Control Clinical Data Elements

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

Is this Longitudinal (follow-up) Data? Yes ☐ No ☐

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

Diagnosis (select one): Population/Convenience Control ☐
Aysmptomatic or undiagnosed and genetically related to an affected individual ☐
Relation to proband (if applicable): _____
Family member sample/s in NINDS Repository? Yes☐ No ☐ Unknown (Subject Adopted) ☐
If Yes, relationship/s & IDs: _____

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 ☐
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 ☐

Type of control: Population control ☐ Unaffected spouse ☐ Related to an affected individual ☐

Medical History:	**Present**	**Absent**		**Present**	**Absent**
Alzheimer's	☐	☐	Heart disease	☐	☐
Amyotrophic lateral sclerosis	☐	☐	Hypertension	☐	☐
Ataxia	☐	☐	Memory loss	☐	☐
Autism	☐	☐	Migraine	☐	☐
Bipolar	☐	☐	Multiple sclerosis	☐	☐
Brain aneurysm	☐	☐	Muscle disease	☐	☐
Cancer	☐	☐	Obsessive Compulsive	☐	☐
Dementia	☐	☐	Parkinson's disease	☐	☐
Depression	☐	☐	Schizophrenia	☐	☐
Diabetes	☐	☐	Stroke	☐	☐
Dystonia	☐	☐	Suicide/attempt	☐	☐
Epilepsy	☐	☐	Tourettes	☐	☐

Other (specify): _____

Family History:	Present	Absent	If present, list affected family members & IDs (if applicable):
Alzheimers	☐	☐	_____
Amyotrophic lateral sclerosis	☐	☐	_____
Ataxia	☐	☐	_____
Autism	☐	☐	_____
Bipolar	☐	☐	_____
Brain aneurysm	☐	☐	_____
Cancer	☐	☐	_____
Dementia	☐	☐	_____
Depression	☐	☐	_____
Diabetes	☐	☐	_____
Dystonia	☐	☐	_____
Epilepsy	☐	☐	_____
Heart Disease	☐	☐	_____
Hypertension	☐	☐	_____
Memory loss	☐	☐	_____
Migraine	☐	☐	_____
Multiple sclerosis	☐	☐	_____
Muscle disease	☐	☐	_____
Obsessive Compulsive	☐	☐	_____
Parkinson's disease	☐	☐	_____
Schizophrenia	☐	☐	_____
Stroke	☐	☐	_____
Suicide/attempt	☐	☐	_____
Tourette	☐	☐	_____
Other (specify): _____	☐	☐	_____

Optional Data:

Smoking History Current ☐ Previous ☐ Never ☐ If applicable, years smoking: _____

Mini-Mental status score and date _____

Neurological exam completed? Yes ☐ No ☐

Handedness Left ☐ Right ☐ Ambidextrous ☐