

Scientific study about EEG and epilepsy in Dup15q syndrome

Dear parents,

We would warmly welcome you to participate in our study about epilepsy in children with Dup15q syndrome. The study aims to better understand the EEG and epilepsy characteristics of the affected children. To achieve this, we combine existing data from the **Dup15q registry** with the **EEG recordings**. One focus of the study is the detailed characterization of an EEG feature that has already been described in scientific reports. This feature may help improve the diagnosis and treatment of children with Dup15q syndrome.

Process of participation

If possible, we kindly ask you to send us all the EEG recordings that have been performed for your child. We only require the EEG recording data of the EEG channels (raw EEG data), the written EEG reports are not needed. If you are able to provide all available EEG recordings, this will allow us to examine changes in the EEG over time and across different age groups.

- You can request the EEG data directly from your child's physician or treating clinic.
- The data can be sent to us either via upload or on a CD/DVD/USB-stick (a return envelope is enclosed for your convenience).
- Preferred data formats include **.edf** or **.bdf**. EEG data can be exported using all commonly used EEG softwares.
- Please include your child's name and date of birth with the data to help us correctly match the recordings.

Upload: If you choose to upload the data, it would be very helpful if you could bundle all the EEG recordings of your child into a single folder in advance. Please name this folder using your child's name and date of birth (e.g. John_Smith_01.01.2000). If possible, we would greatly appreciate it if you could name the individual recordings according to the date of recording so we can comprehend the progression over time. Upload link:

<https://heibox.uni-heidelberg.de/u/d/5221728dad7a4d5eb6e5/>

Mailing address:

Please send the data carriers to the following address:

Universitätsklinikum Heidelberg
Zentrum für Kinder- und Jugendmedizin
Sektion pädiatrische Epileptologie
Epilepsiediagnostik K1 Neurologie
Dup15q Projekt
Im Neuenheimer Feld 430
69120 Heidelberg
Germany

Im Neuenheimer Feld 430
69120 Heidelberg
Luna.zawadzki@
med.uni-heidelberg.de
www.klinikum.uni-
heidelberg.de

Data protection

All collected data will be handled confidentially, stored under a pseudonym and used exclusively for scientific purposes of this study. Participation is entirely voluntary. You may withdraw your consent at any time without negative consequences.

We understand that obtaining EEG data can be time-consuming while managing everyday life. However, the effort made by you and your child's physician is very important for advancing research on Dup15q syndrome and may help make a meaningful difference in the future. We sincerely appreciate your support and participation!

Please feel free to contact me at any time if you have questions or would like further information (luna.zawadzki@med.uni-heidelberg.de).

Kind regards,

A blue ink signature of Luna Zawadzki, consisting of stylized initials and a surname.

Luna Zawadzki
Medical doctoral student

A blue ink signature of Dr. med. Jan Henje Driedger, featuring a large, flowing initial 'J' followed by the surname.

Dr. med. Jan Henje Driedger
Consultant Pediatric Neurologist