

Consent for genetic testing

Patient details (use label):

Name _____ Given name _____
 male female
 Date of birth _____
 Street _____
 Post code _____ City _____

Please return to:

University hospital Würzburg
 Institute for Clinical Genetics
 and Genomic Medicine
 Biozentrum, Am Hubland
 97074 Würzburg



Tel.: 0931-201-29931, Fax: 0931-201-6029931
 E-Mail: Diagnostik_KGGM@ukw.de

The German gene testing act (GenDG) requires written informed consent to be obtained from every patient prior to genetic testing.
 Please read the following carefully, make sure all your questions were answered and tick boxes as appropriate. Not ticked boxes will be valued as "NO".

My doctor has informed me about the following diagnosis / disorder / syndrome :

.....

its genetic basis, options for prevention and treatment and about the scope and aims of the planned genetic test, its predictive value and its limits. I have been informed about the risk of the required blood / tissue sampling. All my questions have been answered to my satisfaction.

I consent that the results of the genetic test(s) are also sent to my other medical professionals, specifically to

Dr.:

yes
 no

The application of such screening tests can result in incidental findings, which are not associated with the above named disease. I wish to be informed of any such incidental findings. A claim of completeness or future actualization of such incidental findings doesn't exist.

yes
 no

By German law, surplus genetic material (blood, DNA sample) must be destroyed after the completion of the genetic test. However, with my consent it may be stored and used for subsequent additional tests (if required) and/or as control for later testing of family members and relatives.

I consent to storage and subsequent use of my genetic material and/or the genetic material of my child for the above purposes.

yes
 no

Internal quality control is an important tool to guarantee the accuracy and reliability of genetic testing methods. For this purpose, genetic material from patients with rare genetic variants is an indispensable control material.

I consent to my DNA and/or the DNA of my child to be stored and used for internal quality control in the laboratory. Before such use, my sample and/or the sample of my child will be anonymised.

yes
 no

Genetic material from patients is also important for studying biological mechanisms which contribute to the development of hereditary diseases.

I consent to my DNA and/or the DNA of my child to be stored for potential disease studies in the laboratory. I consent to be re-contacted before such use.

yes
 no

The German gene testing act requires genetic results to be stored for 10 years and then destroyed. With patient's consent they may be stored for longer. Often, genetic results are required for counselling of children and relatives even after 10 years' time.

I consent to storage of my genetic results and/or the results of my child beyond the legal time-span and its use for my family only.

yes
 no

As required the results may be used for the counselling / analysis of my relatives.

yes
 no

Genetic data will be deposited in a database at the Institute for Clinical Genetics and Genomic Medicine. Selected data will be anonymised and only used for the purpose of quality control and data comparison.

I agree with the collection, processing and storage of personal data in electronic and paper form appropriate the assignment of the German GenDG and the EU-DSGVO. Further information according EU-DSGVO: <https://www.ukw.de/recht/datenschutz/>

I have been informed that I can withdraw my consent at any time without giving reason and without incurring any penalty. I have further been informed that I have the right not to know about my genetic test results and to terminate the testing procedure at any time. I can request my genetic material and/or the genetic material of my child and my genetic results and reports and/or the genetic results and reports of my child to be destroyed before result reporting, if I have changed my mind.

With my signature I consent to the genetic test(s) indicated above and the sampling of blood or tissue for this purpose.

 City, date Signature of the patient or his/her legal representative

 City, date Signature of the doctor