Register with RIKEE

New patient database will advance research

A project called the Rational Intervention for KCNQ2 Epileptic Encephalopathy (or RIKEE) has been created by Dr. Ed Cooper at the Baylor College of Medicine in Houston. It is a collaboration by scientists and doctors to grow understanding and introduce effective treatments for epilepsy and developmental impairments caused by a deficiency in KCNQ2, or Q2.

You can help by registering your child. Talk to your pediatric neurologist or visit … www.KCNQ2.org > Take Action

www.KCNQ2.org Sign up for our e-newsletter

The Jack Pribaz Foundation
P.O.Box 813
Wheaton, Illinois
60187 USA
t. 708-308-1440

Stay connected. Share your story.

KCNQ2 Parent Group

kcnq2.org

Resources for patients and families living with KCNQ2-related epilepsy

KCNQ2 & YOU

Together in search for a cure for KCNQ2-related epilepsy.

www.KCNQ2.org

YOU are not alone

Meet our friends and read their stories at **www.KCNQ2.org**

There is a growing community of families whose children have received a diagnosis of KCNQ2-related epilepsy, Although uncommon, the recognition of this diagnosis is increasing now that genetic testing is available. Researchers are turning their attention to this condition because they believe that what they learn about it will be a pivotal step towards understanding epilepsy in general.

"That was the best feeling: that we weren't alone anymore."
--Liz Pribaz

What is KCNQ2?

KCNQ2 is a gene involved in the proper functioning of potassium channels in neurons (nerve cells) in the brain. Abnormal changes, or mutations, in the gene are associated with seizures. KCNQ2-related epilepsies represent a spectrum of conditions from mild to severe.

Babies diagnosed with "Benign Familial Neonatal Epilepsy" or BFNE have seizures that begin shortly after birth and then stop within several months. Development is usually normal. BFNE may run in families.

Different, non-inherited mutations in KCNQ2 have been associated with a severe form of neonatal epilepsy.

This emerging condition has several names: KCNQ2-related neonatal epileptic encephalopathy, KCNQ2-deficiency syndrome, and KCNQ2-related epilepsy. As new patients are diagnosed, doctors are finding a spectrum of clinical outcomes that includes developmental problems.

Research plans are underway for clinical trials to find the best and safest treatments for KCNQ2-related epilepsy. In the meantime, seizure control and intensive therapy are essential to achieve the best outcome possible.

Visit www.KCNQ2.org for more ways to help your child.