

CPT-SIOP Registry Consent Form

Stamp / letterhead of treating institution

I, _____ willingly agree to participate / allow my child to participate in the international CPT-SIOP Registry, which has been explained to me by

Dr. _____ .

I have received and was given sufficient opportunity to discuss the corresponding written “Information for patients and patients’ families” about the participation in the international CPT-SIOP Registry and my questions regarding the registry have been answered.

The CPT-SIOP Registry is a study that aims to increase our knowledge about tumors of the choroid plexus. To improve treatment results medical information from individual patients will be collected, interpreted and analyzed in a database. Personal information such as name, date of birth and city of treatment will be transferred to the registry office in Hamburg. The German study office may communicate pseudonymized data (see below) to the international CPT study office in Boston.

Participation in this registry is voluntary and may be withdrawn at any time without medical care being affected. There is no financial compensation for enrolling in this registry.

My signature on this form indicates that I have understood to my satisfaction the information regarding my / my child’s participation in this registry and that I agree to participate / to my child’s participation.

<p>CPT-SIOP Registry German Study Office Dr. Uwe Kordes Klinik und Poliklinik für Pädiatrische Hämatologie und Onkologie Universitätsklinikum Hamburg-Eppendorf Martinistraße 52 20246 Hamburg</p> <p>tel 040 7410 57697 fax 040 7410 57544 email cpt@uke.de url www.uke.de/cpt</p>	<p>CPT-SIOP Registry International Study Office Prof. Johannes Wolff Chief, Division of Pediatric Hematology/Oncology; Director, Floating Children's Cancer Center at Tufts Medical Center 755 Washington Street Boston, MA 02111 USA</p> <p>tel 001 617-636-5535 fax 001 617-636-7738 email jwolff@tuftsmedicalcenter.org url www.choroidplexustumors.com</p>
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In case of a relocation of the German study office within the German Society for Pediatric Hematology and Oncology (GPOH), data will be transferred to the new office. If the national principal investigator (director of the study) resigns, he will hand over the study data to the succeeding principal investigator and / or to the GPOH.

Data analysis and processing within the German Brain Tumor Network also contributes to quality assurance of clinical diagnostics and therapy. Therefore data and, if necessary, biological material may be transferred to the following institutions:

- For patients registered in Germany: German Childhood Cancer Registry (Deutsches Kinderkrebsregister, director: Dr. Peter Kaatsch) at the Institut für Medizinische Biometrie, Epidemiologie und Informatik, 55101 Mainz
- For patients registered in Germany: cancer registries of the federal states (Bundesländer)
- Institute of Neuropathology, University Hospital Münster (Prof. Martin Hasselblatt), 48149 Münster and / or Brain Tumor Reference Center, Institute of Neuropathology, University Hospital Bonn (Prof. Torsten Pietsch), 53105 Bonn
- Department of Neuroradiology, University Hospital Würzburg (Prof. Monika Warmuth-Metz), 97080 Würzburg
- Clinic for Radiation Therapy and Radiooncology, University Hospital Leipzig (Prof. Rolf-Dieter Kortmann), 04103 Leipzig

Privacy Rules – What happens to your personal data?

All personal data obtained for the CPT-SIOP Registry, including diagnostic findings, are subject to medical confidentiality and data protection legislation. They will be transferred –without encryption– to the German Study Office at the University Hospital Hamburg-Eppendorf, to the pathology and radiology reference centers of the CPT-SIOP Registry in Münster, Bonn and Würzburg (see above), respectively, and, in case of patients within Germany, to the German Childhood Cancer Registry and to the cancer registry of the respective Bundesland. They will be recorded in paper form and on electronic media and pseudonymized (pseudonymization replaces personal data (such as name and other recordings that can be allocated to a specific person) with a number code, allowing allocation only by authorized persons). Use and analysis of the data will occur only after pseudonymization. This is also true for the passing on, if any, of the data for research purposes to further institutions and for the publication of research results.

You are entitled to request particulars about your / your child's personal data stored in the CPT-SIOP Registry. You also have the right to be either notified, or exclude such notification, about possible results within the study regarding your own / your child's personal data. If necessary, the principal investigator (director) of the Registry will ask you for your decision on that.

The data recordings are kept for at least 10 years; if possible, even longer. This is especially important for childhood cancers to allow a long-term follow-up in order to get more knowledge about long-term consequences for health state and quality of life of affected individuals.

If you change your mind later, this would be no problem. Upon withdrawal of your consent your / your child's personal data collected so far will be either deleted or anonymized (the allocation code will be destroyed and the data set will be changed in such a way that allocation is no longer possible at all or only with an unreasonably high effort.)

Furthermore, tumor tissue will be sent to the neuropathology institutes of the University Hospital Münster and / or Bonn. There it will be analyzed and put in storage to be of help in answering scientific questions about this tumor type in the future.

