## PRE-TEST CONSULTING INFORMATION

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

- 1. DNA testing may not be able to detect all genetic mutations associated with the suspected condition.
- 2. DNA testing may uncover non-paternity or an undisclosed adoption.
- 3. Participation in genetic testing is completely voluntary.
- Accurate interpretation of the test results may depend on correct information of the family history and the true biological relationships of the family members provided to HKCMGC.
- 5. DNA testing may produce inconclusive results of uncertain 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 may change as new knowledge is acquired. It is the physician's responsibility to seek updated information periodically.
- 7. Confidentiality will be maintained as required by the applicable health privacy laws of Hong Kong. However, an individual's genetic test results may be used anonymously to help interpret test results of his/her family members.
- 8. To maintain confidentiality, the test results will only be reported to the medical professionals or healthcare providers indicated on the test requisition form.
- Upon completion of testing, any residual DNA may be stored indefinitely except as prohibited by Law. An individual may request destruction of their DNA sample at any time.
- 10. Upon provision of the appropriate Clinical Research Ethics Board approval in Hong Kong, samples that are slated for disposal will be de-identified (name and all personal identifying information removed) and may be given to research investigators to help further research.
- 11. Samples will be de-identified prior to any usage, if any, for laboratory quality assurance purposes and new test development.