
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: Early Baseline Data Findings

Current hopes for reducing the burden of neurodegenerative disease rely on the idea of preventing disease onset and slowing progression so that individuals may live a longer portion of their lifespan as healthy, fully functioning individuals. For this to be possible, promising drugs must be tested for their use in slowing the onset of symptoms.

One of the goals of the PREDICT research study is to learn what measures, like cognitive tests or brain scans, may be useful in understanding the effectiveness of new drugs being developed. Our research will also help us figure out when the best time in a person's life would be to start taking these drugs.

So far in the PREDICT study, we have looked at 438 participants who were gene positive, but did not meet diagnostic criteria for HD and had no change in their ability to do daily tasks. The goal of this study was to learn how estimated time to diagnosis of HD was related to striatal volumes (brain scan data) and cognitive test performance. Findings showed that the estimated time to diagnosis (based on CAG repeat and age) was consistently related to changes in motor signs, brain scan data, and test performance. The results of the study suggested that signs of disease begin one to two decades prior to diagnosis; with minimal impairment detected 15-20 years from estimated diagnosis, and then a gradual rate of decline. (Minimal signs detected decades before diagnosis are typically only seen by trained professionals and are not noticed by the average person.) The findings from PREDICT show the approximate time of earliest measurable disease development and pinpoint disease markers that may be useful in future preventive trials.

With repeated testing on individuals across time, the accuracy of our findings strengthens. You, as a PREDICT participant, continue to help make these research projects successful with each yearly visit that you complete. We appreciate your time and willingness to assist us!

Nutrition: Benefits from Increasing Calories for Very Active HD Individuals

- * Improvement of coordination
- * Lessen involuntary movements
- * Cushion body parts from injury
- * Improvement of alertness
- * Improvement of mood
- * Improvement of responsiveness
- * Increase in functional ability



Recommended Number of Servings in 3000 Calorie Diets for Very Active Individuals Experiencing Weight Loss



Bread, Cereal, Rice and Pasta (oz.): **15**
Meat (lean) and Meat Alternates (oz.): **8**
Vegetable (cups): **6**
Fruit (cups): **6**
Milk and Milk Products (cups): **3**
Fat (tsp.): **12**

Study Involvement: Encourage Participation

Every year scientists advance research in Huntington's disease (HD) and use these developments to initiate clinical trials. With input from hundreds of families and professionals, researchers from around the world exchange ideas and discuss issues important to HD. I have never known more dedication among HD researchers and yet, like many of you, I sometimes find it difficult to maintain enthusiasm because I can not visually see or tangibly touch the achievements that have been made. Although challenging at times, I remember to

celebrate each and every accomplishment, knowing them to be a part of something larger and more significant for the future.

Last month, I attended a presentation about genetic therapy to turn off the expanded HD gene. I learned that researchers were successful in stopping the expression of the HD gene without disrupting healthy functioning in experimental mouse models of HD. Animals injected with the HD gene expansion are given the gene therapy treatment and go on to survive without symptoms of the disease. The main obstacle in “translating” this research into human beings is ensuring the delivery of therapeutic agents to the *human* brain. These treatments have been effective in animals and researchers are now studying how to achieve delivery to human beings.

On the level of research, there is no doubt that significant progress has been made. Every day, science is advancing, both in terms of our understanding the biological process of Huntington’s disease and with regard to innovative new drug therapies. HD research is gaining recognition and momentum.

I encourage participation in research because I believe it is through human study research that we’ll understand the mechanism of Huntington’s disease and the key to its prevention. Research volunteers make this dream possible and I sincerely thank you for your on-going commitment to PREDICT-HD. I invite you to stay excited about the research agenda and to share my hope that the years ahead bring a cure for HD.

