

# Centre for Cellular and Molecular Biology

Uppal Road. Hyderabad 500 007

## *Informed Consent for Genetic Analysis*

By signing below, I hereby authorize Dr \_\_\_\_\_ to obtain \_\_\_\_\_  
(Nature)  
sample from \_\_\_\_\_ of \_\_\_\_\_  
(Patient Name) (Address)  
\_\_\_\_\_ for the genetic analysis of \_\_\_\_\_  
(Disease)

It has been explained to me and I have understood that:

- \* DNA testing, which is done on a small sample of blood or other tissue, looks at one or more parts of the particular gene associated with above disease. Genes contain the information that guides proper functioning of the body. A change in genetic information can result in an abnormal gene that doesn't work properly.
- \* Most often DNA testing directly detects the most common disease-causing changes in a gene, the test result is highly accurate (~98%). In other cases, an indirect method called linkage analysis is used which may produce an (3-5%) uncertainty in predicting carrier status or diagnosis due to naturally occurring rearrangements in the DNA (recombination). Rare variations in individuals can also cause uncertainty in the results. In other words, the test is not 100% accurate.
- \* The linked markers may not be informative in some families and hence, this DNA test can not provide results for the family, or for some members of that family.
- \* Based on the results from initial tests, subsequent analysis may be performed on the sample for better understanding of the disease
- \* If the DNA testing does not show a known genetic change, the probability that the person is a carrier or is affected is reduced. However, there is still a small chance to be a carrier or to be affected because the current testing cannot find all the possible changes within a gene.
- \* The accuracy of DNA analysis is entirely dependent on clinical diagnosis made elsewhere, the samples collected and forwarded and CCMB cannot be responsible for erroneous clinical diagnosis or sample related problems made at other centres.
- \* Unknown genetic changes are different in different populations. Providing the laboratory with accurate information about family history and ethnic background will make the interpretation of the test results more accurate.
- \* The results of this testing will be disclosed **ONLY** to the patient/relative specified by the patient/doctor named above and to associated medical personnel.
- \* A part of this sample not used for diagnostic testing may be stored and used for medical research or education as long as any names and other identifying information have been removed. In some cases, it may be possible to reanalyse the leftover samples in the future using new and improved methods.

\_\_\_\_\_  
*Signature*

\_\_\_\_\_  
*Name* *Date*

*Relationship to patient :* *self/parent/guardian*

\_\_\_\_\_  
*Signature of witness*

\_\_\_\_\_  
*Name* *Date*