Form Approved
OMB No. **0923**-XXXX
Exp. Date xx/xx/20xx

Attachment 6

Text of Voluntary Survey Modules

ONE TIME SURVEYS MODULES

Questionnaire to be divided into 6 survey modules by topic

The purpose of this questionnaire is to obtain some general information about yourself, as well as information on lifestyle factors.

1.1.1.1.1 General Instructions

- Please read these questions carefully and answer to the best of your knowledge.
- When answering choice questions, click on the box(es)

1.1.2 : BACKGROUND INFORMATION MODULE 1

1. What is your date of birth? ☐☐ Month ☐☐ Day ☐☐☐☐ Year

2. How old are you today? ☐☐ years old

3. How old were you when you were told by a neurologist that you had ALS. ☐☐ years old

4. What is your gender? 1☐ Male 2☐ Female

5. What is your current marital status?

1☐ Never married 2☐ Married 3☐ Separated
4☐ Divorced 5☐ Widowed 6☐ Living with partner

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7. What is the highest level of education that you have completed?

1 Did not complete High School – Specify highest grade completed

2 High school diploma or GED

3 Technical or trade school diploma Some college credit

4 College degree (AA, BA, BS, etc)

5 Graduate school degree

6 Other (specify):________________

8. Do you consider yourself Spanish, Hispanic, or Latino/Latina?

1 No

2 Yes, Puerto Rican

3 Yes, Mexican, Mexican American, Chicano

4 Yes, Cuban

5 Yes, other Spanish, Hispanic, or Latino/Latina (specify): ______________________

8. What do you consider to be your race or ethnic group? If you belong to more than one of these groups, please indicate all groups that apply to you.

1 White

2 Black or African-American

3 Native American or Alaska Native

4 Asian Indian

5 Chinese

6 Filipino

7 Japanese

8 Korean

9 Vietnamese

10 Other Asian (specify):_______________

11 Native Hawaiian

12 Guamanian or Chamorro

13 Samoan

14 Other Pacific Islander (specify):_______________

99 Don't know

9. In what country were you born?

____

10. What is your current height? (FT) (IN)

11. What is your current weight? (LBS)

12. What was your height at age 40 years? (FT) (IN)

13. What was your weight at age 40 years? ☐☐☐ (LBS)

1.1.3 LIFESTYLE INFORMATION

We are now going to ask you to answer a few questions about your occupation and other lifestyle factors.

MODULE 2

OCCUPATION

14. What is your current employment status?

1☐ Full-time employed
2☐ Part-time employed
3☐ Retired
4☐ Disabled
5☐ Full-time student
6☐ Homemaker
7☐ Unemployed
8☐ Other (specify):________________

15. If currently employed, what is your occupation? ***Please indicate your job title and the industry in which you worked***.

____

JOB TITLE

____

INDUSTRY

15a. For how many years were you employed in this occupation? ☐☐ years

16. Thinking about your entire working career, in which job were you employed for the longest period of time? ***Please indicate your job title, occupation, and the industry in which you worked***.

____

JOB TITLE

____

INDUSTRY

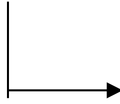
6a. For how many years were you employed in this occupation? ☐☐ years

MODULE 3

MILITARY HISTORY

17. Were you ever a member of the armed forces?

1☐ Yes 2☐ No (go to question 18) 9☐ Don't know (go to question 18)



17a. If yes, in which branch of service were you employed?

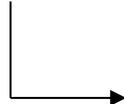
1☐ Army 2☐ Navy 3☐ Marines

4☐ Air Force 5☐ Reserves/National Guard

6☐ Coast Guard

17b. Were you ever deployed to a war arena?

1☐ Yes 2☐ No (go to question 15)



17c. If yes, to which war arena were you deployed? ***Please specify all arenas (for example, WWII Europe, Vietnam).***

1 ______________________________

2 ______________________________

3 ______________________________

4 ______________________________

MODULE 4

SMOKING

18. Have you ever smoked one or more cigarettes per day for six months or longer?

1☐ Yes 2☐ No (go to question 19) 9☐ Don't know (go to question 19)

18a. If yes, how old were you when you first started smoking one or more cigarettes per day? ☐☐ years old

18b. Are you still a cigarette smoker?

1☐ Yes 2☐ No 9☐ Don't know

18c. If no, at what age did you last stop smoking cigarettes?

