KCNQ2-related Epilepsy and Developmental Disorders
The RIKEE Network Patient Registry

What is KCNQ2-related epilepsy?

KCNQ2-related epilepsy ranges from mild to severe. It is most commonly seen when you have a mutation in the KCNQ2 or KCNQ3 genes. These genes control the function of potassium channels in the brain. So far, only a small number of patients who have KCNQ2 mutations have been diagnosed. Many patients with KCNQ2 mutations remain undiagnosed. Even after diagnosis, many are not reported in the medical information available to the public. Not knowing about the range of KCNQ2-related epilepsy continues to make helping new cases hard.

What is the RIKEE registry?

The RIKEE Network is a group of doctors and scientists working to understand and better treat KCNQ2-related epilepsy. A "registry" is an organized system to collect information about this condition. By enrolling your child in the registry, you will be contributing to efforts by doctors, scientists, and family-led groups to understand KCNQ2-related illnesses better and develop new treatments. Participation is completely voluntary.

How can I participate?

If your child has been diagnosed with a mutation in KCNQ2 or KCNQ3, or your family is known to have epilepsy in newborn babies, you can get more information and enroll in the registry by emailing kcnq2info@bcm.edu. You can also speak with your treating neurologist who can anonymously enroll you in the registry if you give them verbal permission.

What can I expect if I participate?

If you choose to participate in the registry, your file will first be assigned a research code number. We will also ask your permission to look in the patient's medical record to gather any additional information we may need for the registry. All information will then be added in the registry. Your information will be grouped with other participant information so that researchers and doctors can better understand patterns of KCNQ2-related illness. The results will be discussed in scientific articles and conferences, and used for planning new research and treatments.

We have also created a website, www.RIKEE.org, including basic information on known KCNQ2 variants available to families, researchers, doctors and others counseling patients. You will be given the option to allow your child's or your family's limited information to be included in this website listing. There will be no information included that will identify you.