

Cooperative Huntington Observational Research Trial (COHORT): Baseline Mental Health Risks

Background

COHORT is a prospective observational study enrolling research participants with manifest Huntington disease (HD), pre-manifest HD, 50% risk for HD, and family members with no risk for HD. Major objectives are to provide systematic clinical assessments and associated biological samples for scientific investigation, expedite recruitment for therapeutic trials, and identify emerging clinical risks among COHORT participants.

Methods

We analyzed baseline demographic and clinical data for the four participant groups as of September 16, 2008. We assessed mental health risks by examining Unified Huntington Disease Rating Scale ratings for the frequency and severity of depressed mood and suicidal thoughts and compared subpopulations with elevated “risk” scores (> 2 on depressed mood or > 1 on suicidal thoughts).

Results

In COHORT, 1523 participants have enrolled at 39 research sites in Australia, Canada and the United States.

Category	Depressed Mood (%) <i>Risk Score > 2</i>	Suicidal Thoughts (%) <i>Risk Score > 1</i>	Total (n)	Female (%)
Pre-manifest	16.8*	5.4* [#]	152	67.1
Manifest	14.2*	3.1*	777	52.5
50 % risk	11.8	1.6	267	65.5
No Risk	8.0	0.6	327	52.0

* p < 0.01 vs. No Risk, # p = 0.03 vs. 50% Risk

Conclusion

Mental health risks including elevated depressed mood and suicidal thoughts are in keeping with the genetic risk of inheriting the HD gene. The predominance of women in the pre-manifest and at-risk subpopulations compared with manifest HD and family members with no risk for HD is consistent with the gender disproportion observed in the PREDICT and PHAROS observational trials.

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Appendix

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