☐☐ year old

18d. During periods when you smoked, for how many years in total did you smoke cigarettes? ☐☐ years

18e. During periods when you smoked, how many cigarettes did you usually smoke in a day? One pack contains 20 cigarettes. ☐☐ number cigarettes per day

ALCOHOL

19. Did you ever drink alcoholic beverages such as wine, beer and spirits at least once a month for 6 months or more?

1☐ Yes 2☐ No (go to question 20) 9☐ Don't know (go to question 20)

19a. Are you still drinking alcoholic beverages at least once per month?
1☐ Yes 2☐ No

19b. During periods when you were drinking alcoholic beverages, for how many years in total did you drink alcoholic beverages?☐☐ years

19b. During periods when you were drinking, how many alcoholic beverages did you usually have in a week ***OR*** month? A drink is 12 oz. beer, 4 ounces of wine or a drink containing 1 oz. of liquor.

Please check one

☐☐ number of drinks per 1☐ week ***OR*** 2☐ month

MODULE 5

PHYSICAL ACTIVITY

20. Have you ever engaged in a routine that includes vigorous leisure-time physical activity for at least 10 minutes a day that caused heavy sweating or large increases in breathing or heart rate?

1☐ Yes   2☐ No   9☐ Don't know

20a. If yes, please indicate the number of times per week, month ***OR*** year that you engaged in vigorous activity for at least 10 minutes for each age period **(*up to your current age period)*. *If you did not engage in vigorous activity for any age period (up to your current age period), fill in the number of times as 00.***

Age period	Engaged in Physical Activity	Number of Times	Please check one Week	Month	Year
15-24 years	1☐ Yes 2☐ No	☐☐	1☐	2☐	3☐
25-34 years	1☐ Yes 2☐ No	☐☐	1☐	2☐	3☐
35-44 years	1☐ Yes 2☐ No	☐☐	1☐	2☐	3☐
45-54 years	1☐ Yes 2☐ No	☐☐	1☐	2☐	3☐
55-64 years	1☐ Yes 2☐ No	☐☐	1☐	2☐	3☐
65 years or older	1☐ Yes 2☐ No	☐☐	1☐	2☐	3☐

MODULE 6

FAMILY HISTORY

The following questions relate to biological family members including parents, sisters and brothers (including half siblings) and children. Please **do not** include adopted relatives.

21. How many biological sisters (including half-sisters) do you have, living or deceased?

□□ number

21. How many biological brothers (including half-brothers) do you have, living or deceased?

□□ number

22. How many biological children do you have, living or deceased?

□□ number

Please complete a few questions about **each** of your immediate relatives with respect to particular medical conditions they may have had.

Among your biological relatives, including your parents, sisters, brothers and children, has anyone ever been diagnosed by a physician with any of the following conditions?

YOUR BIOLOGICAL PARENTS:

Relationship	Is the family member living?	What is the family member's current age or the age at his/her death?	Has the family member ever been diagnosed by a physician with any of the following medical conditions?	At what age was he/she diagnosed with the condition?
Mother	1☐ Yes 2☐ No 9☐ Don't know	☐☐ years old	Amyotrophic lateral sclerosis: 1☐ Yes 2☐ No 9☐ Don't know	10. ☐☐ ☐ 11. Age Don't know
			Alzheimer's disease: 1☐ Yes 2☐ No 9☐ Don't know	12. ☐☐ ☐ 13. Age Don't know
			Parkinson's disease: 1☐ Yes 2☐ No 9☐ Don't know	14. ☐☐ ☐ 15. Age Don't know
Father	1☐ Yes 2☐ No 9☐ Don't know	☐☐ years old	Amyotrophic lateral sclerosis: 1☐ Yes 2☐ No 9☐ Don't know	16. ☐☐ ☐ 17. Age Don't know
			Alzheimer's disease: 1☐ Yes 2☐ No 9☐ Don't know	18. ☐☐ ☐ 19. Age Don't know
			Parkinson's disease: 1☐ Yes 2☐ No 9☐ Don't know	20. ☐☐ ☐ 21. Age Don't know

YOUR BIOLOGICAL SIBLINGS:

