Biannual Telephone Interview
National Registry of Veterans with ALS

Registry ID #_____ **Interviewer Name: _____**

Date of Interview: _____/_____/_____ **Time of Interview: _____** AM PM

Survey Interval:

_____ Baseline	_____ 18-month	_____ 36-month
_____ 6-month	_____ 24-month	
_____ 12-month	_____ 30-month	

Hello. This is (NAME) from the National Registry of Veterans with ALS. May I speak to (name of veteran, or proxy who provided information on the previous interview)?
I am calling to ask you a few questions about your (*the veteran's*) health as part of our regular follow-up for the registry. Is this a good time to talk? (If no, note a day and time when you should call back: _____)

If participant has died, note death date: _____/_____/_____

Proxy Respondent? _____Yes _____No
If yes, specify ____Spouse _____Child ____Sibling ____Parent ____Partner _____Friend
_____ Health Care Provider _____Other (specify):_____
Name of proxy respondent: _____

(*If new proxy, get contact information)* Address_____
_____
_____
Phone (____)_____

A. **Only ask if: Suspected ALS, or an Indeterminate diagnosis. (All others, skip to ALSFRS)**
We would like to ask you about your current diagnosis, since we know that diagnoses can change over time.

1. What is your (*the veteran's*) current diagnosis? (*Check all that apply*)
O ALS (confirmed by a physician)
O Maybe/Possibly ALS (not yet determined/diagnosed)
O Primary lateral sclerosis
O Progressive bulbar palsy
O Progressive muscular atrophy
O Other (please specify): _____

2. Have you seen a neurologist or had any medical tests since the last time we spoke with you (*insert date here in database if possible*)? O YES O NO
If No, skip to Section B

3. We would like to request copies of these new medical records so we can add them to your medical record file with the Registry. What is the name of the neurologist you saw or the medical facility where you had tests?
a. Neurologist Name (if applicable) :_____

Medical Facility (if applicable): _____

Is this a neurologist you have seen before or a medical facility you have visited before?
O YES O NO
If Yes, skip to next neurologist/facility (if applicable) or Section B
If NO, obtain address of neurologist of facility:
_____
_____

b. Neurologist Name (if applicable) :_____

Medical Facility (if applicable): _____

Is this a neurologist you have seen before or a medical facility you have visited before?
O YES O NO
If Yes, skip to next neurologist/facility (if applicable) or Section B
If NO, obtain address of neurologist of facility:
_____
_____
_____

c. Neurologist Name (if applicable) :_____

Medical Facility (if applicable): _____

Is this a neurologist you have seen before or a medical facility you have visited before?
O YES O NO
If Yes, skip to Section B
If NO, obtain address of neurologist of facility:
_____
_____
_____

B. ALS Functional Rating Scale (For all participants)

These following questions ask you about limitations due to your health (*the veteran's health*). For each item, please indicate the category that most describes your current state of health.

1. Speech
   ___ (4) Normal speech processes
   ___ (3) Detectable speech disturbance
   ___ (2) Intelligible with repeating
   ___ (1) Speech combined with non-vocal communication
   ___ (0) Loss of usual speech

2. Salivation
   ___ (4) Normal
   ___ (3) Slight but definite excess of saliva in mouth, may have nighttime drooling
   ___ (2) Moderately excessive saliva, may have minimal drooling
   ___ (1) Marked excess of saliva with some drooling
   ___ (0) Marked drooling, requires constant tissue or handkerchief

3. Swallowing
   ___ (4) Normal eating habits
   ___ (3) Early eating problems – occasional choking
   ___ (2) Dietary consistency changes
   ___ (1) Needs supplemental tube feeding
   ___ (0) Nothing taken by mouth (exclusively parenteral or enteral feeding)

4. Handwriting (with dominant hand)
   ___ (4) Normal
   ___ (3) Slow or sloppy: all words are legible
   ___ (2) Not all words are legible
   ___ (1) Able to grip pen but unable to write
   ___ (0) Unable to grip pen

Uses a feeding tube: **No- go to Q. 5a**
Yes- go to Q. 5b

5a. Cutting food and handling utensils (patients without gastrostomy)
   ___ (4) Normal
   ___ (3) Somewhat slow and clumsy but no help needed
   ___ (2) Can cut most foods, although clumsy and slow; some help needed
   ___ (1) Food must be cut by someone, but can still feed slowly
   ___ (0) Needs to be fed

5b. Use of feeding tube (for patients with gastrostomy)
   ___ (4) Normal
   ___ (3) Clumsy but able to perform all manipulations independently
   ___ (2) Some help needed with closures and fasteners

