

We are happy to meet you.

Welcome to our CDKL5 community

By Karen Utley, IFCR President

Hello! Please accept my warmest welcome to our CDKL5 community. I have been in your shoes as a newly diagnosed family, and I understand that this diagnosis can bring a world of uncertainty, questions, or fears. **Please know that you are not alone on this journey.** I'd like to share a few things you should know about CDKL5.

- 1) The **International Foundation for CDKL5 Research (IFCR) is here to support you.** Our organization was started with one goal in mind - to make a healthier future for our children. Incredible progress has been made since we began in 2009.
- 2) No one can tell you what the future holds for your child. While there are common symptoms that our children experience, **no two children with CDKL5 Deficiency Disorder are exactly alike - even those with the same genetic change.** Your child will write their own story.
- 3) CDKL5 research is thriving and **you can take an active role in furthering CDKL5 research, if you wish.** An easy place to start is to "[Connect CDKL5](#)." Let us know who you are, and we will do our best to share opportunities to get involved.

Please sign up for our [newsletter](#) and follow us on social media to stay connected. Email me (kutley@cdkl5.com) with any questions, comments, or concerns. I would love to communicate with you!

In Hope,
Karen (Mom to Samantha)

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