Relationship	Is the family member living?	What is the family member's current age or the age at his/her death?	Has the family member ever been diagnosed by a physician with any of the following medical conditions?		At what age was he/she diagnosed with the condition?	
1☐ Sister 2☐ Brother	1☐ Yes 2☐ No 9☐ Don't know	☐☐ years old	Amyotrophic lateral sclerosis:	1☐ Yes 2☐ No 9☐ Don't know	☐☐ Age	☐ Don't know
			Alzheimer's disease:	1☐ Yes 2☐ No 9☐ Don't know	☐☐ Age	☐ Don't know
			Parkinson's disease:	1☐ Yes 2☐ No 9☐ Don't know	☐☐ Age	☐ Don't know
1☐ Sister 2☐ Brother	1☐ Yes 2☐ No 9☐ Don't know	☐☐ years old	Amyotrophic lateral sclerosis:	1☐ Yes 2☐ No 9☐ Don't know	☐☐ Age	☐ Don't know
			Alzheimer's disease:	1☐ Yes 2☐ No 9☐ Don't know	☐☐ Age	☐ Don't know
			Parkinson's disease:	1☐ Yes 2☐ No 9☐ Don't know	☐☐ Age	☐ Don't know
1☐ Sister 2☐ Brother	1☐ Yes 2☐ No 9☐ Don't know	☐☐ years old	Amyotrophic lateral sclerosis:	1☐ Yes 2☐ No 9☐ Don't know	☐☐ Age	☐ Don't know
			Alzheimer's disease:	1☐ Yes 2☐ No 9☐ Don't know	☐☐ Age	☐ Don't know
			Parkinson's disease:	1☐ Yes 2☐ No 9☐ Don't know	☐☐ Age	☐ Don't know

YOUR BIOLOGICAL SIBLINGS:

Relationship	Is the family member living?	What is the family member’s current age or the age at his/her death?	Has the family member ever been diagnosed by a physician with any of the following medical conditions?	At what age was he/she diagnosed with the condition?
1☐ Sister 2☐ Brother	1☐ Yes 2☐ No 9☐ Don’t know	☐☐ years old	Amyotrophic lateral sclerosis: 1☐ Yes 2☐ No 9☐ Don’t know	☐☐ Age ☐ Don’t know
			Alzheimer’s disease: 1☐ Yes 2☐ No 9☐ Don’t know	☐☐ Age ☐ Don’t know
			Parkinson’s disease: 1☐ Yes 2☐ No 9☐ Don’t know	☐☐ Age ☐ Don’t know
1☐ Sister 2☐ Brother	1☐ Yes 2☐ No 9☐ Don’t know	☐☐ years old	Amyotrophic lateral sclerosis: 1☐ Yes 2☐ No 9☐ Don’t know	☐☐ Age ☐ Don’t know
			Alzheimer’s disease: 1☐ Yes 2☐ No 9☐ Don’t know	☐☐ Age ☐ Don’t know
			Parkinson’s disease: 1☐ Yes 2☐ No 9☐ Don’t know	☐☐ Age ☐ Don’t know
1☐ Sister 2☐ Brother	1☐ Yes 2☐ No 9☐ Don’t know	☐☐ years old	Amyotrophic lateral sclerosis: 1☐ Yes 2☐ No 9☐ Don’t know	☐☐ Age ☐ Don’t know
			Alzheimer’s disease: 1☐ Yes 2☐ No 9☐ Don’t know	☐☐ Age ☐ Don’t know
			Parkinson’s disease: 1☐ Yes 2☐ No 9☐ Don’t know	☐☐ Age ☐ Don’t know

YOUR BIOLOGICAL CHILDREN:

Relationship	Is the family member living?	What is the family member's current age or the age at his/her death?	Has the family member ever been diagnosed by a physician with any of the following medical conditions?	At what age was he/she diagnosed with the condition?
1☐ Daughter 2☐ Son	1☐ Yes 2☐ No 9☐ Don't know	☐☐ years old	Amyotrophic lateral sclerosis: 1☐ Yes 2☐ No 9☐ Don't know	☐☐ Age ☐ Don't know
			Alzheimer's disease: 1☐ Yes 2☐ No 9☐ Don't know	☐☐ Age ☐ Don't know
			Parkinson's disease: 1☐ Yes 2☐ No 9☐ Don't know	☐☐ Age ☐ Don't know
1☐ Daughter 2☐ Son	1☐ Yes 2☐ No 9☐ Don't know	☐☐ years old	Amyotrophic lateral sclerosis: 1☐ Yes 2☐ No 9☐ Don't know	☐☐ Age ☐ Don't know
			Alzheimer's disease: 1☐ Yes 2☐ No 9☐ Don't know	☐☐ Age ☐ Don't know
			Parkinson's disease: 1☐ Yes 2☐ No 9☐ Don't know	☐☐ Age ☐ Don't know
1☐ Daughter 2☐ Son	1☐ Yes 2☐ No 9☐ Don't know	☐☐ years old	Amyotrophic lateral sclerosis: 1☐ Yes 2☐ No 9☐ Don't know	☐☐ Age ☐ Don't know
			Alzheimer's disease: 1☐ Yes 2☐ No 9☐ Don't know	☐☐ Age ☐ Don't know
			Parkinson's disease: 1☐ Yes 2☐ No 9☐ Don't know	☐☐ Age ☐ Don't know

