

Epilepsy Clinical Data Elements

Principal Investigator Responsible for Accuracy of Data (Name): _____		Subject ID number: _____																																																																					
Is this data Longitudinal (Follow-Up) Data? Yes <input type="checkbox"/> No <input type="checkbox"/>																																																																							
Subject Zip Code (1 st 3 digits): _____		Country of Residence _____																																																																					
Relationship to Proband: _____																																																																							
Family Member Samples in Repository? Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown (subject adopted) <input type="checkbox"/>																																																																							
If Yes, list subject ID/s and Relationship/s: _____																																																																							
Year of Birth: _____ Gender: Male <input type="checkbox"/> Female <input type="checkbox"/> Affected Status: Yes <input type="checkbox"/> No <input type="checkbox"/> At Risk <input type="checkbox"/>																																																																							
Age at time of sample collection: _____ Age unit: Years <input type="checkbox"/> Months <input type="checkbox"/> Weeks <input type="checkbox"/> Days <input type="checkbox"/> Fetal Weeks <input type="checkbox"/> Newborn <input type="checkbox"/>																																																																							
Age at diagnosis: _____ Age unit: Years <input type="checkbox"/> Months <input type="checkbox"/> Weeks <input type="checkbox"/> Days <input type="checkbox"/> Fetal Weeks <input type="checkbox"/> Newborn <input type="checkbox"/>																																																																							
Age at symptom onset: _____ Age unit: Years <input type="checkbox"/> Months <input type="checkbox"/> Weeks <input type="checkbox"/> Days <input type="checkbox"/> Fetal Weeks <input type="checkbox"/> Newborn <input type="checkbox"/>																																																																							
Date of Assessment: _____ Date of Death (if applicable): _____ Last Known Alive Date (optional): _____																																																																							
Ethnic Category (as reported by subject) Check One: Hispanic or Latino <input type="checkbox"/> Not Hispanic or Latino <input type="checkbox"/>																																																																							
Racial Categories (as reported by subject) Check One:																																																																							
American Indian/Alaska Native <input type="checkbox"/> Asian <input type="checkbox"/> Native Hawaiian/ Other Pacific Islander <input type="checkbox"/>																																																																							
Black/African American <input type="checkbox"/> White/Caucasian <input type="checkbox"/> More than One Race <input type="checkbox"/> Other <input type="checkbox"/> Unknown <input type="checkbox"/>																																																																							
Additional Racial and Ethnicity Information: _____																																																																							
Diagnosed By (select one): Neurosurgeon <input type="checkbox"/> Neurologist <input type="checkbox"/> Pediatric Neurologist <input type="checkbox"/> Primary Care Physician <input type="checkbox"/>																																																																							
Pediatrician <input type="checkbox"/> Psychiatrist <input type="checkbox"/> Psychologist <input type="checkbox"/> Does Not Apply (Population or Family-Based Control) <input type="checkbox"/>																																																																							
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Seizure Disorders (check if present):

- Epilepsy (≥ 2 unprovoked seizures)** Age of onset, if applicable _____
- Single Unprovoked seizure** Age at occurrence, if applicable _____
- Febrile seizures** Age of onset, if applicable _____
- Status Epilepticus** Age of onset, if applicable _____
- Acute Symptomatic Seizures** Age of onset, if applicable _____
- Other** Age of onset, if applicable _____

Etiology of unprovoked seizures (unprovoked seizures only – not applicable to other seizures):

- Idiopathic Cryptogenic Remote symptomatic Acute symptomatic Febrile Unknown

Specific Etiology (applicable to unprovoked and other seizures):

- Trauma Stroke Hypoxia Meningitis Encephalitis Antenatal insult
Error in brain development (specify) _____ Cortical dysplasia Mitochondrial disorder
Chromosomal disorder Other (specify) _____ Unknown

Associated Conditions:

- None Known Cerebral palsy Mental retardation Autism Dementia Neurodegenerative disorder
Other (specify) _____

Treatment: Medically refractory Yes No Unknown Surgical treatment Yes No

EEG: Normal Epileptiform Abnormalities Non-Epileptiform Abnormalities Both Abnormalities Not Done
Generalized spike and wave: <2.5Hz slow 2.5-3.5 Hz >3.5Hz

Focal spikes: Temporal Extra temporal Multifocal
Nonepileptiform Abnormalities Focal Slowing: Temporal Extra temporal Other (specify) _____

Imaging: Normal Abnormal Not Done **Specify Abnormality** _____

Optional Data:

- Smoking history Never Previous Current Years Smoking, if applicable _____
Neurological exam completed Yes No Mini-Mental status score and date _____
Handedness Left Right Ambidextrous