OUR MISSION

To treat and cure CDKL5 Deficiency Disorder by funding scientific research, while helping affected individuals and their families to thrive.

The IFCR is committed to funding research, both scientific and clinical, that will bring about treatments and, ultimately, a cure for CDKL5. We strive to raise awareness of this rare disorder within the medical and lay communities.

Above all, we seek to support all CDKL5 families and caregivers, whether newly diagnosed or well into adulthood, by providing the most current information on treatment advances and how to live their best life possible.

HOPE | LOVE | CURE

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GIVE THE GIFT OF HOPE

IFCR

International Foundation for CDKL5 Research

CDKL5.COM

WHAT IS CDD?

CDKL5 Deficiency Disorder (CDD) is a rare developmental and epileptic encephalopathy caused by mutations on the CDKL5 gene.

CDD manifests in a broad range of clinical symptoms and severity. The hallmarks are early-onset, intractable epilepsy and neurodevelopmental disability impacting cognitive, motor, speech, and visual function.

Although rare, the occurrence of CDD is believed to be approximately 1:40,000 - 75,000 live births, making it one of the most common forms of genetic epilepsy.

"We feel strongly that a **unified global effort** will be necessary to reach a cure and the IFCR plays a **key role** in that effort."
-Martha, Mom to Elsah

HELP OUR FAMILIES

We are the leading patient advocacy organization for CDD.

Our Board of Directors is made up of passionate and dedicated CDKL5 parent volunteers.

Our work is funded by generous donations from our CDKL5 families and their networks. *It's not easy to fundraise while at the same time caring for a medically complex child.*

Our families need help.

Our CDKL5 families depend on us, can we depend on you?

ABOUT US

The International Foundation for CDKL5 Research (IFCR) is a non-profit organization led by parent volunteers. Our children have CDKL5 Deficiency Disorder (CDD) and we are on a mission to treat and cure this rare disease.

Since we began in 2009, we have funded ground-breaking research and worked hard to support our patient population. We have established Centers of Excellence across the United States where families can access CDKL5 specific care. We also have a comprehensive resource library available on our website.

DONATE AT CDKL5.COM