MOTOR NEURON DISORDERS CLINICAL DATA ELEMENTS

Principle Investigator Responsible for Accuracy of Data (Name): _____**Subject ID: _____**

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

Relative's sample in Repository? Yes ☐ No ☐ Unknown (subject adopted) ☐ if yes, ID/s & relationship/s: _____

Year of Birth: _____ **Age at Diagnosis (Year): _____**

Age at Onset (Year): _____ **Date of Death (MM/DD/YYYY, if applicable): _____**

Last Known Alive Date (MM/DD/YYYY): _____

If Date of Death is known, please specify time for <u>disease duration</u> from onset of symptoms to death (Years/Months):_____

Gender: ☐ Male ☐ Female **Country of Residence: _____**

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

Racial Category (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 Ethnicity Info: _____**

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

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

Subject ZIP Code (1st 3 digits only): ☐☐☐ **(1st 3 digits of postal code if U.K. or Canada)**

Family History (Attach Pedigree):	**Present**	**Absent**	**Unknown**	**Indicate Relative(s)**
ALS/other MND	☐	☐	☐	_____
Parkinson's Disease	☐	☐	☐	_____
Alzheimer's Disease	☐	☐	☐	_____
Other Dementia	☐	☐	☐	_____
Other Neurodegenerative Disease	☐	☐	☐	_____

Medical History: Does the ALS subject have a history of any of the following? (check all that apply):

☐ Alzheimer's	☐ Brain Aneuryism	☐ Diabetes	☐ Hypertension	☐ Schizophrenia
☐ Ataxia	☐ Cancer	☐ Dystonia	☐ Multiple Sclerosis	☐ Suicide Attempt
☐ Autism	☐ Dementia	☐ Epilepsy	☐ Muscle Disease	☐ Stroke
☐ Bipolar	☐ Depression	☐ Heart Disease	☐ Parkinson's Disease	

Primary Clinical Diagnosis (check one):
☐ ALS (see below for El Escorial Criteria) ☐ Progressive Muscular Atrophy
☐ Other (specify): _____ ☐ Primary Lateral Sclerosis

Secondary Neurological Diagnosis (check all that apply):
☐ Frontotemporal Dementia (Neary Criteria) ☐ Other (specify):_____ ☐ Not Applicable

Site Of Onset of Progressive Weakness (check one):
☐ Bulbar ☐ Truncal ☐ Generalized ☐ Respiratory ☐ Limb Specify:☐ Upper ☐ Lower

Current treatment (indicate all that appy):
☐ Riluzole ☐ PEG ☐ NIPPV ☐ Tracheotomy ☐ Other (specify):_____
☐ Start Date of Assisted Ventilation >23 Hours (month/year) _____/ _____ ☐ No Treatment

Signs Supporting ALS Diagnosis (check all present at time of examination):

Upper Motor Neuron Signs:

Bulbar	☐ Definite	☐ Indeterminate	☐ Absent	☐ Not tested
Cervical/upper limbs	☐ Definite	☐ Indeterminate	☐ Absent	☐ Not tested
Thoracic/chest	☐ Definite	☐ Indeterminate	☐ Absent	☐ Not tested
Lumbosacral/lower limbs	☐ Definite	☐ Indeterminate	☐ Absent	☐ Not tested

Lower Motor Neuron Signs:

Bulbar	☐ Definite	☐ Indeterminate	☐ Absent	☐ Not tested
Cervical/upper limbs	☐ Definite	☐ Indeterminate	☐ Absent	☐ Not tested
Thoracic/chest	☐ Definite	☐ Indeterminate	☐ Absent	☐ Not tested
Lumbosacral/lower limbs	☐ Definite	☐ Indeterminate	☐ Absent	☐ Not tested

EMG Studies: (check all that apply)

Bulbar	☐ Acute Denervation	☐ Chronic Denervation	☐ Negative	☐ Not tested
Cervical/upper limbs	☐ Acute Denervation	☐ Chronic Denervation	☐ Negative	☐ Not tested
Thoracic/chest	☐ Acute Denervation	☐ Chronic Denervation	☐ Negative	☐ Not tested
Lumbosacral/lower limbs	☐ Acute Denervation	☐ Chronic Denervation	☐ Negative	☐ Not tested

Genetics: (if tested or known)

SOD1 mutation ☐ Present ☐ Absent ☐ Unknown
If tested, please specify mutation that was screened for: _____

TARDBP (TAR DNA binding protein; alias TDP-43) mutation ☐ Present ☐ Absent ☐ Unknown
If tested, please specify mutation that was screened for: _____

FUS (fused in sarcoma) mutation ☐ Present ☐ Absent ☐ Unknown
If tested, please specify mutation that was screened for: _____

VCP (valosin containing protein) mutation ☐ Present ☐ Absent ☐ Unknown
If tested, please specify mutation that was screened for: _____

C9ORF72 (chromosome 9 open reading frame 72) repeat expansion ☐ Present ☐ Absent ☐ Unknown
If tested, please provide relevant comments, if any: _____

Other mutation ☐ Present ☐ Absent ☐ Unknown
If tested, please specify mutation that was screened for: _____

Atypical Features of ALS/MND (check all that apply):

☐ Sensory ☐ Autonomic ☐ Cerebellar ☐ Cognitive ☐ Parkinsonian ☐ Sphincter
☐ Ocular ☐ Other_____

Optional Data:

Current ALSFRS-R: _____/48 **FVC**: _____%

Escorial Criteria: ☐ Definite ☐ Probable ☐ Lab supported-Probable ☐ Possible ☐ Suspected

Smoking History ☐ Current ☐ Previous ☐ Never Years smoking, if applicable_____

Handedness ☐ Left ☐ Right ☐ Ambidextrous