordinator and Genetic Counselor for NCRAD, at alzstudy@iupui.edu.

About 90 percent of people with AD have the late-onset variety, which strikes people age 65 and older. There is no obvious inheritance pattern with late-onset AD, but researchers have identified one “risk factor” gene, the ε4 variant of apolipoprotein E (apoE). This discovery has opened up many important avenues to understanding the biological and environmental interactions that may be important to the development of late-onset AD. While scientists have drawn significantly closer to identifying at least four regions of chromosomes where other risk factor genes might be, a workshop convened by NIA in March 2002 strongly recommended that further collection and analysis of larger sample sets are needed to root out these genes.

The NIA, part of the National Institutes of Health at the U.S. Department of Health and Human Services, leads the Federal Government’s effort to support and conduct research on aging and age-related disorders and diseases, including AD. In fiscal year 2003, the NIA will spend an estimated $480.5 million on AD research, the largest single component of its nearly $1 billion budget. The Alzheimer’s Association is the largest private supporter of research on AD. Through its national network of advocates and chapters, the Association advances research, improves services and care, creates awareness of AD and mobilizes support.

For more information on Association participation in this Initiative, contact the Association at 312-335-4078. To contact the NIA’s Office of Communications and Public Liaison, call 301-496-1752.