Epilepsy Clinical Data Elements

Principal Investigator Responsible for Accuracy of Data (Name): **Subject ID number:**

Is this data Longitudinal (Follow-Up) Data? Yes ☐ No ☐

Subject Zip Code (1st 3 digits): _____ **Country of Residence_____**

Relationship to Proband: _____

Family Member Samples in Repository? Yes ☐ No ☐ Unknown (subject adopted) ☐

If Yes, list subject ID/s and Relationship/s: _____

Year of Birth: _____ **Gender**: Male ☐ Female ☐ **Affected Status**: Yes ☐ No ☐ At Risk ☐

Age at time of sample collection: _____ **Age unit**: Years ☐ Months ☐ Weeks ☐ Days ☐ Fetal Weeks ☐ Newborn ☐

Age at diagnosis: _____ **Age unit**: Years ☐ Months ☐ Weeks ☐ Days ☐ Fetal Weeks ☐ Newborn ☐

Age at symptom onset: _____ **Age unit**: Years ☐ Months ☐ Weeks ☐ Days ☐ Fetal Weeks ☐ Newborn ☐

Date of Assessment: _____ **Date of Death (if applicable)**: _____ **Last Known Alive Date (optional)**: _____

Ethnic Category (as reported by subject) Check One: Hispanic or Latino ☐ Not Hispanic or Latino ☐

Racial Categories (as reported by subject) Check One:

American Indian/Alaska Native ☐ Asian ☐ Native Hawaiian/ Other Pacific Islander ☐

Black/African American ☐ White/Caucasian ☐ More than One Race ☐ Other ☐ Unknown ☐

Additional Racial and Ethnicity Information: _____

Diagnosed By (select one)**:** Neurosurgeon ☐ Neurologist ☐ Pediatric Neurologist ☐ Primary Care Physician ☐
Pediatrician ☐ Psychiatrist ☐ Psychologist ☐ Does Not Apply (Population or Family-Based Control) ☐

Data Collected By (select one)**:** Neurosurgeon ☐ Neurologist ☐ Pediatric Neurologist ☐ Primary Care Physician ☐
Pediatrician ☐ Psychiatrist ☐ Psychologist ☐ Research Coordinator ☐ Registered Nurse ☐
Research Coordinator/ RN ☐

	Present	Absent	Unknown	
Family History of Epilepsy:	☐	☐	☐	If present, list family members & type_____
Other Paroxysmal Disorder:				
Migraine	☐	☐	☐	If present, list family members & type_____
Dystonia	☐	☐	☐	If present, list family members & type_____
Known Genetic Syndrome:	☐	☐	☐	Please specify, if applicable:_____
Known Mutation/s in DNA:	☐	☐	☐	Please specify, if applicable:_____

Seizure type:	**Present**	**Absent**	**Notes**
Simple partial	☐	☐	_____
Complex partial	☐	☐	_____
Partial with secondary generalizations	☐	☐	_____
Generalized – typical absence	☐	☐	_____
Generalized – atypical absence	☐	☐	_____
Myoclonic	☐	☐	_____
Clonic	☐	☐	_____
Tonic	☐	☐	_____
Tonic-Clonic	☐	☐	_____
Atonic	☐	☐	_____
Infantile spasms	☐	☐	_____
Unclassified seizure	☐	☐	_____
Status epilepticus	☐	☐	_____
Simple febrile seizure	☐	☐	_____
Complex febrile seizure	☐	☐	_____
Prolonged febrile seizure	☐	☐	_____

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 ☐