

Attachment 6
 Approved Surveys (screenshots)
 (16 Voluntary Survey Modules and Disease Progression Survey)

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Please Note: OMB Burden Statement appears on the individual's Survey Accounts page. Because participants can take surveys in any order, the OMB Burden Statement was placed on the one page that everyone has to view.


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National Amyotrophic Lateral Sclerosis (ALS) Registry

ALS Registry Home

- [Registry Resources](#)
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My Account

- [Account Information](#)
- [Surveys](#)

Contact Us:

- 
 Agency for Toxic Substances and Disease Registry
 4770 Buford Hwy NE
 Atlanta, GA 30341
- 
 800-232-4636
 TTY: (888) 232-6348
 Monday-Friday:
 8am-8pm
 Closed Holidays
- 
[Contact CDC-INFO](#)

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[Manage My Account](#)
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Persons with ALS (PALS) Account

The persons with ALS account is designed to allow easy access to all resources available to you as a registrant. From this page, you can take available surveys and update your account, change your password, and contact the system administrator for assistance with your account.

Account

Update Account

This page allows you to make changes to your personal information, such as your address or security questions.

Change Password

This page allows you to change the password you use to log into your account.

Contact System Administrator

This page provides you a point of contact to the ALS web portal system administrator.

Surveys

Available Surveys

This page allows you to take surveys for the National ALS Registry. Please check back periodically for additional surveys.

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 Page last updated: Nov 05, 2015
 Content source: Centers for Disease Control and Prevention

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 Contact CDC: 800-232-4636 / TTY: 888-232-6348




Figure 1: PALS Login Landing Page to Access Surveys

National Amyotrophic Lateral Sclerosis (ALS) Registry

- ALS Registry Home**
- Registry Resources
- Research Notification
- Bioregistry
- Surveillance Projects
- Feedback and Help
- ALS Reports
- Publications and Conferences
- Education & Training
- Multimedia Tools
- Order Registry Materials
- My Account**
- Account Information
- Surveys

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Survey modules are brief and include some questions about who you are, where you lived or worked, family history of ALS, and how you are coping with your disease. You will only be asked to answer Surveys 1-15 and Supplements A & B one time. Twice a year, you will be asked to complete questions on Disease Progression. You can do the survey modules whenever you want. You can do them all at once or over a period of time. Although you can complete the surveys in any order, we recommend that you start with Survey 1 and complete them in order.

Form Approved
OMB No. 0923-0041
Exp. Date xx/xx/201x

[General Instructions](#)

Contact Us:

Agency for Toxic Substances and Disease Registry
4770 Buford Hwy NE
Atlanta, GA 30341

800-232-4636
TTY: (888) 232-6348
Monday-Friday:
8am-8pm
Closed Holidays

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Surveys

Survey	Status	Date Completed
Survey 1	In Progress	
Survey 2	In Progress	
Survey 3	In Progress	
Survey 4	In Progress	
Survey 5	In Progress	
Survey 6	In Progress	
Disease Progression	New	
Survey 8	In Progress	
Survey 9	In Progress	
Survey 10	In Progress	
Survey 11	In Progress	
Survey 12 (Women only)	In Progress	
Survey 13	In Progress	
Survey 14	In Progress	
Survey 15	In Progress	
Supplement A	In Progress	
Supplement B	In Progress	

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 (0923-0041) Expiration : 09/30/16.

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Figure 2: Select Survey to Take

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

General Instructions

How to fill in answers:

- Please read each survey question carefully and answer to the best of your knowledge.
- Answers to questions come in several formats:
 - Radio buttons and drop-down selections allow only one input per question. **Example:** radio button (or) Yes drop-down
 - Check box selections allow multiple answers per question. **Example:** check box 1 check box 2
 - Text boxes allow you to type in an answer. Text box entries are identified as an empty box or selection labeled "Other (specify)". **Example:** text box
- Some questions within each survey will appear "grayed-out" because of your answer to an earlier question. These questions do not apply to you and you can continue onto the next survey question or page.

How the system works:

- Each time you go to the next page of a survey your answers to the previous page are saved.
- You have the option to save and quit a survey at anytime. When you decide to save and quit the survey your responses are saved and you can finish the survey later.
- At the end of each survey, you have the option to review and change your answers. You can also print a copy of your answers. Once you submit your answers, you will not be able to change or print them later.
- There is no time limit to take surveys. However, if you stay logged in and do not work on the survey an alert will display. You will be informed that your session will time out if no further activity takes place.

[Take Survey](#)

[Return to Surveys Homepage](#)

[Print](#)

Figure 3: General Instructions

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Survey 1

1. What is your date of birth?
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?
 Male
 Female
5. What is your current marital status?
6. What is the highest level of education that you have completed?
 Did not complete High School
(Specify highest grade completed):
 High school diploma or GED
 Technical or trade school diploma
 Some college credit
 College degree (AA, BA, BS, etc)
 Graduate school degree
 Other
(specify):

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[Save & Quit](#)

Figure 4: Survey 1, Page 1 of 4

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Survey 1

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

- No
- Yes, Puerto Rican
- Yes, Mexican, Mexican American, Chicano
- Yes, Cuban
- 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.

