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Creation and Evaluation of a Registry of Patients with Dup15q Syndrome

Consent Form for Parents/Legal Guardians

I 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). I have received and read the written information for participants. During the information session, I had the opportunity to ask questions. I have received satisfactory answers to all my questions. I voluntarily agree to participate in the study. I am aware that participation in the study is free of charge for me, that I will not receive any remuneration, and that I am not entitled to any compensation. I have been given sufficient time to make my decision.

Data protection
I am 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: I have been informed and voluntarily agree that data is 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. My name 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. I am aware that this consent can be revoked at any time, in writing or verbally, without giving any reason and without any inconvenience to me. This does not affect the legality of the data processing carried out until revocation. In this case, I can decide whether the collected data should be deleted or whether it can continue to be used for the purposes of the study. I am aware that subsequent deletion of anonymized data is no longer possible.

☐ I 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 I 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.)*

☐ I would like to limit the use of my data for other/future research purposes as follows:

_____

☐ I agree to the sharing of my medical reports and findings (e.g., molecular genetic diagnostics, EEG, MRI) for the registry. In this case, I 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 patient

_____
Signature

Oral information (to be completed by the person providing the information): Person providing the information
I have informed the patient 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.

_____ _____
Place, Date Name, first name of the person providing the information

_____
Signature