

UNITY



Our mission is to educate and to advance research leading to treatments or a cure for patients living with the genetic disorder KCNQ2.

The Alliance raises awareness and improves diagnosis of KCNQ2, educates families and medical professionals about the disease and advances research for improved treatments.

We rely on donations from individuals, businesses, and philanthropic foundations to support our work. Donations are tax-deductible.
(EIN # 47-1810644)

Started by parents of children suffering from KCNQ2 epilepsy, KCNQ2 Cure Alliance is 100% volunteer run.



"KCNQ2 Encephalopathy

is a severe epilepsy and developmental disorder beginning in the newborn period. While epilepsy may settle in infancy, the child's development may often be very impaired. Other co-morbidities can occur such as autism spectrum disorder. Research and collaboration are the way forward to improve the lives of children and their families living with KCNQ2 Encephalopathy. "

Professor Ingrid Scheffer, University of Melbourne

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 [KCNQ2 EPILEPSY PARENT GROUP](https://www.facebook.com/KCNQ2EpilepsyParentGroup)
KCNQ2 CURE ALLIANCE



CURE

 **KCNQ2
Cure**
unity. hope. strength. love.

*Decoding
KCNQ2 Epilepsy
and bringing
families together.*



HOPE, LOVE & COURAGE



Research efforts: We have supported mouse models with Jackson Labs, cell lines with Pairnomix and investigational research on the interaction of sodium and potassium channels.

Partnering: We participate at the American Epilepsy Society annual meeting, and work with Global Genes, NORD, REN, and other organizations dedicated to rare diseases.

Fundraising Events: KCNQ2 Cure conducts fundraising events through the year to support research, education, and our annual summit. Contact us to learn how to help.

International Conferences: KCNQ2 Cure Alliance Summit provides families and professionals with an opportunity to meet and learn about scientific and treatment advances.

Regional Family Gatherings: KCNQ2 Cure supports small regional meetings for families to network, share resources and receive support.

International Registry: The purpose of the registry is to develop a comprehensive openly accessible database of individuals with KCNQ2 in order to better understand the disorder and determine areas that need further research.

What is KCNQ2 Encephalopathy (KCNQ2E)?

KCNQ2E typically presents with seizures in the first week of life. Seizures appear as stiffening of the body (tonic) often associated with jerking and changes in breathing or heart rate. The seizures are usually quite frequent (many per day) and often difficult to treat. Typically, the seizures are associated with abnormal brain wave patterns on an EEG during this time.

The seizures in KCNQ2E often resolve within months to years but children have some degree of developmental impairment involving one or more domains (motor, social, language, cognition). This can range from mild to severe, depending on a number of different factors. Some children may also have autistic features.

Also known as

- ➡ KCNQ2-Related Neonatal Epileptic Encephalopathy
- ➡ Early infantile epileptic encephalopathy 7 (EIEE7)

KCNQ2 Cure provides support to families during difficult times that require emotional support. We hope to help family feelings of stress and isolation by providing connection and assistance to families at a critical time.