



genetic technologies

Informed Consent for Genetic Testing Hereditary Non-Polyposis Colorectal Cancer (HNPCC) Genes

I, _____ (Print Name), hereby agree to participate in DNA testing for Hereditary Non-Polyposis Colorectal Cancer gene mutations. I understand that a blood sample will be removed from me using standard techniques that carry very little risk.

I understand that:

1. The mutation detection system used by Genetic Technologies Corporation (GTG) for testing the HNPCC genes is among the most sensitive and specific yet developed. Testing may identify the presence of a mutation in one of the HNPCC genes but it cannot predict the age of onset or the type of cancer that may develop as a result. Identification of a mutation in an individual does not mean they will definitely develop cancer, it is however associated with a significantly increased risk of certain cancers.
2. In other cases, the DNA test is unable to identify a mutation, even though a mutation may still exist in one of the HNPCC genes. This event may be due to the current lack of knowledge in the scientific community of the complete gene structures, or a rare inability of the current technology to identify certain types of changes (mutations) in these genes. In addition, GTG may not detect a mutation because the mutation may occur in an additional, as yet undiscovered gene.
3. Because of the complexity of genetic testing and the important implications of the test results, results will only be reported to me through a medical specialist, GP, or certified genetics professional. The result reports are kept strictly confidential. Participation in genetic testing is completely voluntary.
4. The test result may have implications for other members of my family. I will decide whether to advise them of this. I understand that the test could potentially affect my ability, and the ability of my family members, to obtain some types of insurance.
5. Genetic tests are being improved and expanded continuously. GTG will store my sample and at my future request and with my consent, may in some cases, re-analyse the DNA by a new procedure(s). This additional testing may incur a further cost. My test results will be de-identified and may be used for statistical purposes. An anonymised sample of my DNA may be used in Institutional Ethics Committee -approved research programmes to improve the diagnosis and management of colon cancer.

If you don't want your results/sample to be kept for these purposes please tick here.

Signature: _____

Witnessed by: _____ Date: _____

(Signature)

(Print Name)

Physician's/Counsellor's Statement: I have determined that this individual may be at an increased risk for inherited HNPCC. I have discussed genetic testing with them, presented the information outlined above, discussed the options available to them and have answered their questions. Results from these tests may be used to direct medical management.

Signature: _____ Date: _____

(Print Name)