

REN



To Do:
REN
registry

Rare Epilepsy Network

[Aaron's Ohtahara](#) [Aicardi Syndrome Foundation](#) [Dravet Syndrome Foundation](#) [Dup15q Alliance](#)
[Lennox Gastaut Syndrome Foundation](#) [PCDH19 Alliance](#) [International Foundation for CDKL5 Research](#)
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The Rare Epilepsy Network Registry, funded by PCORI, will be opening for enrollment in about a month, and we will need as many families as possible to participate in order to make this successful and useful for us all. The Aicardi Syndrome Foundation is fortunate to be involved in such a great organization as the REN, so let's make the most out of this, by providing as much information as we can. This registry is unique in that it is patient-driven and patient-centered. Please take a moment to read a bit about it and consider participating and help all of those living with Aicardi Syndrome and other Rare Epilepsies.

Here is a checklist of things you may want to gather to complete the registry survey:

- ✓ Genetic tests results / reports
- ✓ Latest EEG results / report
- ✓ Latest MRI results / report
- ✓ Record / list of past and current medications from doctor or pharmacy
- ✓ Cognitive testing results/IQ

What is the Rare Epilepsy Network?

The Rare Epilepsy Network, or REN for short, is a collaboration between the Epilepsy Foundation, RTI International, Columbia University, and many different organizations that represent patients with a rare syndrome or disorder that is associated with epilepsy or seizures. The REN will establish a registry of these patients which includes patient or caregiver-reported data in order to conduct patient-centered research. This research will be in the form of natural history studies and completion of surveys. The registry will also create the infrastructure for future research such as clinical trials. All of the research will be patient-centered, which means it will address research questions and topics that are important to the patients and caregivers with the ultimate goal of having patients and caregivers better able to participate in healthcare decisions. You may stop participating in the research at any time.

We will be sending out another announcement when the registry is open for enrollment so please stay tuned!

Thank you in advance for your participation!