

Pre-Test Counselling Information

Division of Genome Diagnostics, Molecular Genetics Laboratory

To ensure informed consent, the following points should be discussed with the individual and / or guardian(s) prior to ordering genetic testing.

1. Current testing may not be able to detect all genetic mutations associated with the suspected condition. Please refer to www.genebc.ca, or the appropriate testing laboratory website, for details related to the specific test being requested. The sensitivity, specificity, implications and limitations of this testing should be reviewed with the individual prior to testing.
2. DNA testing may uncover non-paternity or an undisclosed adoption.
3. Provision of molecular confirmation of the diagnosis in a family will ensure the most accurate interpretation of testing of unaffected family members (predictive or carrier testing); uncertainty in the clinical diagnosis or in the genetic lesion segregating in the family could lead to false reassurance.
4. Accurate interpretation of test results may depend on knowing the correct relationship between family members.
5. DNA testing may provide results of unclear clinical significance. In these cases, it may not be possible to confirm or rule out the condition of interest.
6. Testing is based on the current level of knowledge in medical genetics; interpretation of genetic variants can change as new knowledge is acquired. **It is the individual and / or physician's responsibility to seek updated information periodically, especially before any reproductive decisions are made.**
7. Confidentiality will be maintained as required by the applicable health privacy laws and the College of Physicians and Surgeons of BC. However, an individual's test results may be used anonymously to help interpret test results of other family members.
8. As with any medical test, genetic testing can result in an inability to access private insurance.
9. Only a sufficient amount of DNA to complete the requested clinical testing will be extracted. Residual DNA will *not* generally be available for additional testing or for transfer to other British Columbia laboratories.
10. Upon completion of testing, any residual DNA will be held for 6 months prior to disposal. Please refer to the Division of Genome Diagnostic DNA Extraction and Retention policy for details (www.genebc.ca). An individual may request destruction of their DNA sample at any time prior to slated date of disposal; please see the Directive to Destroy Residual DNA form available at www.genebc.ca.
11. Samples that are slated for disposal may be de-identified and used for quality assurance / quality control / validation / verification purposes related to the initial diagnostic test requested, or anonymized and use for test validation or verification.
12. Upon provision of appropriate Clinical Research Ethics Board approval, samples that are slated for disposal may be de-identified or anonymized and given to research investigators to help further research.