Individually, rare epilepsies are infrequent, but together they make up a powerful group who can teach the world more about the brain, epilepsy and medical care.

Participation in REN is via online survey and can be done at any time or place convenient for you!
Over 1,450 patients with a rare epilepsy have enrolled. VISIT EPILEPSY.COM/REN TO GET STARTED.

Distribution of rare epilepsy in the United States

KEY
- < 50 CASES
- > 100 CASES

RARE EPILEPSY NETWORK:
The Epilepsy Foundation
RTI International
Columbia University
Aaron’s Ohtahara Foundation
Aicardi Syndrome Foundation
Alternating Hemiplegia of Childhood Foundation
Aspire for a Cure
Bridge the Gap SYNGAP
The Brain Recovery Project
Carson Harris Foundation
CFC International
Chelsea’s Hope
The Cute Syndrome Foundation
CSWS & ESES Foundation
Doose Syndrome Epilepsy Alliance
Dravet Syndrome Foundation
Dup15q Alliance
Hope for Hypothalamic Hamartomas
Infantile Spasms Community
International Foundation for CDKL5 Research
International Rett Syndrome Foundation
The Jack Pribaz Foundation
KCNQ2 Cure Alliance
Lennox-Gastaut Syndrome Foundation
NORSE Institute
PCDH19 Alliance
Phelan-McDermid Syndrome Foundation
Pitt-Hopkins Research Foundation
RASopathies Network
Ring 14 USA Outreach
Ring 20 Chromosome Alliance
SLC6A1 Connect
TESS Foundation
Tuberous Sclerosis Alliance
Wishes for Elliott

For more information, visit: EPILEPSY.COM/REN

Your experience is critical to understanding causes and finding cures. Join thousands of other patients and caregivers by signing up for the Rare Epilepsy Network today. Just a few minutes of your time could impact so many others.

Community is key to the success of projects like this one. Join Us.
What is rare epilepsy?
A rare epilepsy is one which affects fewer than 200,000 people. In the world of neurology, a “rare epilepsy” is a disorder or syndrome that is defined by a particular cause, certain type of seizure(s), or seizures plus a specific collection of symptoms. Seizures are part of the clinical picture for many rare disorders.

Our mission
The REN is committed to addressing the urgent health challenges of our rare epilepsy community by engaging patients and caregivers, making data available to researchers, and investigating causes and consequences in order to improve diagnosis, treatment, and find cures.

Our opportunity to share your story and participate in research to make a difference.
- Help researchers understand your rare epilepsy
- Help researchers identify individuals at risk
- Help others obtain an early diagnosis or avoid misdiagnosis
- Find better treatments
- Unlock the cause and lead the way to cures for your rare epilepsy

Community is key to the success of projects like this one. Join Us.

REN Activities:
The REN launched in 2014 with a baseline survey that enrolled over 1,450 participants. In 2019, the Epilepsy Foundation expanded the REN’s activities, with the following pillars:

ACCELERATE RARE RESEARCH
- Streamline the REN enrollment survey and share data
- Initiate new rare epilepsy studies
- Provide clinical trial design consultation for drug and device companies in the rare epilepsy space

IMPROVE RARE CARE
- With the Epilepsy Learning Healthcare System, ensure patients are referred appropriately for comprehensive rare epilepsy care
- Develop recommended standards for rare epilepsy centers of excellence

ENHANCE RARE CONNECTIONS
- Provide a secure online environment for physicians to connect with professional peers and rare epilepsy experts to share knowledge of best practices in diagnosis, treatment and standards of care for patients

REQUIREMENTS FOR ELIGIBILITY
- A diagnosis by a physician of a rare syndrome or disorder that is related to seizures or epilepsy in majority of patients
- The patient has had at least one seizure in their lifetime not caused by fever or as a direct result of a head injury

For more information, visit: epilepsy.com/ren