

What Are Huntington Disease Clinical Trials?

Never before in the history of Huntington's disease has there been a time when so many potential treatments are in, or planned for clinical trials. And, for the first time in our history, we have the power to bring treatments more quickly to our families by participating in clinical trials.

There can be no treatment advances in HD without clinical trials. This brochure has been developed to help educate people with Huntington's Disease and their families about the importance of participating in HD Research/ Clinical Trials. It contains both basic information on clinical trials and resources where you can register to participate in Huntington's Disease research and clinical trials.

Register Today!

Every single clinical trial volunteer can be a hero for this generation!

www.HDTrials.org

Why sign up for HD studies?

Because every person will be needed. Right now more than 800 HD persons are needed for currently recruiting trials:

HART - ACR16, (many sites)
Call for info 800-487-7671

2CARE - Coenzyme Q10 (many sites)
Call for info 800-487-7671

HORIZON – Dimebon Phase III (many sites)
Call for info 800-487-7671

COHORT - Observational (many sites)
Call for info 800-487-7671

Predict-HD - Observational (many sites)
Call for info 800-487-7671

And Coming soon!
CREST-E – creatine

Clinical Trials Resources

HDTrials.Org
www.HDTrials.org

Huntington Study Group (HSG)
www.huntingtonstudygroup.org

Huntington Society of Canada
www.huntingtonsociety.ca

Huntington 's Disease Society of America:
www.HDSA.org

Euro-HD Network
<http://www.euro-hd.net>

CHDI, Inc.
<http://www.chdifoundation.org/>

Hereditary Disease Foundation
<http://www.hdfoundation.org>

National Institute of Health
<http://www.nih.gov/>

ClinicalTrials.gov:
www.clinicaltrials.gov

Center Watch
<http://www.centerwatch.com>

HD Lighthouse
www.hdlighthouse.org

HDDrug Works
www.hddrugworks.org

Stanford University HOPES Project
<http://www.stanford.edu/group/hopes/>

HDRoster
<http://hdroster.iu.edu>

Canadian Movement Disorders Group
<http://www.cmdg.org/>

National Research Council of Canada
<http://www.nrc-cnrc.gc.ca/eng/index.html>

HDTrials.org

Enabling and Accelerating Clinical Trial Participation

Learn more.

Enabling and Accelerating Clinical Trial Participation

HDTrials.org is the web initiative of major Huntington organizations and volunteer groups from the United States and Canada. These include:

- HDAdvocacyCenter
- HDDrugworks
- Huntington's Disease Society of America
- Huntington Society of Canada
- HDlighthouse.
- Huntington Study Group
- HD Roster

To enable clinical trial participation, the HDTrials.org web site will:

- Provide quick notification to HD families of opportunities for participation in clinical trials and studies through a confidential email list. This information can speed the time it takes to recruit participants.
- Create a separate voluntary and confidential recruitment list using only zip or postal codes. This information will help our scientists identify locations where subjects for clinical trials are available. In this way, HDTrials.org will help meet recruitment goals.



What Are Clinical Trials?

- They are research studies utilizing human volunteers to answer specific disease questions or to test treatments.
- Each is conducted according to a specific protocol. The protocol describes the type of patient that will be included, the schedules of tests and procedures, the drug and dosages that will be tested, the length of the study, and the type of outcome measures. Outcomes are usually measures of motor, cognitive or behavioral function.
- You must agree to follow the study procedures.
- Your participation in any study is voluntary and you can stop at any time.

Why Do Clinical Studies and Trials?

- To find biomarkers that can be used to speed up other clinical trials testing drugs.
- To find out if supplements or available drugs are safe and effective treatments.
- To test new experimental drugs.

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Helpful Questions To Ask Before Enrolling in a Clinical Trial?

- What is the main purpose of the study?
- Does the study involve a placebo or a treatment already available on the market?
- How will the treatment be given?
- How long will the study last, and what will I be asked to do?
- What has already been learned about the study treatment?
- Is there any reimbursement for travel or childcare?
- Will I be able to see my own doctor?
- Will I be able to continue drugs or supplements that I am taking?
- If the treatment works for me, can I keep using it after the study?
- Can anyone find out that I'm participating in a clinical trial? How will my information be kept confidential?
- Will I receive follow up care after the study is completed?
- How long will the study last, and what will I be asked to do?
- What has already been learned about the study treatment?