GENETIC TESTING OF MINORS

Huntington Society of Canada does not endorse predictive genetic testing for Huntington disease (HD) for individuals who have not yet reached the age of majority. While every circumstance is unique, the international guidelines for predictive testing recommend a minimum age of 18 years of age. Minors at risk for HD requesting predictive testing should have access to genetic counselling, emotional support, and education on all of their options regarding the reality of living at risk for the HD mutation.

It is understood that HSC will engage in a regular review, and this position is subject to revision in light of future developments in treatment, particularly if links are established between pre-symptomatic interventions, clinical trials outcomes, and access to potential new treatments.

It is also understood that in exceptional situations, and following extensive consultation involving the referring physician, medical genetics clinic team, and the individual/family in question, confirmation genetic testing of a minor may be identified as the appropriate course of action in obtaining a diagnosis of HD.

What is Predictive Testing for HD?

Predictive testing is available through medical genetics clinics in most major centres in Canada. This is a process that may involve multiple appointments with the genetic counsellor, geneticist and other health care professionals. The predictive test involves the examination of an individual's DNA, which is obtained from a blood sample. Testing is done to determine the number of CAG repeats in both copies of the HD gene. As everyone has two copies of the HD gene, it is common for a person to have two different CAG repeat sizes (one inherited from their mother and one inherited from their father). Should the person learn they have inherited the gene mutation that causes HD, they are said to be "positive" for the mutation. This does not tell us when the symptoms of HD may appear. Should the mutation be absent, they are said to be "negative" and will not develop HD.

What is Confirmation Testing for HD?

Confirmation testing is genetic testing that is pursued because of developmental concerns that parents typically share with their children's pediatrician or family physician. If there is a family history of HD, the physician may suggest a genetic test after ruling out other possible causes of atypical developmental changes in the child. This genetic test is said to confirm whether or not the symptoms observed are caused by the HD gene mutation. As Juvenile Huntington Disease is extremely rare, it is important that the physician takes the time to assess for other childhood developmental conditions that may have treatment options.

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What is Genetic Counselling?

The goal of genetic counselling for HD is to help individuals better understand the impact of the genetic testing results for them, their partner and their family. Anyone considering genetic testing should have genetic counselling. There is no fee for genetic counselling or genetic testing (if deemed appropriate) as it is covered by provincial health insurance.

For More Information: HSC RESOURCES

Ongoing support, education and information is available from HSC. You can find a listing of our Family Services team members at www.huntingtonsociety.ca/family-services-team

Fact sheets on a variety of other related topics including Juvenile Huntington Disease, Living at risk for HD, Genetic testing, Genetic discrimination and the Genetic Non-Discrimination Act (GNDA) can be found at www.hdfactsheets.ca

HSC's Mentorship Program is a formal program that provides one-on-one support for youth to connect with a mentor who is also from a family with HD. Learn more at www.huntingtonsociety.ca/learn-about-hd/youth/youth-mentorship-program

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Sources:

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MACLEOD, R., et al. (2012). Recommendations for the Predictive Genetic Test in Huntington's Disease. *Clinical Genetics,* 1-10.

TYLER, A., WALKER, R., WENT, L., and WEXLER, N. (1994). Guidelines for the Molecular Genetics Predictive Test in Huntington's Disease. *Journal of Medical Genetics,* 31, 555-559.

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