Clinical Data

Record ID: _____ Last Exam Date: _____

Physician Name: _____ Weight (kg): _____

Clinic Name: _____ Height (cm): _____

Region Name: _____

Diagnosis

El Escorial - Revised Category
- ◯ Clinically Definite
- ◯ Lab Supported Probable
- ◯ Clinically Probable
- ◯ Clinically Possible

UMN Involvement (check all that apply) ☐ Bulbar ☐ Cervical ☐ Lumbar ☐ Thoracic

LMN Involvement (check all that apply) ☐ Bulbar ☐ Cervical ☐ Lumbar ☐ Thoracic

Date of Diagnosis: _____ Date of Symptom Onset: _____

Region of Sympton Onset (check all the apply):
- ☐ Bulbar
- ☐ Upper Extremity
- ☐ Lower Extremity
- ☐ Respiratory
- ☐ FTD/Cognitive
- ☐ Unknown

Genetics

Is there a family history of ALS?
- ◯ No
- ◯ Yes
- ◯ Not available
- ◯ Unknown

If YES, please specify:
- ☐ Paternal
- ☐ Maternal

Affected relatives (specify): _____

Is there a family history of neurodegenerative disease?
- ◯ Yes
- ◯ No
- ◯ Unknown

If YES, please specify: _____

Genetic Tests

Was a genetic test performed?
- ◯ Yes
- ◯ No
- ◯ Unknown

If YES, what type of testing was performed? (check all that apply)
- ☐ SOD1
- ☐ TDP
- ☐ FUS
- ☐ C9orf72 Complete
- ☐ Exome
- ☐ Other

If other, please specify: _____

Date of test: _____

Laboratory: _____

Was a mutation found?
- ◯ Yes
- ◯ No
- ◯ Negative

Which genes were involved? (check all that apply):
- ☐ SOD1
- ☐ TDP
- ☐ FUS
- ☐ C9orf72
- ☐ VUS
- ☐ DCTN1
- ☐ PRP4
- ☐ SMN1
- ☐ Other

Please specify SOD1 mutation: _____

Please specify C9orf72 number of repeats: _____

Other, please specify: _____

Sequence and variant information (if available): _____

Clinical Features

Ongoing affected regions (check all that apply):
☐ Bulbar ☐ Upper Extremity ☐ Lower Extremity ☐ Respiratory ☐ FTD/Cognitive ☐ Unknown

Non-invasive ventilation:
- ◯ Pre-existing (other diagnosis)
- ◯ Recommended
- ◯ Recommended & used
- ◯ Recommended and declined
- ◯ Recommended and not tolerated
- ◯ Not yet indicated
- ◯ Not available
- ◯ Unknown

Tracheostomy:
- ◯ Yes
- ◯ No
- ◯ Unknown

Feeding Tube:
- ◯ Pre-existing (other diagnosis)
- ◯ Obtained and used
- ◯ Not yet indicated
- ◯ Obtained and not yet used
- ◯ Recommended
- ◯ Recommended and declined
- ◯ Recommended and not tolerated
- ◯ Not available
- ◯ Unknown

Cognitive Assesment

Does this individual display cognitive impairment?
- ◯ Yes
- ◯ No
- ◯ Unsure

Which screening test was used? (Please specify): _____

Does this individual display behavioral impairment?
- ◯ Yes
- ◯ No
- ◯ Unsure

Which screening test was used? _____

Has the patient been assessed by a behavioral neurologist?
- ◯ Yes
- ◯ No
- ◯ Unknown

ALSFRS-R Survey is Administered

Clinical Trials

Has the patient participated in a clinical trial?
- ◯ Yes
- ◯ Never
- ◯ Past
- ◯ Other

If YES or PAST above please specify trial(s): _____

Vital Capacity:
- ◯ Reliable
- ◯ Unreliable
- ◯ Not available
- ◯ Unknown

Last FVC (%) _____

Date _____

Peak Cough Flow _____

Riluzole:
- ◯ Yes
- ◯ No
- ◯ Past
- ◯ Stopped
- ◯ Declined
- ◯ Unknown

Interventions

Secretion Interventions

Are secretion interventions in use?
- ◯ Yes
- ◯ No
- ◯ Not available
- ◯ Unknown

If YES above, check all that apply:

☐ Botulinum toxin	Date: _____
☐ Radiation	Date: _____
☐ Oral medications	Date: _____
☐ Surgery	Date: _____
☐ Atropine drops	Date: _____
☐ Oral suctioning	Date: _____
☐ Other	Date: _____

Airway Interventions

Are airway interventions in use?
- ◯ Yes
- ◯ No
- ◯ Not available
- ◯ Unknown

If YES above, check all that apply:
- ☐ Breath stacking/augmentation Date: _____
- ☐ Suction Date: _____
- ☐ Insufflator/Exhalator Date: _____
- ☐ Manual cough assist Date: _____

Does the patient use a manual chair?
- ◯ Yes, independently
- ◯ Yes, assisted
- ◯ Recommended
- ◯ Not yet indicated
- ◯ Declined
- ◯ Not available
- ◯ Unknown

