

CDKL5 REGISTRY PROGRESS



"Given the heterogeneity of the seizures and the trajectory of the patients and their natural history, it creates, I believe, a real opportunity for people to work together and share data"

Dr. Femida Gwady-Sridhar, CEO and Founder of Pulse Inf FRAME



DEVELOPMENT

The **CDKL5 Registry** was developed by the **Loulou Foundation** and **Orphan Disease Center** at the University of Pennsylvania to collect data for research and therapeutic development, and help caregivers track their loved one's symptoms

PLATFORM

Pulse Inf FRAME provides a secure, data privacy compliant, centralized, evidence-generating platform which meets regulatory requirements for clinical data

PROGRESS

- Multiple pharmaceutical companies working to develop treatments for CDD
- Support and alignment with a multi-center NIH-funded research study to develop clinical outcome measures specifically suited for CDD
- CDKL5 Registry is now available in English, French, German, Italian and Spanish

WHAT'S NEXT?

The launch of the CDKL5 Registry in additional languages including Arabic, Chinese, Russian and Japanese

LEARN MORE

CDKL5 Registry:
www.cdkl5registry.org/

Pulse Inf FRAME:
www.pulseinf FRAME.com/