



## CONNECT CDKL5 INTERNATIONAL REGISTRY

**Connect CDKL5** is an international patient database. It is a way for patients with CDKL5 Deficiency (CDD) and their caretakers to learn about research opportunities while sharing crucial information with the world community. Your information will help answer urgent CDD questions such as incidence (risk of having a child with CDKL5), prevalence (how many people are currently living with CDKL5), and Genotype-Phenotype relationships (known variants and associated CDD disease severity) found in CDD. Participation is completely voluntary, and you may choose to have your information removed at any time. There is no cost to join this database and your information will never be sold.

When you join Connect CDKL5 you agree to let us contact you. We may contact you about:

- Opportunities to participate in studies that may lead to improved care and outcomes for CDKL5
- Updating information that you have already entered
- Providing more information

Connect CDKL5 will let you share your information and keep you informed

- You can choose to share your information directly with study doctors, research staff and patient organizations (PAGs).
- Your information will be stored in our secure database and kept confidential to the extent permitted by law.
- Receive news about new or ongoing CDKL5 studies
- Receive information about your disease
- Receive information on activities from patient advocacy groups
- Have a chance to be contacted directly by researchers to join studies

We may send you information about:

- New and ongoing research studies
- Clinical centers where you may be able to participate in studies
- What is being learned from studies
- Other announcements and activities

You may decide now or later that you do not want to share your information with the Connect CDKL5 database and International Foundation for CDKL5 Research (IFCR). If so, contact the IFCR, and they will remove your information from the database. However, IFCR cannot take back information that was shared before you changed your mind. Email [connect@CDKL5.com](mailto:connect@CDKL5.com) to remove your data.

View our full privacy policy here: <https://www.cdkl5.com/privacy-statement/>