



PHAROS

SPOTLIGHT

This newsletter is dedicated to our PHAROS participants and their families.



PHAROS... A Roadmap to the Future for HD

Volume 6

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Dear PHAROS Participants,

We would like to share with you that the PHAROS grant was recently reviewed by the National Institutes of Health (NIH) and judged to be of high quality. The study was described by reviewers as a 'national treasure' and 'a model of how other studies should or could be undertaken.' NIH has also indicated that it will provide an additional 3 years of support to expand and complete the PHAROS study.

These comments and the additional award from NIH are a tribute to you, the research participants, as well as to the scientific value of this unique research.

Knowledge from PHAROS depends critically on the follow-up evaluations of research participants. The longer the follow up in PHAROS, the more valuable the information to our HD research. We wish to convey to our PHAROS participants:

- *Those who have withdrawn are more than welcome to return for PHAROS visits.*
- *Those still active in PHAROS who have not been seen recently for their follow-up visits, we urge you to do so as soon as possible.*
- *Those who have undergone genetic testing are still critical to PHAROS and should return for visits.*
- *Those still active in PHAROS who have returned in a timely fashion for follow-up visits, we thank you for your committed research involvement.*

Thank you for your continued support and participation in PHAROS.

Sincerely,

*Ira Shoulson, MD
Principal Investigator*

*Anne B Young, MD, PhD
Co-Principal Investigator*

PHAROS Spotlight Newsletters can now be found online at:

<http://www.huntington-study-group.org/PHAROSNewsletterVolumes.htm>



*PHAROS
"A National Treasure"*

PHAROS Continuation

Over a four year period July 1999 to January 2004, 1001 participants were enrolled from 43 institutions into the PHAROS study. Although we expected initially to complete our study in about five years, we have realized that a longer period of participation and observation will provide more knowledge and greater returns on the commitments made by participants and investigators. Although the PHAROS study is going well, we have not completed all of the study aims. By extending the study visits to 2009 we will gain significant information to meet the goals set out for PHAROS. The knowledge gained from this research will help to create efficient designs and appropriate conduct of clinical trials that could delay the onset of illness in individuals who carry the gene causing HD.

Questions about PHAROS Continuation

What should I do if I decide to move during PHAROS?

PHAROS has 41 participating sites across the US and Canada. If a participant moves to another state your site can work with you to transfer your study information to a new site. If you prefer not to transfer we can support your travel to your current site.

What if I have a change in work schedule, new job or retire?

Your site investigator and coordinator are available to work with you to develop a reasonable plan to help make appointments at a time that are most convenient.

New Items in the PHAROS Grant

1. Surveys

We would like to thank you for the extraordinary time and effort you have invested in completing the PHAROS surveys.

Many participants have asked why we don't ask about exercise and it's relationship to HD. As scientists are learning in the lab there may be link with an enriched environment where mice receive more attention and participate in activities regularly. With the extension of the PHAROS study, participants will be asked to fill out two additional environmental surveys that include the Physical Activities (Exercise) Questionnaire and the Leisure Activities Scale. These additional surveys examine whether more physical activity or greater environmental enrichment can be associated with age at onset of HD and/or rate of disease progression.



PHAROS

Success depends critically on follow-up research visits

2. Blood & Urine Collection

The extended PHAROS study will include collection of a small sample of blood and urine for analysis of potential markers of DNA and RNA damage. These markers have been found in other research studies to be elevated in the blood and urine of individuals with manifest HD and in some gene carriers who have not yet manifested HD. The analysis of these samples will help to determine the value of these indicators of DNA/RNA damage as biomarkers of HD activity in PHAROS participants. All samples will be bar-coded in order to protect the participants identity. Additional information will be provided in the informed consent.

3. Unique Identification

Looking at data across studies is important for HD researchers for designing future studies. In order for us to accomplish this we need a way to identify people (with their permission) who participate in multiple HSG studies without personnel identifiers (eg. name, initials). The Clinical Trials Coordination Center (CTCC) at the University of Rochester developed a system to track participants across studies in such a way that their identity cannot be revealed. When a participant enters a study, they will be instructed on how to obtain a 9-digit Unique Identification Number. This ID system has the ability to track individual participants across multiple studies without storing any personally identifiable information. The protected system uses an algorithm of nine data element inputs: last name at birth, first name at birth, gender at birth, day, month, year of birth, city and country of birth, and mothers maiden name. With this information an electronic “fingerprint” output is produced. The system stores only the “fingerprint” and clears the individuals inputted data elements from memory. The participant is then assigned a 9-digit Unique ID Number that is associated with their electronic “fingerprint” that will stay with a participant throughout future studies. In the new consent that you will sign for PHAROS you will be asked to provide this information.



