

The KCNT1 Epilepsy Foundation and NORD® Launch Global KCNT1 Registry

The global registry invites families to contribute critical data that may accelerate research and improve care for KCNT1-related conditions.

SCOTTSDALE, AZ, UNITED STATES, April 30, 2026 /EINPresswire.com/ -- The [KCNT1 Epilepsy Foundation](#) in partnership with the National Organization for Rare Disorders (NORD®), has launched the KCNT1 International Registry, a global research initiative focused on individuals with genetic changes in the KCNT1 gene. The gene variants can be associated with a range of outcomes, from mild to severe, including early-onset epilepsy and developmental challenges. Currently, there is no cure for conditions linked to KCNT1 mutations.

The KCNT1 International Registry provides a platform for individuals and families around the world to share their experiences and contribute critical information. This information will support clinicians, researchers and regulators in advancing drug development, improving treatment options and inform standards of care. "The KCNT1 International Registry will provide a complete picture of each patient's experience with a spectrum of symptoms from mild to severe KCNT1-related epilepsy and associated conditions," said Sarah Drislane, Executive Director of the KCNT1 Epilepsy Foundation.

Participants may enter their information securely through the IAMRARE® platform from anywhere in the world. The registry is open to individuals with a known KCNT1 gene variant, regardless of whether they experience symptoms. All data is securely stored, with access granted



KCNT1 EPILEPSY
HOPE IS ON THE HORIZON

Logo of the KCNT1 Epilepsy Foundation, a nonprofit supporting research and families worldwide



KCNT1
INTERNATIONAL
REGISTRY
Building Knowledge One Piece at a Time
NORD® IAMRARE® Platform

KCNT1 International Registry

to approved researchers to support collaborative efforts in KCNT1-related science and care.
Reach out with questions: kcnt1_registry@Kcnt1epilepsy.org

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