~Elizabeth Penziner, Recruitment Coordinator
University of Iowa



Participant Feedback: Participants Rate PREDICT-HD Research Site Performance

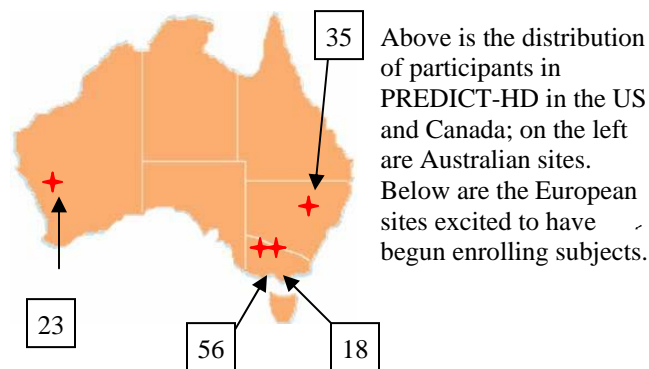
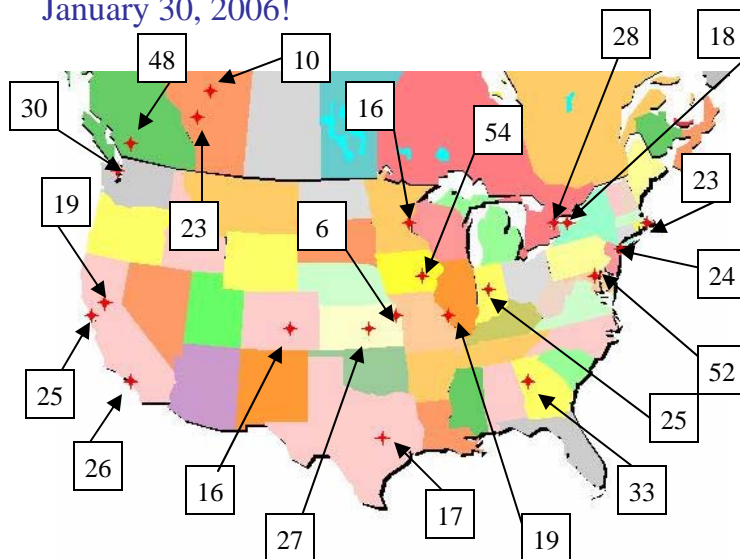
PREDICT-HD has supported many projects and initiatives that focus on retaining volunteer participants. We need all volunteers to continue in the study and would like to hear from you about how we can enhance your study visit. Help us learn from you and ensure the study’s success.

The chart shows the average scores across all sites for questions on the confidential visit evaluation form with 5.0 being the highest possible score.

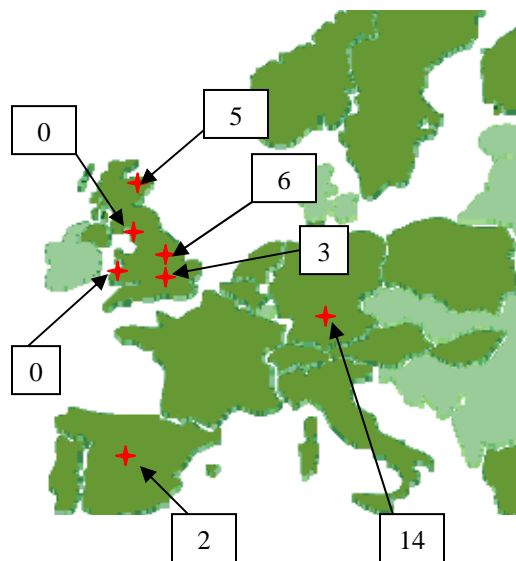
Question	Avg. Score
1. Scheduling	4.625
2. Travel	4.702
3. Parking	4.464
4. Refreshments	4.570
5. Breaks	4.770
6. Staff	4.870
7. Environment	4.766

Average 4.68

Current Enrollment: 701 Participants as of January 30, 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 excited to have begun enrolling subjects.



Participant feedback regarding our newsletter and the PREDICT study is always welcomed! If you are interested in sharing your experiences with other PREDICT participants, we are happy to involve you in our future newsletters. Comments may be sent to: Stacie at stacie-vik@uiowa.edu or by calling 319-353-3716.