Does the patient use a power chair?
- ◯ Yes, independently
- ◯ Yes, assisted
- ◯ Recommended
- ◯ Not yet indicated
- ◯ Declined
- ◯ Not available
- ◯ Unknown

Does the patient use orthoses?
- ◯ Yes
- ◯ No
- ◯ Not yet indicated
- ◯ Recommended
- ◯ Declined
- ◯ Not available
- ◯ Unknown

If YES above, check all that apply:
- ☐ Cervical
- ☐ Hand/Wrist
- ☐ Shoulder
- ☐ Ankle/Foot

Social Data

Is necessary transportation available?
- ◯ Yes
- ◯ No
- ◯ Unknown
- ◯ Not feasible

How many hours of paid home care per day does the patient receive? (in hours) _____

From:
- ◯ Government
- ◯ Private
- ◯ Unknown

Is respite care available?
- ◯ Yes
- ◯ No
- ◯ Unknown

Tissue Inventory

Has the patient provided tissue samples that are available for future testing?
- ◯ Yes
- ◯ No
- ◯ Declined
- ◯ Unknown

If YES above, indicate the tissue and location
- ☐ DNA Lab Location: _____
- ☐ CSF Lab Location: _____
- ☐ Muscle biopsy Lab Location: _____
- ☐ Nerve biopsy Lab Location: _____
- ☐ Brain Lab Location: _____
- ☐ Spinal cord Lab Location: _____
- ☐ Fibroblasts Lab Location: _____

End Of Life

Does the patient have a personal directive?
- ◯ Yes
- ◯ No
- ◯ Unknown

If YES, check one:
- ◯ Full care
- ◯ Comfort care
- ◯ Defined limitations
- ◯ Not available

If NO, check one:
- ◯ Undecided
- ◯ Refused
- ◯ Not possible
- ◯ Unknown

Patient Form

Personal Data

Date of Birth: _____

City of Birth: _____

Province/State of Birth: _____

Country of Birth: _____

Lifestyle Information

At the present time, do you smoke cigarettes daily, occasionnally, or not at all?
- ◯ Daily
- ◯ Occasionally
- ◯ Not at all
- ◯ Declined

Have you smoked at least 100 cigarettes in your life?
- ◯ Yes
- ◯ No
- ◯ Declined

How many cigarettes per day do you or did you consume?
- ◯ 1 - 10
- ◯ 11 - 19
- ◯ 20 or more
- ◯ Declined

Is anyone else in your household a smoker?
- ◯ Yes
- ◯ No
- ◯ Declined

Have you ever suffered a major physical trauma that required medical attention?
- ◯ Yes
- ◯ No

Other Information

Are you participating in any other registries?
- ◯ Yes
- ◯ No
- ◯ Unknown

If YES, please specify registry: _____

Which occupations have you held?
- ☐ Management
- ☐ Natural and Applied Sciences
- ☐ Sales and Service
- ☐ Trades, Transport, Equipment Operator
- ☐ Art, Culture, Recreation and Sport
- ☐ Processing, Manufacturing, Utilities
- ☐ Business, Finance or Administration
- ☐ Primary Industry (Agriculture, Mining, Oil & Gas, Exploration, Fishing)
- ☐ Health
- ☐ Social Science, Education, Gov't Service, or Religion
- ☐ Patient has never worked
- ☐ Unknown
- ☐ Other _____

Did you complete any military service?
- ◯ Yes
- ◯ No
- ◯ Unknown

What is the patient's highest level of education?
- ◯ Elementary
- ◯ High School
- ◯ Post-secondary
- ◯ Some post-secondary
- ◯ Declined

What is the patient's total household income before taxes?

- ◯ Less than $5,000
- ◯ $5,000 - $9,999
- ◯ $10,000-$14,999
- ◯ $15,000-$19,999
- ◯ $20,000-$24,999
- ◯ $25,000-$29,999
- ◯ $30,000-$34,999
- ◯ $35,000-$39,999
- ◯ $40,000-$44,999
- ◯ $45,000-$49,999
- ◯ $50,000-$59,999
- ◯ $60,000-$69,999
- ◯ $70,000-$79,999
- ◯ $80,000-$89,999
- ◯ $90,000-$99,999
- ◯ $100,000-$124,999
- ◯ $125,000-$149,999
- ◯ $150,000 or more
- ◯ Declined
- ◯ Unknown

Are you registered with the local ALS society?
- ◯ Yes
- ◯ No
- ◯ Declined
- ◯ Unknown

To which population group does the patient belong?
(check all that apply)

- ☐ White
- ☐ Chinese
- ☐ South Asian
- ☐ Black
- ☐ Filipino
- ☐ Latin American
- ☐ Arab
- ☐ Southeast Asian
- ☐ Korean
- ☐ West Asian
- ☐ Japanese
- ☐ Aboriginal/First Nations
- ☐ Unknown
- ☐ Visible minority
- ☐ Declined
- ☐ Not available
- ☐ Other

If other, please specify: _____

Notes

Notes: _____