

Requesting Raw EEG Data in Electronic EDF Format

Below are some steps on how to collect your EEG data for upcoming or past appointments.

Create a CRID Number: To participate in research such as an EEG study, the disease registry or the biobank, we are requesting that you create a clinical research ID number so that we can use this number, instead of your name. Go to www.TheCRID.org and create a number for your child and save it in a safe place. (We will ask for this number in our Registry and other studies.)

For Upcoming EEG or Sleep Study Appointments

If you have a future EEG or sleep study scheduled, at the time of the test or when you are scheduling your appointment, tell them you'll be requesting a copy of the report AND the raw EEG data in electronic EDF format. They may suggest you bring a 64 GB [flash drive](#).

Step 1: Ahead of your appointment, download and fill out the facilities *Release of Medical Information Form* and take it with you, they may not have one readily available to sign. Consider taking a blank flash drive with you, label it with your child's name and DOB.

Step 2: When you check-in for your appointment, provide the Release form and ask if you could leave with a copy of today's EEG, and past EEGs. Remind them you are asking for the report you and a "copy of the raw EEG data in electronic **EDF** format". They may not be able to share for 24 hours until the MD writes a report. If you brought a blank 64 flash drive, let them know you have that as well.

Step 3: Upon receiving the EEGs, notify the Foundation that you have a copy.

For Past EEG or Sleep Studies

Step 1: Go to facility/hospital website and download the *Release of Medical Information Form*. Fill it out.

Step 2: Contact either the EEG lab or Sleep lab directly (depending on where you had your test) and tell them you'd like to get copies of your child's past EEGs. It is highly likely that the Medical Records Department will NOT be able to help you.

They will likely require a written request, so send the following letter to the EEG lab, addressed to the Chief Technician:

Subject: Request for raw EEG data in electronic, EDF format

Please mail my child's [insert first and last name and date of birth] EEG reports and RAW DATA IN ELECTRONIC FORMAT (EDF format) from studies performed on the following date(s): _____ and _____ to _____ [Your Name and Address]. I can be reached at [phone] or [email] if you have any questions.

We can provide an alternative mailing address if you'd like. (Email us.)

Note: If the facility charges you a fee, please keep your receipt because we may be able to reimburse you.

Step 3: Notify the Foundation that you have your EEG data. Hold onto your EEG data for future use.