

Pre-test Counselling Information

Molecular Genetic Testing

We recommend that the following points be discussed with the patient and/or guardian(s) prior to ordering molecular testing.

1. Blood samples will be collected and DNA will be extracted. Testing will be performed in the requested laboratory or in the Molecular Genetics Laboratory at the Royal University Hospital as requested. After testing has been completed, any remaining DNA will be stored temporarily at an outside lab or indefinitely if at RUH.
2. Current genetic testing may not be able to detect all genetic mutations associated with the suspected condition. The accuracy, implications, and limitations of this testing should be reviewed prior to testing.
3. DNA analysis is limited to the requested test and cannot rule out other genetic conditions or mutations. The correct clinical diagnosis in this patient, or affected family members, is important for accurate DNA results.
4. Genetic testing can usually only be interpreted appropriately in the context of a family. It is therefore essential a comprehensive and accurate pedigree (family tree) that indicates all other known affected individuals or carriers of the condition and includes the names of all close relatives is obtained.
5. Testing is based on the current level of knowledge in medical genetics. It is the patient and/or physician's responsibility to periodically seek updated information especially before any reproductive decisions are made. Patients are responsible for keeping their physicians informed of address changes and new medical and family history information.
6. Improved or additional testing may become available either because of changes in laboratory techniques or because of new information regarding the genetic cause of the condition(s). It is the responsibility of the patient's physician(s) to initiate repeat testing.
7. DNA testing may reveal information about genes or gene changes other than the requested genetic test. The significance of such a gene change may be unclear. DNA testing may also uncover non-paternity or an undisclosed adoption. Accurate test results depend on knowing the correct relationship between family members.
8. Confidentiality will be maintained to the best of our ability as required by the applicable health privacy laws and the College of Physicians and Surgeons. The results may be used anonymously to help interpret test results for other family members. Information that DNA has been banked may be shared to prevent needless repeat blood drawing.
9. Anonymous samples of DNA may be given to research centres, with appropriate research ethics board approval, to help further research. Identifying patient information will be kept confidential.
10. Participation in genetic testing is completely voluntary. Patients may withdraw consent or request that their sample be destroyed at any time.
11. DNA testing may result in some forms of discrimination (insurance, employment or other).