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# PREDICT-HD

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Unlike most previous HD research, PREDICT-HD (Neurobiological Predictors of Huntington's disease) is designed for healthy preclinical gene carriers. The study will be recruiting people who received the genetic test for HD but who are not yet diagnosed with HD. PREDICT-HD will detect the early signs of HD so that knowledge of how HD develops can inform treatments to slow disease progression or delay disease onset. The study uses advanced brain imaging and clinical assessments to document subtle signs of HD. Participants volunteer at 32 sites: 17 in the United States, 4 in Canada, 4 in Australia and 7 in Europe.

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## Research Highlight: Recent PREDICT-HD Study Publication

In June 2006, the Archives of Neurology journal published the PREDICT-HD early study results! The data analysis and baseline findings were determined using data from the first 17 months of the PREDICT study which included 505 individuals who had undergone predictive testing based on having a family history of HD. As mentioned in the February 2006 issue of the PREDICT newsletter, several variables showed progressive decline as people advanced closer to manifest disease. Striatal volumes in the brain (MRI), cognitive performances and even psychiatric ratings declined significantly as motor symptoms appeared and progressed. These preliminary findings suggest several clinical end points (or biomarkers) that will be critical to examine during future preventive clinical trials.

Clinical trials of experimental medications to slow, reverse, or halt disease progression during the earliest period of disease are on the horizon, and data obtained from the PREDICT-HD study will help refine the design of these trials.

Longitudinal study is critical to validate possible biomarkers for pre-diagnosed HD. Every additional year that participants complete a PREDICT study visit, we strengthen the accuracy of our findings. We thank you for your dedication and commitment to making the PREDICT study a success!



For the complete article please visit [www.archneurolog.com](http://www.archneurolog.com) and locate the June 2006 issue. Article title: "Preparing for Preventive Clinical Trials: The Predict-HD Study" by Jane Paulsen and colleagues.

## Participant Corner: Frequently Asked Questions

We continue to present PREDICT information and findings to participants and HD families across the world and have begun to compile a list of the most frequently asked questions. We have included these questions and our answers below.



**Why are so many additional gene negative individuals needed for the study?** Recently the PREDICT steering committee approved the addition of 100 gene negative participants. As with any research study, you must have a control group for comparison in order to determine if changes are HD-specific or are related to other factors that these groups might have in common. The number of gene positive participants continues to grow each year; therefore, we need to increase gene negative participants to help validate results from tests and measures.

**Originally the study was only 4 years long, what was the reason for extending it?** Longitudinal data is the most critical aspect of the PREDICT study as it is used to validate possible biomarkers. With each additional year of data, we are able to:

1. Strengthen the accuracy of our findings.
2. Identify the most sensitive measures of change.
3. Uncover important patterns and interactions associated with behaviors, abilities and symptoms.

**I know people who are interested in participating in PREDICT; what do I tell them?** PREDICT is currently enrolling gene positive and gene negative individuals at all 32 research sites around the world. Please have interested individuals visit the PREDICT-HD link at [www.huntington-study-group.org](http://www.huntington-study-group.org) for a listing of sites and contact information.

**I know someone interested in enrolling but they are not 26 years old yet. Is there a way for them to help the study?** Currently there are a limited amount of sites approved to accept 18-25 year old individuals. This will change in the coming weeks when all sites will be asking their Internal Review Boards (IRB) or ethics boards to allow this age group to participate in the study. Presently, we ask that you please have the individual contact the site closest to them and let the

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site coordinator know of their interest. The site coordinator will promptly contact the individual when the site is able to enroll people from this age group.

**What if I've moved, or need to relocate, and I'm currently in the study?** Please provide your site coordinator with your new contact information both prior to and after you are relocated. You are more than welcome to continue your yearly visits at the same site; however, if distance from your current site is an inconvenience, your site coordinator can assist you in finding a site closer to your new home.



### Event Highlights: Huntington's Society of America Convention & PREDICT-HD Presentations

The 21<sup>st</sup> Annual Huntington's Disease Society of America (HDSA) convention was held in Milwaukee, Wisconsin, USA from June 9-11 with over 600 people in attendance! Professionals, HD families and friends from across the country came together to inspire each other in the fight against HD. Several workshops, presentations and small round tables were available for attendees. With a multi-track format, there was something at the convention for everyone; whether you are new to HD, a person with HD, caregivers or professionals, everyone walked away from the convention with new and valuable information to incorporate into their daily lives.