YOUR BIOLOGICAL CHILDREN:

Relationship	Is the family member living?	What is the family member's current age or the age at his/her death?	Has the family member ever been diagnosed by a physician with any of the following medical conditions?	At what age was he/she diagnosed with the condition?
1☐ Daughter 2☐ Son	1☐ Yes 2☐ No 9☐ Don't know	☐☐ years old	Amyotrophic lateral sclerosis: 1☐ Yes 2☐ No 9☐ Don't know Alzheimer's disease: 1☐ Yes 2☐ No 9☐ Don't know Parkinson's disease: 1☐ Yes 2☐ No 9☐ Don't know	☐☐ Age ☐ Don't know ☐☐ Age ☐ Don't know ☐☐ Age ☐ Don't know
1☐ Daughter 2☐ Son	1☐ Yes 2☐ No 9☐ Don't know	☐☐ years old	Amyotrophic lateral sclerosis: 1☐ Yes 2☐ No 9☐ Don't know Alzheimer's disease: 1☐ Yes 2☐ No 9☐ Don't know Parkinson's disease: 1☐ Yes 2☐ No 9☐ Don't know	☐☐ Age ☐ Don't know ☐☐ Age ☐ Don't know ☐☐ Age ☐ Don't know
1☐ Daughter 2☐ Son	1☐ Yes 2☐ No 9☐ Don't know	☐☐ years old	Amyotrophic lateral sclerosis: 1☐ Yes 2☐ No 9☐ Don't know Alzheimer's disease: 1☐ Yes 2☐ No 9☐ Don't know Parkinson's disease: 1☐ Yes 2☐ No 9☐ Don't know	☐☐ Age ☐ Don't know ☐☐ Age ☐ Don't know ☐☐ Age ☐ Don't know

TWICE YEARLY SURVEY MODULE

Self-Administered Rating Scale

The following rating scale is used to assess changes in physical functioning in persons with ALS and other motor neuron diseases.

The questions refer to how you are currently functioning at home. Please read each item carefully and base your answers on your functioning today compared to the time before you had any symptoms of ALS. Please choose the answer that best fits your functional status today. Place an “x” in the box next to your answer.

Compared with the time before you had symptoms of ALS or motor neuron disease:

1. Have you noticed any changes in your speech?

- ☐ no change
- ☐ I have a noticeable speech difference.
- ☐ My speech has changed. I am asked often to repeat words or phrases.
- ☐ My speech has changed. I sometimes need the use of alternative communication methods (i.e. computer, writing pad, letter board or eye chart).
- ☐ I am unable to communicate verbally.

2. Have you noticed any changes (increases) in the amount of saliva in your mouth (regardless of any medication use)?

- ☐ no change
- ☐ I have slight but definite excess of saliva with or without night time drooling.
- ☐ I have moderate amounts of excessive saliva with or without minimal day time drooling.
- ☐ I have marked amounts of excessive saliva with some daytime drooling.
- ☐ I have marked excessive saliva with marked drooling requiring a constant tissue or handkerchief.

Compared with the time before you had symptoms of ALS or motor neuron disease:

3. Have there been any changes in your ability to swallow?

- ☐ no changes for all foods and liquids
- ☐ I have some changes in swallowing or occasional choking episodes (including coughing during swallowing).
- ☐ I am unable to eat all consistencies of food and have modified the consistency of foods eaten.
- ☐ I use a feeding tube (PEG) to supplement what is eaten by mouth.
- ☐ I do not eat anything by mouth and receive all nutrition through a feeding tube (PEG).

Public reporting burden of this collection of information is estimated to average 5 minutes per module, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed and completing and reviewing the data collection of information. An agency may not conduct or sponsor and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Information Collection Review Office, 1600 Clifton Road NE, MS D-74, Atlanta, GA 30333; ATTN: PRA (0923-XXXX).

4. Has your handwriting changed? Please choose the best answer that describes your handwriting with your dominant (usual) hand without a cuff or brace.

- ☐ no changes
- ☐ My handwriting is slower and/or sloppier but all the words are legible.
- ☐ Not all my words are legible.
- ☐ I am able to hold a pen but unable to write.
- ☐ I am unable to hold a pen.

5. The following question refers to your ability to cut foods and handle utensils (feed yourself). Compared with the time before you had symptoms of ALS or motor neuron disease:

a. Is most of your nutrition through a feeding tube (PEG)?

