



UNIVERSITÄTS
KLINIKUM
HEIDELBERG

Genetische Poliklinik | Im Neuenheimer Feld 440 | 69120 Heidelberg

Institut für Humangenetik

Prof. Dr. med. Christian Schaaf
Ärztlicher Direktor

Genetische Poliklinik

Leitung: Prof. Dr. med. Maja Hempel

Im Neuenheimer Feld 440

D-69120 Heidelberg

☎ +49 (0)6221 56-5087

📠 +49 (0)6221-56-5080

sprechstunde.genetik@med.uni-heidelberg.de

www.med.uni-heidelberg.de/humangenetik

Creation and Evaluation of a Registry of Patients with Dup15q Syndrome

Consent Form for Parents/Legal Guardians

We have been informed in a detailed and understandable manner about the purpose and procedure of the study, as well as the associated risks (see study information). We have received and read the written information for participants. During the information session, we had the opportunity to ask questions. We have received satisfactory answers to all our questions. We voluntarily agree to participate in the study on behalf of our child or ward. We are aware that participation in the study is free of charge for us, that we will not receive any remuneration, and that we are not entitled to any compensation. We have been given sufficient time to make our decision.

Data protection

We are aware that personal data will be processed as part of this study. Data processing is carried out in accordance with legal regulations and requires the following declaration of consent in accordance with Article 6 A. 1 (a) of the General Data Protection Regulation: We have been informed and voluntarily agree that data of the index patient collected in the study, in particular information relating health, genetic data, and biometric data, may be recorded and evaluated in pseudonymized form for the purposes described in the study information and, if necessary, shared in pseudonymized form with external universities/clinics. As part of this study, pseudonymized data might also be shared with third countries outside the EU and the European Economic Area for analysis purposes. These are countries for which the European Commission has determined an adequate legal level of data protection. No third parties will have access to the personal documents. The name of the index patient will not be mentioned when the study results are published. Personal data will be pseudonymized as soon as possible for the purposes of the research. The data will be stored indefinitely after the study has ended. We are aware that this consent can be revoked at any time, in writing or verbally, without giving any reason and without any inconvenience to us. This does not affect the legality of the data processing carried out until revocation. In this case, we can decide whether the collected data should be deleted or whether it can continue to be used for the purposes of the study. We are aware that subsequent deletion of anonymized data is no longer possible.

- ☐ We agree to be contacted for future research purposes (e.g., therapy studies) via the following email address *(Please check the box if you wish.)*:

Email _____

- ☐ The data we enter into the registry may be shared in pseudonymized form with external research institutions for other research purposes. *(Please check the box if you wish.)*

- ☐ We would like to limit the use of our data for other/future research purposes as follows:

- ☐ We agree to the sharing of the index patients' medical reports and findings (e.g., molecular genetic diagnostics, EEG, MRI) for the registry. In this case, we allow that relevant data from these reports could be entered into the study database in pseudonymized form *(Please check the box if you wish.)*

Place, date

Last name, first name of parents/legal representatives

Signature

Signature

Oral information (to be completed by the person providing the information): Person providing the information

I have informed the patient's parents (or legal representatives, if applicable) during a discussion about the purpose and conduct of the study, as well as the risks. I have given a copy of the study information and the consent form to the patient's parents/legal representatives.

Place, Date

Name, first name of the person providing the information

Signature

