PREDICT-HD: Paving the Way Toward Clinical Trials

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Disclosures

• PREDICT-HD is supported by the National Institutes of Health, National Institute of Neurological Disorders and Stroke (NS40068) and CHDI Foundation, Inc.
New YouTube video

Roll it!
PREDICT-HD: The basics

• An observational study of people with a family history of Huntington disease who have been tested for the HD gene.

• The study, which began in 2001, is the largest presymptomatic HD study, with 28 sites in 6 countries.
Why study people at risk for HD?

• We want to find the earliest detectable changes in thinking skills, emotions and brain structure as Huntington disease develops.

• With the knowledge gained from PREDICT-HD, researchers hope future drug trials can be targeted toward treatment that may slow the progression of the disease or prevent it altogether.
What have we learned so far in PREDICT-HD?

- We have identified markers of early HD that are detectable up to 15 years before estimated motor diagnosis of HD.
- These findings will allow for promising therapeutic agents to be identified and developed to see if they will delay onset of HD.
New PREDICT-HD findings

- Anthony Vaccarino and others found that the UHDRS may not be the best way to measure changes in early HD\(^1\).

New PREDICT-HD findings (cont.)

• Justin O’Rourke and others found the Trail Making Test may be particularly useful as a cognitive measure in early HD\(^1\).

• K.C. Rowe and others found self-paced timing also has potential to be used as a cognitive measure in early HD\(^2\).

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New PREDICT-HD findings (cont.)

• Elizabeth Aylward and others found that a decrease in size of the striatal part of the brain may occur faster in individuals with higher CAG repeat lengths, just like with clinical progression\(^1\).

• In a separate article, Aylward and her coauthors concluded that measures of volume change in striatum and white-matter volume may serve as excellent outcome measures for future clinical trials in early Huntington disease\(^2\).

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\(^1\) Aylward, Elizabeth; Mills, James; Liu, Dawei; Nopoulos, Peggy; Ross, Christopher A.; Pierson, Ronald; Paulsen, Jane S. Association between Age and Striatal Volume Stratified by CAG Repeat Length in Prodromal Huntington Disease [Internet]. Version 12. PLoS Currents: Huntington Disease. 2011 Apr 6 [revised 2011 May 11]:PMC3092625

New PREDICT-HD findings (cont.)

- In an article by Janet Williams and others, the following benefits were reported by people who have an HD family history or have undergone predictive HD testing:
  - Knowledge and understanding
  - Connections with others
  - Life meaning and insight
  - Life planning
  - Receiving social support
  - Renewed hope and optimism

- "Those who related benefits seemed to have sensed they have something to offer the world, whether participation in research and the advancement of knowledge, or in teaching others."

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To date PREDICT-HD has:

• Reduced sample size for early HD clinical trials (from 2,097 to 880 people)
• Developed a database of scans, bloods, DNA, phenotypic assessment
• PREDICT-HD data is being used to develop models of disease
• Applied for and been rewarded grants for sub-studies that have produced more findings
• Policy statement for “The Huntington’s Disease Parity Act.”
PREDICT-HD: The vision moving forward

- Moving toward an early HD clinical trial.
- A “leaner and meaner” PREDICT-HD.
- Pressing “pause” on our recruitment of gene-negative individuals.
- Fewer enrolling sites
- Making the visit day shorter

www.predict-hd.net
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PREDICT-HD study sites: global and local

U. of British Columbia
U. of Alberta
U. of Toronto
U. of Washington
UC San Francisco
UC Davis
UCLA
UC San Diego
Hereditary Neurological Disease Center
U. of Iowa
Cleveland Clinic
U. of Rochester
Indiana U.
Johns Hopkins U.
Emory U.
Washington U.

Graylands, Selby-Lemnos & Special Care Health Services
U. of Melbourne and St. George Health Service
Clinical Genetics Centre
Cambridge Centre for Brain Repair
U. of Manchester
Cardiff U.
National Hospital for Neurology and Neurosurgery
U. of Ulm
Westmead Hospital

U.S.A.
CANADA
AUSTRALIA
EUROPE

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Eligibility to participate in PREDICT-HD

- Men and women who are at risk for HD and have been tested, but are not diagnosed with any symptoms of HD.
- We are currently emphasizing enrollment of gene-positive individuals.
- Must be 18 years of age or older.
- Need the commitment of a companion to attend visits or complete surveys via mail.
- Must be able to undergo a brain MRI.
What our participants are saying

• “It was well explained and administered. The testing was done by staff who were knowledgeable and experienced. It was a very positive experience.”

• “Every aspect of this trial is exceptional. This was my second year and it is fun for me to be able to help with future research for my children and grandchildren.”

• “Everyone here is very nice, interested, knowledgeable and helpful. Everything was planned well and communication with me was excellent. I look forward to continuing the research study here.”

• “You are all so special to me and my family. Thank you for all you do and your genuine concern for all your participants.”

• “Another very useful visit. It is good to be part of a study that not only goes towards helping the HD situation, it also enables me to find out all the updated information regarding the HD research program. Thank you.”

• “Glad I can help!”
Resources

• PREDICT-HD Press
• PREDICT-HD YouTube Channel
• HD Buzz ([www.hdbuzz.net](http://www.hdbuzz.net))
• [www.predict-hd.net](http://www.predict-hd.net)
Coming soon!

PREDICT-HD
An observational study of the earliest signs of Huntington disease

You don't have to be a superhero to participate in PREDICT-HD
Click here for eligibility info and become an HD research hero

What is the PREDICT-HD Huntington disease study?
Read more

Recent News
PREDICT-HD part of research project that receives NIH funding
Web exclusive: PREDICT-HD cognitive team looking at new measures for early HD
Web exclusive: Full Q&A with UCLA Coordinator Ank Johnson

Upcoming Events
HDSA National Convention
Numerous PREDICT-HD staff will once again be in attendance at the HDSA National Convention in Minneapolis, MN.
Read more

Interested in PARTICIPATING? click here
Visit our YouTube Channel

What do you think of our website redesign?
- I love it! A major improvement.
- I like it.
- I'm not a fan.

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Thank you!

• To all of our amazing participants
• Our coordinators, investigators and other staff at our 29 sites
• To the Huntington’s Disease Society of America for allowing us to hold this meeting at the convention and for its continued support

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