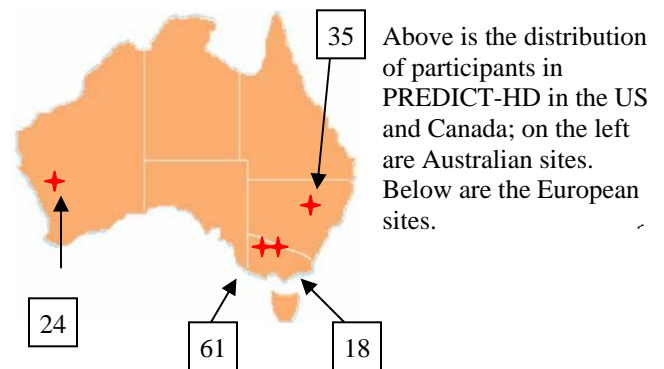
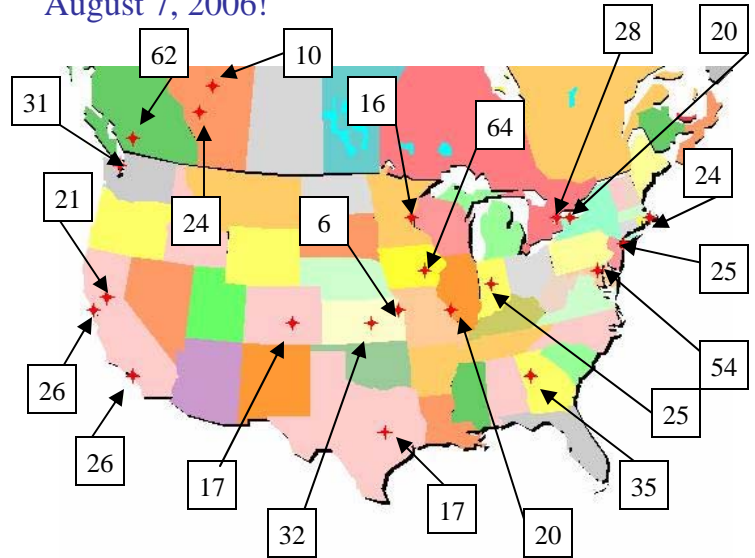
For the second consecutive year, the PREDICT-HD study hosted a luncheon for PREDICT participants and study researchers. Dr. Jane Paulsen, PREDICT's principal investigator, provided exciting research study updates and findings. She also extended her sincere thanks to everyone for their dedication to this important research study. Dr. Paulsen and her research team will continue to travel the world throughout the next year to update all of you about PREDICT. Look for presentations occurring in your area or at your site in the near future!

### Mark Your Calendar: Future PREDICT-HD 2006 Presentations Around the World

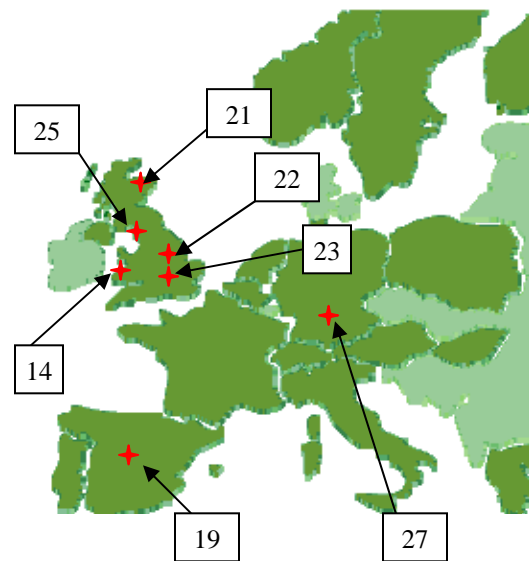


- August 19: John Hopkins University presentation in Baltimore, Maryland for enrolled participants only
- September 30: Minnesota HD Conference in Eden Prairie, Minnesota
- October 6-8: Huntington Disease Association Conference in Germany
- October 21: HD Symposium in Seattle, Washington
- November 16 & 17: National HD Conference in Melbourne, Australia

### Current Enrollment: 872 Participants as of August 7, 2006!



Above is the distribution of participants in PREDICT-HD in the US and Canada; on the left are Australian sites. Below are the European sites.



Participant feedback regarding our newsletter and the PREDICT study is always welcomed. Comments or questions may be sent to: Stacie at [stacie-vik@uiowa.edu](mailto:stacie-vik@uiowa.edu) or by calling 319-353-3716.