

Information about genetic consultation

You have registered with us for genetic counselling. We would like to explain to you what genetic counselling consists of and what you can personally achieve through it.

A genetic counselling aims at answering questions and possible problems concerning a potential congenital disease or developmental disorder, which is confirmed for you, your children or other family members. The extent, in which the genetic consultation can be helpful depends on the respective disorder and your personal questions. Both determine what is discussed in the context of genetic counselling and determine the accuracy of our statements on genetic risks. In case that we discover hints to additional risks you are not yet aware of, we will point these out to you. Nevertheless you will be able to determine whether or not and to what degree you want to be further informed.

A genetic counselling regularly includes:

- Clarification of your personal questions and intentions concerning the consultation,
- the collection of your personal and family medical history (anamnesis),
- the evaluation of previous medical evidence and reports,
- the physical examination of you or your relatives if relevant for the diagnosis,
- blood or other tissues examination if relevant for the diagnosis,
- a medical-genetic diagnosis as precise as possible,
- detailed information about the respective disorders or disabilities,
- an estimation of specific genetic risks,
- a counselling about genetic risks in general,
- a detailed counselling about possible consequences of this information for your life- and family-planning and, when indicated, your physical health.

We will only initiate or conduct a medical-genetic diagnostic if you wish so. The counselling should serve as a decision-making aid and help you to evaluate and adjust to possible health risks. It is your decision only and you draw the consequences of the counselling conversation.

There is a possibility of abnormalities showing during the medical-genetic diagnostic process, which, may have no connection with the diagnosis in question, but can have consequences for your own health or for the health of you family members. We will only inform you about these so-called secondary findings, if they have a significant relevance for a treatable or preventable medical condition.

Please acknowledge, that it is neither possible to give you a comprehensive education about all conceivable congenital disorders in general nor can we eliminate every risk of disease for you or your relatives and especially for your children. In some cases a precise statement about the probability of occurrence for a specific disorder is not possible. Even if only a low (recurrence) risk is indicated, there is still a chance of occurrence. Even without an apparent increased risk, the average frequency of severe congenital disorders or developmental defects lies at 3%.

We might also require prior medical examination reports. If so, we are obliged to protect your patient confidentiality from unauthorized access by third parties. **Therefore we are asking you for your consent if further medical reports are required.**

Since congenital traits, disorders or diseases are often very rare and complex to classify, taking photographs can be a useful method. For the same reason, depending on the issue, we seek to consult other medical staff of our institute even during the counseling interview. Additionally, every counselling is presented and, when indicated, discussed during our weekly medial conference.

We endeavor to inform our advice-seeking patients based on recent scientific and medical knowledge. To achieve this aim our participation in research is essential. **Therefore we are asking you for your consent to use your data for research purposes if they can contribute further knowledge.** Patient data used for scientific publication will always be anonymized.

The consultation interviews most important topics will be summarized in a comprehensible letter and sent to you. In case of further questions or the appearance of new problems subsequent to the consultation, please don't hesitate to contact us.

Our collaborations with other physicians are regulated in the medical appointment regulation. According to these regulations, you co-decide to what degree other physicians are informed. You can also name further physicians who are to receive a copy of the written summary of the consultation.

Information on data protection (EU-DSGVO)

We process your personal data (or the data of your minor children, which you present to us for human genetic counselling), in particular your health data based on legal requirements in order to fulfil the treatment contract and the associated obligations, exclusively via hardware and software of the University Hospital of RWTH Aachen University. This complies with current data security and data protection regulations. Your personal data will be processed exclusively by the responsible employees of the Institute of Human Genetics. These are subject to medical secrecy (§ 203 StGB) and are bound to secrecy or data secrecy. Unauthorized third parties will neither be provided with data nor made accessible in any other way.

The collection of health data is a prerequisite for your treatment. This includes anamnesis, diagnoses and findings that we and other doctors collect. For this purpose, doctors with whom you are under treatment can also provide us with data (e.g. in doctor's letters). We only transfer personal data to third parties if this is permitted by law or if you have given your consent. The recipients of this data can be doctors, health insurance companies, health insurance companies or the medical service of the health insurance companies. The data is mainly transmitted for the purpose of billing you for services rendered, clarifying medical questions and questions arising from your insurance relationship.

You have the right to obtain information about the personal data concerned. You may also request the correction of incorrect data. Furthermore, under certain conditions you have the right to the deletion of data, the right to restriction of data processing and the right to data transferability. Your data will be processed on the basis of legal regulations and after expiry of the legally prescribed retention periods you have the right to have your data deleted. You have the right to revoke your data protection consent at any time. The revocation of consent does not affect the legality of the processing carried out on the basis of the consent until revocation (revocation with effect for the future).