

Informed Consent To Participate in the NPC-2016 Registry

Surname, first name

Date of birth

Agreement

I have been informed by the treating physician: _____ regarding the purpose, significance and procedure of the registry and the benefits and risks that can be associated with registering. All my questions have been answered to my satisfaction. I have had plenty of time to reconsider my decision to participate in the NPC-2016 Registry. I have read the "Information for Patients" form, one copy of this was handed to me.

1. Consent to the transmission, storage, and scientific evaluation of personal data.

I hereby, agree to the transmission, storage and scientific evaluation of my personal data or that of my child. I agree that an employee of the NPC-2016 Registry may inspect the original medical records and that medical records may be archived at the centres named in the Information Sheet. I agree that data relating to me or my child (including, but not limited to, disease data from medical records) may be stored in the study database under supervision of the institutions named in the Information Sheet, may be exchanged with cooperation partners and project leaders involved in the study and published in the form of study results in a pseudonymised form. Data (storage, transmission, modification and deletion) are electronically processed in compliance with the legal regulations on data protection. All parties who have insight into the stored data, are subject to maintain secrecy and confidentiality.

I hereby, consent to this procedure: Yes No

2. Consent to the collection and use of biomaterials for scientific research

I agree that my / my child's tumour, blood and pharyngeal washings are made available to the following cooperation partners for the research of rare malignant diseases:

Prof. Dr. med. Henri-Jacques Delecluse
Pathogenesis of infection-related tumours
German Cancer Research Centre (DKFZ)
Department of Tumour Virology
Im Neuenheimer Feld 242, D-69120 Heidelberg

Investigations on the significance of Epstein-Barr virus in the development of nasopharyngeal carcinoma:

Yes

No

Prof. Dr. med. Uta Behrends
Children's Hospital Munich Schwabing,
Klinikum rechts der Isar
Technical University of Munich and
Klinikum Schwabing of StKM GmbH,
Kölner Platz 1, D-80804 Munich

Investigations on the immunity to Epstein-Barr virus in patients with nasopharyngeal cancer:

Yes

No

Furthermore, the registry intends the collection and storage of organic materials in the Centralized Biomaterial Database of the medical faculty of RWTH Aachen University (short: RWTH cBMB) for future scientific research. Independent patient information and consent are available for this purpose ("RWTH cBMB patient information in preparation of verbal information by the attending physician and consent to the use of biomaterials for research purposes). I transfer ownership of the biomaterials to the Nasopharyngeal Carcinoma Registry of the Society for Paediatric Oncology and Haematology (GPOH) or to the RWTH Aachen University Medical School for samples that go to the RWTH cBMB.

I have been informed that I can withdraw my consent to the Nasopharyngeal Carcinoma Registry of the Society for Paediatric Oncology and Haematology (GPOH) at any time without giving any reason. Upon withdrawal, at my request, the remaining biomaterials and the data collected are destroyed, deleted or made anonymous. Data from already performed analyzes cannot be removed anymore.

I agree to this procedure: Yes No

I agree that I may be contacted again at a later date (please tick "no" if applicable)

- For the purpose of obtaining further information / biomaterials No
- For the purpose of providing feedback on health outcomes for me / my child No

This feedback should be given by the facility where my biomaterials / data were obtained or via the following doctor (if requested, please specify):

Name and address of the physician:
.....

3. Informing the family doctor about participating in the registry

I agree that my family doctor will be informed about participation in the NPC-2016 registry and about the course of therapy.

I agree to this procedure: Yes No

4. Information about the withdrawal of consent

I know that I can withdraw my consent at any time and without giving any reasons to the initially mentioned institutions. This does not affect any further medical treatment. The revocation leads to the immediate deletion of the data.

I have been informed about the option of withdrawing my consent:
 Yes No

I / we agree with all points ticked and confirm that I / we have had sufficient time to make a decision. I am / We are aware of the voluntary participation in the registry.

I / we want to receive a copy of the signed consent form for my / our documents. The original remains in the treating clinic:
 Yes No

Patient:

Name place, date, signature

Obligatory with at least 16-year-old or younger patients who have the capacity to understand the content

Guardians:

Sole guardian (s)

Name place, date, signature

Guardians:

Name place, date, signature

Physician responsible for informing the patient:

Name place, date, signature

Witness:

Name place, date, signature