

Predictive Testing of Minors

Approved by the Board of Directors, October 1998

The Huntington Society of Canada (HSC) does not endorse predictive testing for Huntington disease (HD) for individuals who have not yet reached the age of majority.

In adopting this position, the Huntington Society recognizes that HD is, except in rare cases, an adult onset disorder; that in the absence of effective therapies, identifying individuals with the disease-causing mutation in the HD gene in childhood would not produce any clinical benefit for these individuals; and that for these reasons the right of individuals to make informed decisions as adults remains paramount.



It is understood that HSC's policy will require ongoing review, and is subject to revision in light of future developments in treatment, particularly if links are established between pre-symptomatic interventions and improved clinical outcomes.

It is also understood that in exceptional situations, and following extensive consultation involving the predictive testing centre and the individual/family in question, predictive testing of a minor may be identified as the appropriate course of action.

Huntington Society
of Canada
20 Erb St. W,
Suite 801,
Waterloo, ON
N2L 1T2

1-800-998-7398

info@huntingtonsociety.ca
www.huntingtonsociety.ca

Charitable Registration
Number

1 1896 5516 RR0001