<input checked="" type="checkbox"/> White	<input checked="" type="checkbox"/> Black or African-American
<input checked="" type="checkbox"/> Native American or Alaska Native	<input checked="" type="checkbox"/> Asian Indian
<input checked="" type="checkbox"/> Chinese	<input checked="" type="checkbox"/> Filipino
<input checked="" type="checkbox"/> Japanese	<input checked="" type="checkbox"/> Korean
<input checked="" type="checkbox"/> Vietnamese	<input checked="" type="checkbox"/> Samoan
<input checked="" type="checkbox"/> Native Hawaiian	<input checked="" type="checkbox"/> Guamanian or Chamorro
<input checked="" type="checkbox"/> Other Asian (specify): <input type="text"/>	<input checked="" type="checkbox"/> Other Pacific Islander (specify): <input type="text"/>
<input checked="" type="checkbox"/> Don't know	

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Figure 5: Survey 1, Page 2 of 4

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Survey 1

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)

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Figure 6: Survey 1, Page 3 of 4

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Survey 1

Survey Review

Thank you for taking the survey. Below are the answers you provided. Please take a minute to look over your answers. When you are finished, you can change your answers, save them to look at later, or submit them. If you would like a copy of your answers, please print them now. Once you submit your answers, you will not be able change or print them later.

Survey Responses:

1. Date of Birth	8/1968
2. Age (today)	39
3. Age (diagnosis)	39
4. Gender	Female
5. Marital Status	Married
6. Education (highest level)	Some college credit
7. Spanish, Hispanic, Latino/Latina	Yes, Cuban
8. Race	White, Black or African-American, Native American or Alaska Native, Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, Other Asian: text, Native Hawaiian, Guamanian or Chamorro, Samoan, Other Pacific Islander: text, Don't know
9. Country	UNITED STATES
10. Height	5(ft) 11(in)
11. Weight	225(lbs)
12. Height (Age 40)	
13. Weight (Age 40)	

Please Check Response:

Invalid response: date of birth and age do not match.

Not Answered

Not Answered

[Change Answers](#)

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[Save & Submit](#)

[Save & Quit](#)

[Print Page](#)

Figure 7: Survey 1, Page 4 of 4

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Congratulations!

You've successfully submitted Survey. Please click the link below to return to the ALS Surveys page.

[ALS Surveys](#)

Figure 8: Survey Taken Confirmation Page (Same for ALL Surveys)

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Survey 2

1. What is your current employment status?

Full-time employed Part-time employed Unemployed

Retired Disabled Other (specify):

Full-time student Homemaker

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

Job Title:

Job Title (specify):

Industry:

Please select a sub-category:

3. For how many years were you employed in this occupation?

years

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Figure 9: Survey 2, Page 1 of 3



National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Survey 2

4. 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:

Other (specify):

Job Title (specify): Advertising Account Exec

Industry

--Select--

Please select a sub-category:

--Industry not selected--

5. For how many years were you employed in this occupation?

years

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Figure 10: Survey 2, Page 2 of 3

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Survey 2

Survey Review

Thank you for taking the survey. Below are the answers you provided. Please take a minute to look over your answers. When you are finished, you can change your answers, save them to look at later, or submit them. If you would like a copy of your answers, please print them now. Once you submit your answers, you will not be able change or print them later.

Survey Responses:

Please Check Response:

1. Employment	Disabled	
2. Occupation (current)		
Job Title	Does not apply	
Industry	Does not apply	
Sub-category	Does not apply	
3. Years (employed)	Does not apply	
4. Occupation (employed longest)		
Job Title	Other (specify):Advertising Account Exec	
Industry		Not Answered
Sub-category	Does not apply	
5. Years (employed)		Not Answered

[Change Answers](#)

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Figure 11: Survey 2, Page 3 of 3

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Survey 3

1. Were you ever a member of the armed forces?
 Yes
 No
 Don't know

2. If yes, in which branch of service were you employed?
 Army Navy
 Marines Air Force
 Coast Guard Reserves/National Guard

3. Were you ever deployed to a war arena?
 Yes
 No

4. If yes, to which war arena were you deployed?
 World War II Persian Gulf
 Korean Conflict Persian Gulf II
 Vietnam War Afghanistan War
 Other (specify):

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Figure 12: Survey 3, Page 1 of 2

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Survey 3

Survey Review

Thank you for taking the survey. Below are the answers you provided. Please take a minute to look over your answers. When you are finished, you can change your answers, save them to look at later, or submit them. If you would like a copy of your answers, please print them now. Once you submit your answers, you will not be able change or print them later.

