

Submitted Publications

Karen Marder MD MPH, Hongwei Zhao PhD, Caroline M. Tanner MD PhD, David Oakes PhD Ira Shoulson MD and the Huntington Study Group PHAROS Investigators. Assessment of dietary intake among adults at risk for Huntington disease: Analysis of PHAROS research participants. *Submitted to Neurology*.

Kimberly Quaid, Melinda Swenson, Shari Sims, Joan Harrison, Carol Moskowitz, Nonna Stepanov, Gregory Suter, Beryl Westphal for the PHAROs Investigators and Coordinators of the Huntington Study Group. What were you thinking? Reproductive decision-making in individuals at risk for Huntington disease. *Submitted to the Journal of Genetic Counseling*.

Full Reports

Penelope Hogarth; Elise Kayson; Karl Kieburzt; Karen Marder; David Oakes; Diana Rosas; Ira Shoulson; Nancy S. Wexler; Anne B. Young; Hongwei Zhao; the US-Venezuela Huntington's Disease Collaborative Research Group; and the Huntington Study Group. Inter-rater agreement in the assessment of the motor manifestations of Huntington's disease. *Mov Dis* 2005;20:3:293-297.

Huntington Study Group PHAROS Investigators (Shoulson I, primary author). At risk for Huntington's disease: The PHAROS (Prospective Huntington at risk observational study) cohort enrolled. *Arch Neurol* 2006;63:991-998.

Hersch S, Erwin C and the Event Monitoring Committee of the Huntington Study Group. Monitoring reportable events and unanticipated problems: the PHAROS and PREDICT studies of Huntington's disease. *IRB: Ethics & Human Research*, 29 no. 3 (2007): 11-16.

Quaid K, Sims S, Swenson M, Harrison J, Moskowitz, Stepanov N, Suter G, Westphal B and the Huntington Study Group Investigators. [Living at risk: Concealing risk and preserving hope in Huntington Disease](#). *Journal of Genetic Counseling*, 2008, 17(1):117-128. PMID 17943424

Oster E, Dorsey ER, Bausch J, Shinaman A, Kayson E, Oakes D, Shoulson I, Quaid K for the Huntington Study Group PHAROS Investigators. [Fear of health insurance loss among individuals at risk for Huntington Disease](#). *Am J Med Genet Part A* (2008) 146A:2070-2077. PMID 18627059

Abstracts

Hogarth P, Rosas D, Zhao H, Kayson E, Oakes D, Kieburzt K, Young A, Shoulson I, Huntington Study Group. A study of inter-rater reliability of the motor diagnosis of Huntington's disease. *Mov Dis* 1999;14:5:901.

Huntington Study Group (Hogarth, P, primary author). A study of the feasibility of clinical research in the Huntington's at-risk population. *18th International Meeting of the World Federation of Neurology Research Group on Huntington Disease*, August 1999.

P. Hogarth, A. Brocht, E. Kayson, C. Orme, H. Zhao, I. Shoulson and the Huntington Study Group. Gender disparity in study participation among individuals at risk for Huntington's disease. *Mov Dis* 2000; 15:1042.

Huntington Study Group (Kayson E, primary author). Preliminary report of the safety and feasibility of a controlled observational study of adults at risk for Huntington's disease

(PHAROS). 19th International meeting of the World Federation of Neurology Research Group on Huntington Disease, August 2001, Abstract #30.

Huntington Study Group (Shinaman A, primary author). Willingness to consent for future genetic testing by individuals at risk for or with Huntington's disease: A preliminary report. *Mov Dis* 2001; 16:5.

Huntington Study Group (Kayson, E. primary author). Safety and feasibility of the prospective Huntington at risk observational study (PHAROS): A preliminary report. *Neurology* 2002; 58:7:Suppl 3.

Huntington Study Group/PHAROS Investigators (E. Kayson, primary author). Safety and feasibility of the prospective Huntington at risk observational study (PHAROS): A progress report. Accepted for presentation at the *World Congress on Huntington's Disease*, August 16-19, 2003, Toronto, Ontario Canada and published in the program booklet of World Congress on Huntington's Disease, 2003 Abstract #70, page 70.

Huntington Study Group/PHAROS Investigators (K. Biglan, primary author). Emerging cohort characteristics in the prospective Huntington at risk observation study (PHAROS). Accepted for presentation at the *World Congress on Huntington's Disease*, August 16-19, 2003, Toronto, Ontario Canada and published in the program booklet of World Congress on Huntington's Disease, 2003 Abstract #81, page 73.

