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FOR IMMEDIATE RELEASE

**Huntington Study Group to Begin Observational Study in
Huntington's Disease**

The Huntington Study Group (HSG), in collaboration with the HP Therapeutics Foundation, Inc. announces plans to launch a multi-center, observational research study in individuals who are part of a Huntington's disease (HD) family. The following individuals will be eligible to participate in this study: 1) those who have HD or tested positive for the HD gene; 2) parents, children, and siblings of individuals who have HD or tested positive for the gene; 3) grandparents and grandchildren of those participating in COHORT who have HD or tested positive for the gene; 4) spouses and gene negative family members of those participating in COHORT who have HD or tested positive for the gene.

This is an ambitious project aimed at integrating prospective collection of research and family history data, along with the creation of a biological specimen repository. The purpose of this study is to uncover information about the natural history and scientific knowledge of HD to further our knowledge of the disease and aid in the development of potential treatments for HD, and to plan future research studies of experimental drugs aimed at slowing or postponing the onset and progression of HD.

The study, entitled "**Cooperative Huntington's Observational Research Trial (COHORT)**," is being organized and conducted by the HSG, a non-profit, cooperative group of HD experts from medical centers in North America, Europe and Australia who are dedicated to improving treatment for persons affected by Huntington's disease. Ira Shoulson, MD, Louis Lasagna Professor of Experimental Therapeutics at the University of Rochester is the Principal Investigator for the COHORT study. Additional expertise is provided from co-Principal Investigators, Tatiana Foroud, PhD who is the Director for the Division of Hereditary Genomics and an Associate Professor in the Department of Medical and Molecular Genetics at Indiana University Medical Center and James Gusella, PhD who is the Bullard Professor of Neurogenetics at Harvard Medical School, Director of the Center for Human Genetic Research and the Huntington's Disease Center Without Walls at Massachusetts General Hospital. Dr. Foroud and Dr. Gusella both have extensive experience and expertise in the genetics of neurodegenerative disorders. Initially there will be 41 HSG clinical sites that will participate in this study across North America and Australia.

"COHORT for the Huntington's disease community is like the well-known Framingham study, which allowed for the discovery and understanding of many important risk factors affecting health and disease" says Ira Shoulson, Professor of Neurology at the University of Rochester. "But unlike the Framingham study, which defined its population by the geographic location of Framingham, Massachusetts, COHORT is defined by the Huntington's disease gene, focusing on individuals within Huntington's disease families who may or may not have inherited the gene. COHORT will eventually provide researchers with new knowledge about the important relationships between

genetic and clinical information, as well as the biological material to explore scientific leads and new approaches to treatment.”

Huntington’s disease is an inherited disorder that affects about 30,000 people in the United States. In addition about another 150,000 people are at risk for developing the disease. Huntington’s disease is caused by a defective gene, which leads to the destruction of brain cells, causing involuntary movements, cognitive problems, and typically psychological problems like depression and paranoia. The disease usually strikes in young to mid-adulthood, individuals are usually in their 30s or 40s. The disease is fatal, and while there are some medications to help alleviate some of the disease symptoms, there is no known cure or medication to help slow the progression.

For more information, contact the Huntington Study Group at 800-487-7671 or www.Huntington-Study-Group.org or visit the Huntington Project web site at www.huntingtonproject.org. The HSG and the Huntington Project are supported by, Huntington’s Disease Society of America, the Hereditary Disease Foundation, the Huntington Society of Canada, and the High Q Foundation.

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