

Declaration of consent for the transfer and processing of personal medical records and examination material

in accordance with the General Data Protection Regulation of the European Union

Patient _____ Date of birth: _____

I am aware that personal data, in particular medical findings about me / my child will be collected, stored and evaluated for the purpose of this registry. The data is used according to legal regulations and follows a voluntarily submitted informed consent form. This means that without the following consent I / my child cannot participate in the registry.

I agree as a patient / legal representative (see consent to study participation) that my / my daughter / son's personal data, in particular information about my health / my child's health and my ethnic / ethnic origin of my child may be collected and recorded on paper and on electronic data carriers at the registry's center.

Head of Registry

Prof. Dr. med. U. Kontrny
Division of Paediatric Haematology, Oncology and Stem Cell Transplantation
Department of Paediatrics
University Hospital RWTH Aachen University
Pauwelsstr. 30, D-52074 Aachen

For the purpose of reference evaluation and consultation, the data may be passed on to other institutions as described in the Information for Patients sheet.

Radiology Reference Centre

Prof. Dr. med. G. Staatz
Division of Paediatric Radiology
Clinic and Polyclinic for Diagnostic and Interventional Radiology
University Medical Centre Mainz
Langenbeckstr. 1, D-55131 Mainz

Pathology Reference Centre

Prof. Dr. med. Christian Vokuhl
Institute of Pathology, Division of Pediatric Pathology, University Medical Centre Bonn,
Venusberg-Campus 1, Building 62, Room 116, D-53127 Bonn
Nuclear Medicine Reference Centre

Prof. Dr. med. Felix M. Mottaghy
University Hospital RWTH Aachen University
Nuclear Medicine Clinic
Pauwelsstr. 30, 52074 D-Aachen

Radiotherapy Reference Centres

Prof. Dr. med. Hans Christiansen
Hannover Medical School
Radiotherapy and special oncology
Carl-Neuberg-Str. 1, D-30625 Hannover

Prof. Dr. em. med. Günther Gademann
University Hospital Magdeburg
Leipziger Str. 44, D-39210 Magdeburg

Prof. Dr. med. Michael Eble
Department of Radiation Oncology and Radiotherapy
University Hospital RWTH Aachen University
Pauwelsstr. 30, D-52074 Aachen

Prof. Dr. med. B. Timmermann
Clinic for particle therapy
University Hospital Essen
Hufelandstraße 55, D-45147 Essen

Head and Neck Surgery Reference Centre

Prof. Dr. med. Jens Peter Klußmann
Department of Otorhinolaryngology, Building 23
Kerpener Str. 62, D-50937 Köln

EBV Diagnostics Reference Centre

Dr. rer. nat. Dipl.-Biol. W. Puppe
Hannover Medical School
Institute of Virology
Carl-Neuberg-Str. 1, D-30625 Hannover

EBV-specific T cells Reference Centre

Prof. Dr. med. Tobias Feuchtinger
Dr. von Haunersches Kinderspital
Hospital of the University of Munich
Lindwurmstr. 2a, D-80337 Munich

Analysis of DPD Exon 14 Skipping Mutation

Prof. Dr. Ingo Kurth
Institut für Humangenetik
Uniklinik RWTH Aachen
Pauwelsstr. 30, D-52074 Aachen

German Children's Cancer Registry (only for patients in Germany)

PD Dr. P. Kaatsch
Institute of Medical Biometry, Epidemiology and Computer Science (IMBEI)
University Medical Centre Mainz
D-55101 Mainz

Late Effects Surveillance System, LESS- Working Group

Prof. Dr. med. Thorsten Langer
University Hospital Schleswig-Holstein, Campus Lübeck
Department of Paediatrics, Paediatric Oncology and Haematology
Ratzeburger Allee 160, D-23538 Lübeck

Quality of life and long-term follow-up study (Lebensqualität und Spätfolgenstudie PEDQOL)

Dr. med. Gabriele Calaminus
Department of Paediatric Haematology and Oncology
University Hospital Bonn, Adenauerallee 119, D-53113 Bonn

Furthermore, as far as necessary, the collected data or the data together with the biomaterials of my / our child may be pseudonymised (encrypted) and forwarded to the following cooperation partners:

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

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 immunity to Epstein-Barr virus in patients with nasopharyngeal carcinoma

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

Centralized Biomaterial Database of the Faculty of Medicine of the RWTH Aachen University (separate patient information and consent)

Furthermore, as far as necessary, the collected data may be passed on pseudonymised (encrypted):

- to the competent supervisory authorities (regional authority or district government) to verify the proper functioning of the registry,
- to the responsible ethics committee.

In accordance with the General Data Protection Regulation (GDPR) of the European Union I have been informed about my rights on information, correction, restriction of processing and data transferability.

I have been informed that I can stop participating in the study at any time. By revoking my consent to participate in the study, I have the right to request the deletion of all my personal data previously stored (Article 17 & 19 GDPR). By revoking my consent to participate in the study, I may decide whether my previously stored personal data may be erased or used in anonymous form for further scientific purposes. Anonymization

means that the identification code is deleted, which can be used to determine from which person the sample originated.

In order to withdraw your consent for the study, please contact: Prof. Dr. med. Udo Kontny, Division of Paediatric Haematology, Oncology and Stem Cell Transplantation, Department of Paediatric and Adolescent Medicine, University Hospital RWTH Aachen, Pauwelsstr. 30, D-52074 Aachen

Likewise, if revoked, I can decide whether the biomaterials should be destroyed or used anonymously for further scientific purposes. Anonymization means that the identification code is deleted, which can be used to determine from which person the sample originated. However such anonymization of your biomaterials / biomaterials of your child cannot completely rule out later matching of genetic material to yourself / your child by other entities. Once the connection between the biomaterials and other data on your person / child has been deleted (anonymization), destruction is no longer possible. In addition, data from previous analyses can no longer be removed.

In order to withdraw your consent, please contact: Prof. Dr. med. Udo Kontny, Division of Paediatric Haematology, Oncology and Stem Cell Transplantation, Department of Paediatric and Adolescent Medicine, University Hospital RWTH Aachen, Pauwelsstr. 30, D-52074 Aachen

I agree that my data will be retained for at least ten years after the registry is terminated or cancelled. Thereafter, my personal data will be deleted, unless legal, statutory or contractual retention periods apply.

Copies of Informed Consent and Information for Patients Sheet were provided.

Patient:

Name (please print)

(Place, date, signature)

Obligatory with a patient over 16 years or younger patients who have the capacity to understand the content

Guardians:

Sole guardian (s)

Name (please print)

(Place, date, signature)

Guardians:

Name (please print)

(Place, date, signature)

Physician responsible for informing the patient:

Name (please print)

(Place, date, signature)

Witness:

Name (please print)

(Place, date, signature)

Date when the patient was informed: _____