

## Information about your genetic counseling appointment

You have made an appointment at our genetic clinic. Ideally, the appointment should take place as a personal consultation on site during our office hours. In some cases, a virtual consultation (via phone or video call) is possible albeit with a limited assessability of existing symptoms. We would like to inform you of the aspects of genetic counseling and what kind of information you might receive in the context of genetic counseling.

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

In some cases evidence for risks previously unknown to you might arise in the course of a genetic consultation. It is also possible that anomalies will be found, that according to current medical knowledge do not cause health problems. While we will bring this to your attention, the decision if and to what extent you want to be informed about them lies with you. A comprehensive assessment and diagnostics 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 the risk is low, the occurrence of said disorder or possibility is possible. Genetic counseling and testing only offer a high informative value of the information provided on parentage and ancestry is correct.

We will summarize the most important content of the consultation for you in writing and send it to you encrypted by email (password via text message to the mobile phone number provided). Depending on your decision the relevant physicians will also be informed. Should any questions or new problems arise, please contact us again. As a general rule, the consequences you draw from the consultation and test results concerning your life and family planning are entirely up to you.

## Part of genetic counseling is

- · offering answers to your questions and the aim of the consultation
- · establishing your personal and your family medical history as far as possible
- the assessment of the available medical documentation
- establishing a medical-genetic diagnosis as precise as possible
- · the comprehensive information on all disorders or disabilities in question
- · the assessment of specific genetic risks
- offering information on general genetic risks
- comprehensive genetic counseling on the possible impact of this information on your life, health and family planning
- the physical examination of the patient if of relevance
- a blood test if important for the specific question and requested

In some cases genetic counseling can be offered via video call to ensure swift counseling and diagnostics. However, we would like to emphasize again, that, if at all feasible, we would always give preference to a personal presentation for the consultation, as some aspects relevant to the consultation can possibly only conceived and thus taken into account in personal contact. We are, therefore, happy to offer a supplementary personal introduction during our office hours over the course of the consultation.

Additionally we can offer thematically limited appointments in some cases, depending on the topic of your consultation. In this case we will focus narrowly on your issue, the consultation letter is often omitted, and further topics may be discussed in a separate appointment.

→ By signing the following page, you acknowledge that you have read and understood the information above.



## 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**

As it has been explained to me above, I have read and taken note of the "information about your genetic counseling appointment". I wish to make use of the genetic counseling offer as it has here been explained to me. I have read the patient information regarding data protection, and I declare myself in agreement with it. In addition, I agree that my personal data can be stored according to the recommendations of the MBO-Ä. I also agree that reports and medical information may be sent to me by email and reminders and important information may be sent via text message. I can withdraw my consent at any time without providing reasons.

first and last name patient	place, date and signature patient
partner (first and last name)	place, date and signature partner
other companions (first and last name)	place, date and signature
email address	mobile phone number