

## **Patient information**

Dear patient,

You have been diagnosed with Multiple Endocrine Neoplasia type 1 (MEN1). As you have probably already been told, this is a hereditary disease involving many organs. Most patients develop a hormonal overproduction of the parathyroid glands leading to an increased level of calcium in your blood. Many patients have tumors of the pituitary gland or the foregut including the pancreas (gastroenteropancreatic tract). Tumors can also grow in the lung (bronchus), thymus and other organs such as the skin and the adrenal glands.

When the diagnosis is new, many patients struggle to cope with the disease. Much strength is needed to get along with personal and familial consequences. In this situation it can be difficult to think about participating in a nationwide database. Nevertheless, we would like to ask you if you could imagine to be registered at the German MEN1 database.

The German MEN1 database has been started in 1995. Many patients and families have been registered. The database helps to get an overview of affected patients in Germany and their medical care. It also helps to elaborate scientific questions related to this complex disease. Our aim is to improve the care of newly affected patients in the future. Maybe there is a possibility to detect individual health-related risk factors in patients at an early stage.

If you decide to take part and to be registered at the German MEN1 database, you have to give your informed consent that all of your medical records (letters, results of examinations such as CT, MRT, PET, blood tests etc.) will be given to us. Only the staff of the German MEN1 database responsible for the documentation will have access to all of your documents.

All data will be anonymized before entering our database. Instead of using your name we use a combination of figures and Roman letters. Therefore, only the staff of the German MEN1 database will be able to draw conclusions regarding the person and his/her data given to the database. The staff, of course, is bound by the obligation of medical confidentiality.

After your first registration it might only once be possible that we will contact you by mail, sending you a questionnaire and probably further information. Of course, the registration at the German MEN1 database is voluntary and you can withdraw your consent to participate at any time without giving any reason.

We would very much appreciate your decision to be registered at our database and to let us accompany you during the course of the disease.

If you have any questions, please do not hesitate to contact us or talk to your doctors.

You can contact us at:

If you do not have any further questions and want to participate, please complete and sign the enclosed informed consent (two copies). Please return one copy, as without this document we cannot use your data. The other copy is for you.

We would like to thank you very much. Without your help it would not be possible to gain new clinical insight in MEN1!

Yours sincerely

Informed consent

Register for MEN1 diseases

Name:

Date of birth:

Address:

I agree to participate in the above mentioned register. I agree that my medical records regarding my disease will be transferred to

All of my data given will be anonymized. The questionnaires and all personal data related to me will be kept separately from the disease-related data.

Only the staff bound by the obligation of medical confidentiality will have access to these data.

I can withdraw my consent to give my data to the register at any time. If I want to terminate my participation, all of my personal and disease-related data will be completely deleted.