WHY?
Global Rare Diseases Patient Registry Data Repository

GRDR

1. Patients provide health information & test results using common data elements (CDEs)
2. A Global Unique data ID (GUID) is assigned; patient data mapped to CDEs
3. Patient data linked to biospecimens via the GUID interfacing with RD-HUB
4. GRDR aggregates de-identified patient clinical information & biospecimen data
5. De-identified registry data available to researchers for biomedical studies & clinical trials
6. Researchers identify potential study participants; submit contact request to original registry owner
7. Registry owners notify identified participants. Interested participants are directed to study PI

Patient Registries

New Registries

Existing Registries

Repository of Aggregated De-identified Data

Assign GUID

RD-HUB Biospecimens

2012
AES @ San Diego
Dravet Syndrome
Hope for HH
Lennox-Gastaut
TS Alliance
RE – Rasmussen Encephalitis
You know, sometimes math does not work. How so? Well, I took two 5 hour energy but it didn't give me ten hours.
2013 Curing Epilepsy Conference – Epilepsy Leaders Convened To Discuss a Rare Epi Registry

PCORI suggested as a potential funding vehicle.

Rare Epilepsy Orgs express interest. Epilepsy Foundation takes the lead.

One registry is created from 10 disparate rare epilepsies; now 30+
Top 10 Reasons to Participate in the Rare Epilepsy Network

1. Help researchers understand your rare epilepsy
2. Enable faster and more efficient epilepsy research
3. Help researchers identify individuals at risk
4. Find better treatments for your rare epilepsy
5. Improve the quality of care for people living with a rare epilepsy
6. Help others obtain an early diagnosis and avoid delayed or misdiagnosis
7. Help change the way rare diseases are studied
8. Unlock the cause and lead to the cure for your rare epilepsy
9. Share your story with researchers who really LISTEN
10. Participate in your pajamas!