- ☐ Yes – Skip to II
- ☐ No – Skip to b

b. Do you eat most of your meals by mouth?

- ☐ Yes – Skip to I

I. Cutting food and handling utensils:

- ☐ no change
- ☐ My cutting food or handling utensils is somewhat slow and clumsy (or different than before) but I do not need assistance or adaptive equipment.
- ☐ I sometimes need help with cutting more difficult foods.
- ☐ My food must be cut by someone else but I can feed myself slowly without assistance.
- ☐ I need to be fed.

II. Using a feeding tube (PEG)

- ☐ I use a PEG without assistance or difficulty.
- ☐ I use a PEG without assistance however I may be slow and /or clumsy.
- ☐ I require assistance with closures and fasteners.
- ☐ I provide minimal assistance to a caregiver.
- ☐ I am unable to perform any of the manipulations.

Compared with the time before you had symptoms of ALS or motor neuron disease: 6. Has your ability to dress and perform self-care activities (i.e. bathing, teeth brushing, shaving, combing your hair, other hygienic activities) changed?

- ☐ no change
- ☐ I perform self-care activities without assistance but with increased effort or decreased efficiency.
- ☐ I require intermittent assistance or use different methods (i.e. sit down to get dressed, fasten buttons with a fastener or your non-dominant hand).
- ☐ I require daily assistance.
- ☐ I do not perform self-care activities and am completely dependent on caregiver.

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7. Has your ability to turn in bed and adjust the bed clothes (i.e.. cover yourself with the sheet or blanket) changed?

- ☐ no change
- ☐ I can turn in bed and adjust the bed clothes without assistance but it is slower or more clumsy.
- ☐ I can turn in bed or adjust the bedclothes without assistance but with great difficulty.
- ☐ I can initiate turning in bed or adjusting the bed clothes but require assistance to complete the task.
- ☐ I am helpless in bed.

Compared with the time before you had symptoms of ALS or motor neuron disease:

8. Has your ability to walk changed?

- ☐ no change
- ☐ My walking has changed but I do not require any assistance or devices (i.e. foot brace, cane, or walker).
- ☐ I require assistance to walk (i.e. cane, walker, foot brace or hand held assistance).
- ☐ I can move my legs or stand up but am unable to walk from room to room.
- ☐ I cannot walk or move my legs.

9. Has your ability to climb stairs changed?

- ☐ no change
- ☐ I am slower.
- ☐ I am unsteady and/or more fatigued.
- ☐ I require assistance (i.e. using the handrail, cane or person).
- ☐ I cannot climb stairs.

Compared with the time before you had symptoms of ALS or motor neuron disease:

10. Do you experience shortness of breath or have difficulty breathing?

- ☐ no change
- ☐ I have shortness of breath only with walking.
- ☐ I have shortness of breath with minimal exertion (i.e. talking, eating, bathing or dressing).
- ☐ I have shortness of breath at rest while either sitting or lying down.
- ☐ I have significant shortness of breath (all of the time) and considering using mechanical ventilation.

11. Do you experience shortness of breath or have difficulty breathing while lying down on your back?

- ☐ no change
- ☐ I occasional have shortness of breath while lying on back but don't routinely use more that two (2) pillows to sleep.
- ☐ I have shortness of breath while lying on back and require more than two pillows (or an equivalent) to sleep.
- ☐ I can only sleep sitting up due to shortness of breath.
- ☐ I require the use of respiratory (breathing) support (BiPAP® or invasive ventilation via tracheostomy) to sleep and do not sleep without it.

12. Do you require respiratory (breathing) support?

- ☐ I need no respiratory support.
- ☐ I need intermittent use of BiPAP®.
- ☐ I need continuous use of BiPAP® at night.
- ☐ I need continuous use of BiPAP® at night and during the day (nearly 24 hours per day).
- ☐ I need mechanical ventilation by intubation or tracheostomy.

13. Please indicate who completed this survey:

- ☐ I completed the survey (patient).
- ☐ I completed the survey with assistance.
- ☐ I completed the survey with assistance from caregiver or family member.
- ☐ The caregiver completed the survey alone.

14. What is your current weight? __ __ __ lbs

15. Have you been hospitalized in the past 6 months? ☐Yes ☐ No

15a. If yes, how many times were you in the hospital? __ __
15b. How many days were you hospitalized? __ __ (total number of days)

16. Have you gone to the Emergency Room in the past 6 months? ☐Yes ☐ No

16a. If yes, how many times have you visited the Emergency Room? __ __