Recent Publications by Your Research Team

Huntington Study Group PHAROS Investigators (Marder, K). Cross-sectional assessment of diet in individuals at risk for Huntington’s disease (PHAROS). (Accepted to *Neurology* for AAN 2007 meeting)

For more information on eligibility criteria and the location of HSG participating sites in the U.S. and Canada, please call the HSG at 1-800-487-7671 or visit the HSG website at www.huntington-study-group.org



New HSG Studies

As we learn more about the course of HD, new drugs are being developed to target the pathways in the brain affected by the expanded CAG repeat length. We are pleased to announce four HD clinical research studies conducted by the Huntington Study Group investigators and coordinators. For further information on these studies please visit the Huntington Study Group Website at <http://www.huntington-study-group.org>.

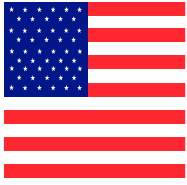
COHORT: Cooperative Huntington's Disease Observational Research Trial is a study to collect prospective data from individuals both adults and children who are affected by HD or part of a HD family in order to relate differences or similarities between individuals and families and to look at genetic factors in order to learn more about HD, develop potential treatments for HD, and to plan for future research studies of experimental drugs aimed at slowing or postponing the onset and progression of HD. Participants will either have the signs and symptoms of Huntington's disease (HD) or be a member of an HD family (including spouses). For more information see the COHORT brochure at www.huntington-study-group.org/Resources/COHORTBrochure.pdf.

RESPOND: This study entitled "An Examination of the Responses to Potential Discrimination from Individuals at Risk for HD" (RESPOND-HD) will examine the experiences of individuals who have undergone genetic testing for Huntington Disease (HD) or who have a family history of HD. It specifically evaluates the social, ethical, and legal issues resulting from being at risk for HD and/or testing positive for HD. This study will recruit people who are participating in PHAROS or PREDICT who live in states with and without discrimination laws. A survey will be used to query about the stigmatization and discrimination these individuals may have experienced. Findings will examine how people perceive possible consequences, choose their behaviors and make decisions after genetic testing or because of a family history of HD.

2CARE: The HSG has been funded by the National Institutes of Health (NIH) to conduct a phase III, placebo controlled study of Coenzyme Q10 (CoQ) in Huntington's Disease (HD). The 2CARE study will be under the direction of Dr. Cudkowicz (Massachusetts General Hospital), Dr. McDermott and Dr. Kieburtz (University of Rochester). The objective of 2CARE is to investigate the efficacy and long-term safety of high dose Coenzyme Q10 (CoQ) treatment in slowing functional decline in early Huntington's disease participants, and also to examine the long-term safety of CoQ in this population.



Upcoming Events



U.S. Events

The 22nd Annual Huntington's Disease Society of America (HDSA) Convention will be held **June 15-17, 2007** in Oklahoma City, Oklahoma. If you have any questions, please contact HDSA at hdsainfo@hdsa.org or toll free at **1-800-345-4372**.



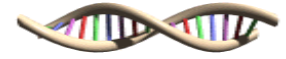
World Events

World Congress on Huntington's Disease (WCHD) will hold its bi-annual conference in Dresden, Germany. The conference will take place **September 8-12, 2007** at the International Congress Center. The WCHD is a joint meeting of the World Federation of Neurology Research Group on Huntington's Disease and the International Huntington Association (IHA). For more information see the WCHD website at: www.worldcongress-hd.net

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<http://www.huntingtonproject.org>

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<http://www.hdfoundation.org>

International Huntington Association
<http://www.huntington-assoc.com>

The HD Lighthouse
<http://www.hdlighthouse.org>

HOPES: Huntington's Outreach Project for Education at Stanford
<http://www.stanford.edu/group/hopes/>

EURO Huntington's Disease Network
<http://www.euro-hd.net>

National Institute of Health Clinical Trials
<http://clinicaltrials.gov/>

National Institute of Neurological Disorders and Stroke
<http://www.ninds.nih.gov/disorders/huntington/huntington.htm>

