CDKL5 DEFICIENCY DISORDER AWARENESS PACKET

June is CDKL5 awareness month and the IFCR wants to make sure you have all you need to spread awareness of CDKL5 Deficiency Disorder.

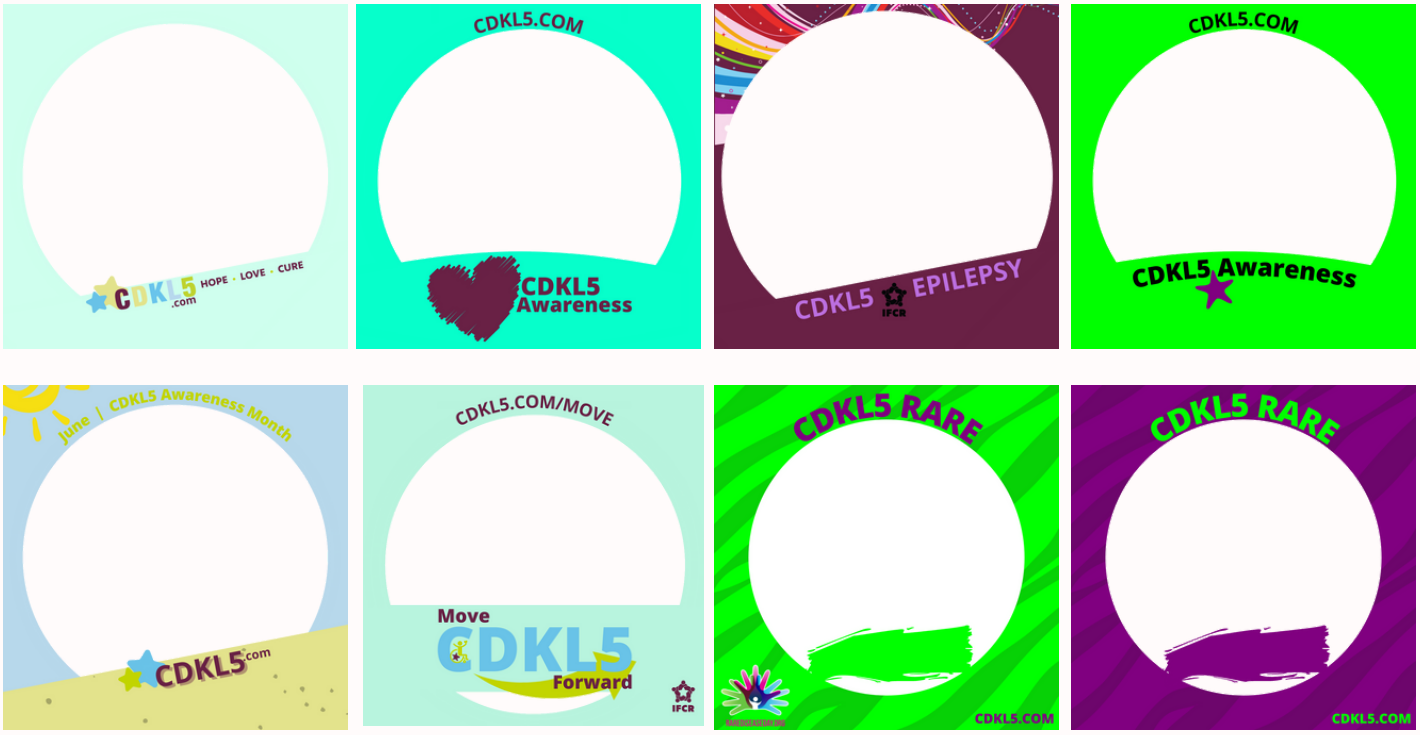
Thank you for sharing about CDKL5!

HOPE • LOVE • CURE

IFCR
International Foundation for CDKL5 Research

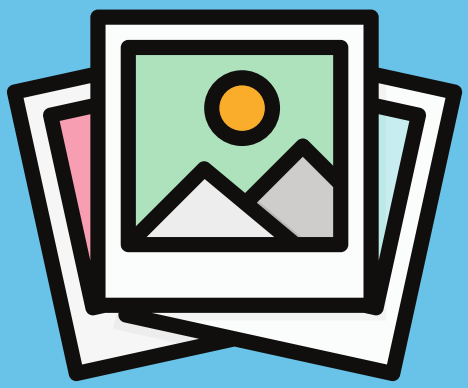
Awareness Month Profile Frames

Click the image and update your profile picture with one of our frames to spread CDKL5 awareness with your followers!



Social Media Downloads

Click the icon and download these sharable images to spread CDKL5 awareness on your social media channels.



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Media Toolkit

Interested in sharing your CDKL5 story with your local media? Check out our "**Media Toolkit**" for helpful information.

Proclamation

Work with your local government to issue a proclamation for CDKL5. June 17th is World CDKL5 Day. **Learn Move**

IFCR Talking Points

We'd love to help you share about our organization and the important work we do for CDKL5. See these "**Talking Points**" for info.

Social Media

Be sure to use hashtags when posting on social media. And don't just post once - post often! Please tag the IFCR for reshare!

#CDKL5
#CDKL5Awareness
#CDKL5Forward
#HopeLoveCure
#StarfishStrong

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What is CDKL5 Deficiency Disorder?

CDKL5 Deficiency Disorder (CDD) is a rare developmental & epileptic encephalopathy caused by changes to a gene called CDKL5.

The CDKL5 gene provides instructions for making proteins that are essential for normal brain and neuron development.

Changes to the gene cause both epileptic activity as well as severe impairment of development. Hallmarks of CDD are the onset of seizures at a very early age and severe neurodevelopmental disability impacting cognitive, motor, speech, and visual function.

There is a spectrum of severity and not all symptoms listed here are experienced by all who are diagnosed.

Learn more about CDD and the work being done to treat and cure this rare disease at CDKL5.COM.

Symptoms

- Seizures starting early in life
  - Epileptic spasms often occurring without hypsarrhythmia
  - Multiple different types of seizures
- Poor muscle tone (hypotonia)
- Cortical Visual Impairment (CVI)
- Gastrointestinal Difficulties
  - Constipation
  - Reflux
- Sleep difficulties
- Limited ability to walk
- Inability to speak but may use complex gestures/vocalization
- Limited hand skills
- Purposeless hand movements (stereotypies)
- Teeth-grinding (bruxism)
- Intellectual disability
- Breathing irregularities (such as hyperventilation)
- Respiratory infections
- Scoliosis
- Behavioral symptoms such as anxiety and social avoidance

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