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For more information, contact:  
Geoff Spencer, NHGRI  
(301) 402-0911  
[spencerg@mail.nih.gov](mailto:spencerg@mail.nih.gov)

Rick Borchelt  
Genetics and Public Policy Center  
(202) 663-5978  
[Rborche1@jhu.edu](mailto:Rborche1@jhu.edu)

## **NHGRI Funds Assessment of Public Attitudes About Population-Based Studies on Genes and Environment** *Pilot Project Will Include Town Hall Meetings in Five States*

**BETHESDA, Md.**, Thurs., Sept. 28, 2006 – The National Human Genome Research Institute (NHGRI), part of the National Institutes of Health (NIH), today announced it has awarded \$2 million to the Genetics and Public Policy Center of the Berman Bioethics Institute at Johns Hopkins University to conduct a public discussion about future potential large U.S. population-based studies examining the roles of genes and environment in human health.

“Data from the Human Genome Project, a better understanding of human genetic variation, and major advances in genetic and environmental technologies have provided an unprecedented opportunity to begin contemplating how large, population-based studies might be designed. Such research could help unravel the complex genetic and environmental factors that contribute to common diseases such as cancer and heart disease,” said NHGRI Director Francis S. Collins, M.D., Ph.D. “However, before we even think of moving forward with such a major national enterprise, it is imperative that we begin a dialogue with the American public. This grant opens the door to that discussion.”

In 2005, NHGRI, in collaboration with other NIH institutes, commissioned a group of experts in genetics, epidemiology, biostatistics, and ethical, legal, and social issues to examine the scientific rationale and the logistical and technical challenges of a large, population-based study of genes, environment and health in the United States. Such studies are already underway in several other countries. Although funding for such an endeavor has not been identified, carefully outlining and considering the goals and key design aspects of such studies was deemed of high scientific importance.

A large, population-based study likely would involve the participation of hundreds of thousands of U.S. volunteers, who would be followed for a period of many

years to ascertain and quantify the major environmental and genetic contributors to common illnesses. Researchers would analyze genetic risk factors; environmental exposures, such as smoking and dietary intake; and the health-care experiences of a wide cross-section of people in the United States. The study would also provide the opportunity to dissect some of the causes of health disparities between different groups, a topic of much concern.

In October 2005, the Department of Health and Human Services Secretary's Advisory Committee on Genetics, Health, and Society held a day-long discussion about the potential of large, population-based studies. The group concluded that broad-based public engagement will be essential in designing and implementing such studies, recommending that efforts begin to assess public attitudes toward this area of research.

"It is important that researchers begin working with the U.S. public now so that, in the event these projects are launched, public input and concerns about issues like patient privacy and informed consent can be incorporated into the design and implementation of such studies," said Jean McEwen, JD, Ph.D., a program director of NHGRI's Ethical, Legal, and Social Implications (ELSI) Branch.

As part of its two-year, \$2 million pilot project, the Washington, D.C.-based Genetics and Public Policy Center plans to obtain input on issues related to large, population-based studies through a series of focus groups in Jackson, Miss.; Kansas City, Mo.; Middletown and Philadelphia, Pa; Phoenix, Ariz.; and Portland, Oregon. In addition to the focus groups, the center will carry out a national web-based survey of 4,000 individuals and will conduct town hall meetings attended by 1,000 people in the five states. Community leaders will be interviewed as well. The grant will also be used to develop educational materials for the participants, providing them with information about large, population-based studies for the focus groups, survey, and town hall meetings.

When, or if, large, population-based studies are launched in the future, the information gathered by the pilot project on public attitudes will be used to develop larger and more targeted forms of community engagement, directed at specific communities from which any potential participants are recruited.

NHGRI is one of the 27 institutes and centers at NIH, an agency of the Department of Health and Human Services. For more information about NHGRI's ELSI Research Program, see [www.genome.gov/10001618](http://www.genome.gov/10001618). For more information about NHGRI, see [www.genome.gov](http://www.genome.gov).

The National Institutes of Health - "The Nation's Medical Research Agency" - includes 27 institutes and centers, and is a component of the U.S. Department of Health and Human Services. It is the primary federal agency for conducting and supporting basic, clinical and translational medical research, and it investigates the causes, treatments, and cures for both common and rare diseases. For more, visit [www.nih.gov](http://www.nih.gov).

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