

PATIENT INFORMATION



on the use of personal data entered in the German Adrenocortical Carcinoma Registry

Dear patient,

You have been diagnosed with an adrenocortical carcinoma (= malignant tumor of the adrenal glands). Since this is a very rare disease, therapeutic progress is made difficult.

The objective of the Adrenocortical Carcinoma Registry is to learn as much as possible about the course and success of different therapies in order to optimize treatment and increase the prospects of curing the disease in the long run. For this reason, data on diagnostics and therapies from patients with adrenocortical carcinoma is recorded nationwide. Your consent constitutes a precious contribution to optimizing the therapy of this rare disease.

Participation is, of course, **on a voluntary basis**.

BACKGROUND and STRUCTURE of the TUMOR REGISTRY

The adrenocortical carcinoma is a very rare disease. Every year, only one to two in one million inhabitants get this disease. Since data has not been collected systematically so far, this figure is, however, also not proven.

Due to the low number of cases of this disease, there are no globally uniform, undisputed therapies. The objective of this Registry is to collect any important data on diagnostics and therapy from as many patients as possible to draw conclusions on the prospects of success of the different treatment strategies. For this reason, data is centrally collected in one place. The German Adrenocortical Carcinoma Registry (German acronym: NKR) is organized by GANIMED (German Adrenal Network: Improving Medical research and EDucation). It is managed and run by the Department of Endocrinology in the University Hospital Wuerzburg. From an administrative point of view, it is affiliated to the Tumor Center of the University Hospital Wuerzburg.

PROCESS

Your data is entered in an appropriate questionnaire and transferred to the assessment center in Wuerzburg, where the data is stored in a relevant computer file. Further scientific assessment and interpretation are carried out anonymously.

In order to assess therapeutic success in the long run it is vital that data about your disease is recorded in the aftermath time and again. For this reason, and subject to your consent, further questionnaires will be completed over the course of time and transferred to the assessment center in Wuerzburg.

CONFIDENTIALITY

Data collected in connection with registration in the Adrenocortical Carcinoma Registry is only seen by scientific staff members who are all subject to professional secrecy. Personal information will be treated strictly confidentially and is subject to general data privacy regulations. Processing and/or transfer of data are always in anonymized form.

PATIENT CONSENT FORM

for the entry of personal data in the
German Adrenocortical Carcinoma Registry



Last name: _____

First name: _____

Date of birth: _____

After a detailed briefing and after reading the patient information, all pertinent questions have been answered. I agree with the storage and processing of my personal data for scientific purposes. I agree to the confidential collection of personal data in accordance with data privacy regulations.

If necessary and reasonable, I also agree that data – for the benefit of treatment and/or optimization of the process - is made available to experts in the relevant field.

Any person who can view personal data is aware of the fact that he/she is obliged to observe data secrecy.

It has been pointed out to me that this consent is voluntarily given and can be revoked any time by written or oral notice without giving reasons, and that this will not lead to any disadvantages whatsoever for me personally.

A copy of the Patient Information Sheet has been handed out to me.

City, date,

Patient's signature
or signature of legal guardian (parent)

City, date

Doctor's name (print)

Doctor's signature