Huntington Study Group/PHAROS Investigators (Elise P. Kayson, University of Rochester; Rochester, NY). The welfare of research participants in the prospective Huntington at risk observational study (PHAROS). *Mov Dis* 2004; 19:9:S352.

Huntington Study Group/PHAROS Investigators (Elise P. Kayson, University of Rochester; Rochester, NY). Features and well being of the prospective Huntington at risk observational study (PHAROS) cohort. *HDF Summer Symposia*, August 13, 2004 Cambridge, MA.

Huntington Study Group/PHAROS Investigators (Aileen Shinaman, University of Rochester; Rochester, NY). Willingness to consent for future use of biological specimens in the prospective Huntington at risk observational study (PHAROS). *HDF Summer Symposia*, August 13, 2004 Cambridge, MA.

Huntington Study Group/PHAROS Investigators (Elise P. Kayson, University of Rochester; Rochester, NY). Depression and suicidality at baseline in the prospective Huntington at risk observational study (PHAROS). *Mov Dis* 2004; 19(9):1128.

Huntington Study Group/PHAROS Investigators (Kevin M. Biglan, MD, Johns Hopkins School of Medicine, Baltimore, MD). Baseline characteristics of the prospective Huntington at risk observational study (PHAROS) cohort. *Annals of Neurology* 2004 56 (suppl 8).

Elise Kayson, Elaine Julian-Baros, Christine Weaver, Aileen Shinaman, Connie Orme, Joseph Weber, Susan Daigneault, Anne B. Young, Ira Shoulson and the Huntington Study Group (HSG) PHAROS Investigators. Recruitment strategies for the prospective Huntington at risk observational study (PHAROS). Published in the program booklet of Huntington Study Group 12th Annual Meeting 2004, Abstract # 8.

K.A. Quaid, M. Swenson, S. Sims, the PHAROS Investigators and Coordinators. Qualitative interviews in a subset of PHAROS participants. *Journal of Neurology, Neurosurgery and Psychiatry* October 2005;76:(suppl 4):A39.

Huntington Study Group PHAROS Investigators (Quaid K.A. primary author). Attitudes towards genetic testing for Huntington's disease in PHAROS participants. *Journal of Neurology, Neurosurgery and Psychiatry* October 2005;76:(suppl 4):A53.

Huntington Study Group PHAROS Investigators (Kayson EP. primary author). Monitoring the mental health and well being of the prospective Huntington at risk observational study (PHAROS) cohort. *Journal of Neurology, Neurosurgery and Psychiatry* October 2005;76:(suppl 4):A22.

Huntington Study Group PHAROS Investigators (M. Aileen Shinaman). Willingness to consent for future use of biological specimens in the prospective Huntington at risk observational study (PHAROS). *Mov Dis* 2006; 21(9);1555-1556.

Marder K and the Huntington Study Group PHAROS Investigators. Cross-sectional assessment of diet in individuals at risk for Huntington's disease (PHAROS). *Neurology* 2007;68(Suppl 1):A230.

Oster E, Dorsey ER, Bausch J, Shinaman A, Kayson E, Oakes D, Shoulson I, Quaid K, and the Huntington Study Group PHAROS Investigators. Factors associated with the decision to pursue genetic testing in individuals at risk for Huntington disease. *Presented at the World Congress on Huntington's Disease, September 10, 2007. Dresden, Germany.*

Oster E, Dorsey ER, Bausch J, Shinaman A, Kayson E, Oakes D, Shoulson I, Quaid K, and the Huntington Study Group PHAROS Investigators. [Influence of insurance on the decision to pursue genetic testing in individuals at risk for Huntington's Disease.](#) *Neurotherapeutics* Volume 5, Issue 2, April 2008 Page 368.

Kayson EP and Huntington Study Group PHAROS Investigators. [Five years of monitoring the safety and feasibility of PHAROS](#) (Prospective Huntington At Risk Observational Study) *Neurotherapeutics* Volume 5, Issue 2, April 2008, Page 366.

Biglan K, Zhao, Oakes D, Kayson E, Shoulson I and the Huntington Study Group PHAROS Investigators. [Longitudinal analysis of the UHDRS in individuals at risk for Huntington's Disease.](#) *Annals of Neurology* 2008;64(Suppl 12): S51.