___ (1) Provide minimal assistance to caregiver
___ (0) Unable to perform any aspect of task

6. Dressing and hygiene
___ (4) Normal function
___ (3) Independent and complete self-care with effort or decreased efficiency
___ (2) Intermittent assistance or substitute methods
___ (1) Need attendant for self-care
___ (0) Total dependence

7. Turning in bed and adjusting bed clothes
___ (4) Normal
___ (3) Somewhat slow and clumsy, but no help needed
___ (2) Can turn alone or adjust sheets, but with great difficulty
___ (1) Can initiate, but not turn or adjust sheets alone
___ (0) Unable to do

8. Walking
___ (4) Normal
___ (3) Early ambulation difficulties (any assistive devices including AFOs)
___ (2) Walk with assistance
___ (1) Non-ambulatory functional movement only
___ (0) No purposeful leg movement

9. Climbing stairs
___ (4) Normal
___ (3) Slow
___ (2) Mild unsteadiness or fatigue
___ (1) Need assistance (including handrails)
___ (0) Cannot do

10a. Dyspnea
___ (4) None
___ (3) Occurs when walking
___ (2) Occurs with one or more of the following: eating, bathing, dressing (ADL)
___ (1) Occurs at rest, difficulty breathing when either sitting or lying
___ (0) Significant difficulty, considering using mechanical respiratory support

10b. Orthopnea
___ (4) None
___ (3) Some difficulty sleeping at night due to shortness of breath, does not routinely use more than two pillows
___ (2) Needs extra pillows in order to sleep (more than two)
___ (1) Can only sleep sitting up

___ (0) Unable to sleep

10c. Respiratory insufficiency
___ (4) None
___ (3) Intermittent use of BiPAP or CPAP
___ (2) Continuous use of BiPAP or CPAP during the night
___ (1) Continuous use of BiPAP or CPAP during the night and day
___ (0) Invasive mechanical ventilation by intubation or tracheostomy

C. Questions about health and medical care

These following questions ask you about your current medical care for ALS.

1. Please name each of the medications (prescription, over the counter, or experimental) that you are (*the veteran is*) currently using. We are interested in medications you are using to treat ALS symptoms, and also medications you are using for other health conditions you may have.

   _____ _____
   _____ _____
   _____ _____
   _____ _____
   _____ _____

2. Please name any dietary products, herbal products, or vitamins you are (*the veteran is*) currently using.

   _____ _____
   _____ _____
   _____ _____
   _____ _____
   _____ _____
   _____ _____

3. Are you (*is the veteran*) using any of the following to assist with breathing?
   _____ CPAP (Continuous Positive Airway Pressure) Start date of use: (M/D/Y)_____
   _____ BiPAP (Bi-level Positive Airway Pressure) Start date of use: (M/D/Y)_____
   _____ Ventilator Start date of use (M/D/Y)_____(at least 2 weeks, 15 hours per day)
   _____ Trach Start date of use (M/D/Y) _____

4. Are you (*is the veteran*) using a feeding tube? O YES O NO O NA

5. What is your (the veteran's) current weight (in pounds) _____
   If don't know, ask for best estimate. If no idea, leave blank.

D. Questions about Previous Trauma (Ask only at baseline interview)

1. Have you (*has the veteran*) ever had a major physical trauma? O YES O NO
   If yes, please specify the type of trauma: _____
   _____

Did this trauma require hospitalization? O YES O NO

2. Have you (*has the veteran*) ever had any fractures? O YES O NO

E. Questions about Smoking (Ask only at baseline interview)

1. Have you (*has the veteran*) ever smoked cigarettes? O YES O NO
   If NO, stop smoking questionnaire here.

2. Have you (*has the veteran*) ever smoked at least 100 cigarettes (or the equivalent amount of tobacco) in your lifetime? O YES O NO

3. Have you (*has the veteran*) ever smoked daily? O YES O NO

4. Do you (*does the veteran*) now smoke daily, occasionally, or not at all?

   (indicate category)_____

   If daily or occasionally, skip to Q.6

5. If "not at all", at what age did you stop smoking? _____

6. For how many years have you smoked/did you smoke? _____

7. On the days that you (did) smoke, what was the average number of cigarettes that you smoked?
   _____

Thank you very much for taking time to answer these questions today. We greatly appreciate your involvement in the National Registry of Veterans with ALS. We will contact you again in approximately six months to ask you this same series of questions. Should you have any questions before then, please contact us at 1-877-342-5257 (1-877-DIAL-ALS).

Ineligible Script (New diagnosis, not ALS or related MND):
Because you have received a new diagnosis that is not ALS or a related disease, we will not ask you to continue with the 6-month follow-up interviews for the Registry. Thank you very much for your

participation in the Veterans ALS Registry. If you have any questions about the Registry in the future, please contact us via the toll-free ALS call line (1-877-342-5257).