

## Consent form: Genetic Analysis

.....  
Name, Surname, Date of Birth

.....  
Street, City, ZIP, Country

### Please read this consent form carefully and mark the appropriate answers

You and/or your family members have been provisionally diagnosed to suffer from a hereditary disorder caused by an alteration or variation of the genome. Most alterations or variations of the genome can be detected by molecular genetic analysis in DNA extracted from blood samples. In this context it is important that you are informed about the significance and consequence of any obtained result of these analyses, including the awareness that the genetic disposition can be inherited by your children, and that your parents and siblings can be carriers for the genetic disposition.

- With your signature you confirm that you have had the opportunity to talk to your physician or genetic counsellor about the significance and possible consequence of genetic analysis. Especially about the fact that a normal finding does not exclude any other but the analyzed disease disposition. You confirm that your questions have been answered to your contentment and that you agree to the planned molecular genetic analysis. Your personal data and the results of the analysis underlie the patient / physician confidentiality. A propagation of the results of the analysis to any family member or physician will always depend on your personal consent. This consent can always be withdrawn.

Hereby I confirm, that I have been informed about the significance and consequence of the molecular genetic analysis and I agree to the planned molecular genetic analysis concerning:

.....  
Clinical diagnosis

- I agree that results report are sent to the following physician:  
.....
- I only want to be informed about genetic results that are relevant to the disease indicated above.  yes  no
- I also want to be informed about secondary, incidental findings with no practical relevance to this disease.  yes  no
- Law regulates that personal data and medical results have to be destroyed after 10 years. Yet, this information can be relevant for you or your children. With your consent we are allowed to archive this information.  
I agree that the information is kept longer than 10 years?  yes  no
- I agree that data and results concerning the above mentioned issue are used in encrypted and pseudonymous form for scientific purposes, and can be published in scientific journals?  yes  no
- Law regulates that remaining specimen have to be destroyed after completion of genetic analysis. With your consent we are allowed to store the sample. Please indicate if and how your samples shall be used after completion of the analysis.
- The sample(s) have to be destroyed immediately after completion of the genetic analysis.  yes  no  
OR (mark each line separately): I agree that the samples are stored and used for
  - a) verification of the obtained genetic results,  yes  no
  - and for further analysis if new diagnostic possibilities and techniques evolve.  yes  noI want to be informed about additional future clinical relevant results.  yes  no
  - b) and means of quality management, academic teaching, scientific research and better diagnostics and therapy related to this genetic disease in encrypted (pseudonymous) form.  yes  no
- I have been informed that I can withdraw my consent at any time without specifying the reasons completely or in parts. This will not have any disadvantages. I am aware that I have the right of not knowing the results. I am aware that I can stop the genetic testing at any time, and request that any result and specimen are destroyed immediately.

.....  
City, Date

.....  
Signature of Patient (or legal representative)

.....  
Legal representative: Name, Adress