

## Information about your genetic counseling appointment

You have made a genetic counseling appointment at our practice. We would like to inform you about the aspects of genetic counseling and what kind of information you might receive in the context of genetic counseling.

A genetic disorder or developmental disorder affects you or one of your family members or is suspected as a possible cause. In the course of the genetic evaluation, we will inform you about the disorder in question, its symptoms, concomitant conditions and medical consequences and the possible recurrence risk. We will discuss with you in detail the possibilities of diagnostics, eligible tests and, if applicable, possible treatment options. The information provided by genetic counseling shall enable you to answer the pertinent questions in this context and to correctly assess the possible risks for your life and family planning.

In some cases in the course of genetic counseling, evidence might arise for risks that had been unknown to you before. It is possible that in the course of the investigations anomalies will be found, that according to current medical knowledge don't cause health problems. We will bring this to your attention, but you yourself decide if and to what extent you would like to be informed.

A comprehensive assessment and diagnostic work-up of all conceivable disorders is not possible. It is equally impossible to exclude all risks of contracting a disease for you, your family members and especially your children. In some cases it is not possible to give a precise risk assessment for the occurrence of a specific disorder or disability. Even if there is a low risk (of recurrence), this still means that the occurrence of the disorder or disability is possible. The genetic counseling and the genetic testing have a high informative value only if the information provided on parentage and ancestry is correct.

We will summarise the main contents of the genetic counseling for you in a written report. You decide which physicians shall also be informed. You can contact us again at any time with questions or if new problems arise. As a general rule, you decide for yourself what consequences you draw from the test results for your life or family planning.

### Part of genetic counseling is

- the clarification of your personal question and the aim of the consultation
- the establishment of your medical history and known family medical background (anamnesis)
- the assessment of the available medical documents
- the establishment of a medical-genetic diagnosis as accurately as possible
- the comprehensive information about the eligible disorders or disabilities
- the assessment of specific genetic risks
- the information about general genetic risks
- the comprehensive counseling about the possible ramifications of this information for your life and family planning and – if applicable - for your health
- a physical examination of you and/or your family members, if this is of relevance for the specific question
- a blood test, if this is important for the specific question and if you request it

### Data protection notice

The protection of your personal data is important to us. According to the EU General Data Protection Regulation (DSGVO) we are obligated to inform you for what purposes we gather, store and forward data in our medical practice. You can find information regarding this and regarding your rights to data protection on our homepage and displayed in our practice rooms.

### Declaration of consent

I/we have read and taken note of the „information about your genetic counseling appointment“. I/we wish to make use of the genetic counseling offer as it has here been explained to me/us. I/we have read the patient information regarding data protection and I/we declare myself/ourselves in agreement with it. In addition I/we agree that my/our personal data can be stored according to the recommendations of the MBO-Ä. I can withdraw my consent at any time without providing reasons.

First and last name of the patient: \_\_\_\_\_

Place and date/signature: \_\_\_\_\_

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