Survey Responses:

- | | |
|-------------------------|----------------|
| 1. Armed Forces | No |
| 2. Branch | Does not apply |
| 3. Deployed (war arena) | Does not apply |
| 4. War Arena | Does not apply |

Check Response:

[Change Answers](#)

Page 2 / 2

[Save & Submit](#)

[Save & Quit](#)

[Print Page](#)

Figure 13: Survey 3, Page 2 of 2

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Survey 4

1. Have you ever smoked one or more cigarettes per day for six months or longer? Yes No Don't know
2. If yes, how old were you when you first started smoking one or more cigarettes per day? years old
3. Are you still a cigarette smoker? Yes No Don't know
4. If no, at what age did you last stop smoking cigarettes? years old
5. During periods when you smoked, for how many years in total did you smoke cigarettes? years
6. During periods when you smoked, how many cigarettes did you usually smoke in a day? One pack contains 20 cigarettes. number of cigarettes per day

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Save & Quit

Figure 14: Survey 4, Page 1 of 3

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Survey 4

- 7. Did you ever drink alcoholic beverages such as wine, beer and spirits at least once a month for 6 months or more? Yes No Don't know
- 8. Are you still drinking alcoholic beverages at least once per month? Yes No
- 9. During periods when you were drinking alcoholic beverages, for how many years in total did you drink alcoholic beverages? years
- 10. 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. number of drinks week month

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Figure 15: Survey 4, Page 2 of 3

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Survey 4

Survey Review

Thank you for taking the survey. Below are the answers you provided. Please take a minute to look over your answers. When you are finished, you can change your answers, save them to look at later, or submit them. If you would like a copy of your answers, please print them now. Once you submit your answers, you will not be able change or print them later.

Survey Responses:

1. Smoked (6 months or longer)	Yes
2. Age (first started smoking)	
3. Still smoker	
4. Age (stop smoking)	Does Not Apply
5. Years Smoking (total)	
6. Cigarettes Smoked (per day)	
7. Drink alcohol (6 months or longer)	No
8. Still drinking (once per month)	Does Not Apply
9. Total years (drinking)	Does Not Apply
10. Drinks (number/frequency)	Does Not Apply

Please Check Response:

Not Answered
 Not Answered
 Not Answered
 Not Answered

[Change Answers](#)

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Figure 16: Survey 4, Page 3 of 3

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Survey 5

1. 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? Yes No Don't know
2. 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? 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**)

Age Period	Engaged in Physical Activity	Number of Times	Please select one
15-24 years	<input checked="" type="radio"/> Yes <input type="radio"/> No	<input type="text"/>	<input checked="" type="radio"/> Week <input type="radio"/> Month <input type="radio"/> Year
25-34 years	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Age not applicable	<input type="text"/>	<input type="radio"/> Week <input type="radio"/> Month <input type="radio"/> Year
35-44 years	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Age not applicable	<input type="text"/>	<input type="radio"/> Week <input type="radio"/> Month <input type="radio"/> Year
45-54 years	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Age not applicable	<input type="text"/>	<input type="radio"/> Week <input type="radio"/> Month <input type="radio"/> Year
55-64 years	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Age not applicable	<input type="text"/>	<input type="radio"/> Week <input type="radio"/> Month <input type="radio"/> Year
65 years or older	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Age not applicable	<input type="text"/>	<input type="radio"/> Week <input type="radio"/> Month <input type="radio"/> Year

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[Save & Quit](#)

Figure 17: Survey 5, Page 1 of 2



National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Survey 5

Survey Review

Thank you for taking the survey. Below are the answers you provided. Please take a minute to look over your answers. When you are finished, you can change your answers, save them to look at later, or submit them. If you would like a copy of your answers, please print them now. Once you submit your answers, you will not be able change or print them later.

Survey Responses:

Please Check Response:

- 1. Physical Activity Yes
- 2. Vigorous Activity (age period/frequency) 2. Vigorous Activity (age period/frequency)

Age Period	Physical Activity	Number of Times	Frequency
15-24 years	Yes	Not Answered	Week
25-34 years	Not answered	Does not apply	Does not apply
35-44 years	Not answered	Does not apply	Does not apply
45-54 years	Not answered	Does not apply	Does not apply
55-64 years	Not answered	Does not apply	Does not apply
65 years or older	Not answered	Does not apply	Does not apply

[Change Answers](#)

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[Save & Submit](#)

[Save & Quit](#)

[Print Page](#)



Figure 18: Survey 5, Page 2 of 2

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Survey 6

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

1. How many biological sisters (including half-sisters) do you have, living or deceased? number
2. How many biological brothers (including half-brothers) do you have, living or deceased? number
3. 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?

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Figure 19: Survey 6, Page 1 of 9

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Survey 6

Relationship: Mother

1. Is your mother still living?
 - Yes
 - No
 - Don't know

2. What is your mother's current age or the age at her death?
 years old

3. Has your mother ever been diagnosed by a physician with any of the following medical conditions?
 - Amyotrophic lateral sclerosis:
 - Yes
 - No
 - Don't know

 - Alzheimer's disease:
 - Yes
 - No
 - Don't know

 - Parkinson's disease:
 - Yes
 - No
 - Don't know

4. At what age was she diagnosed with the condition?

<input style="width: 50px;" type="text"/> age (ALS)	<input type="checkbox"/> Don't know
<input style="width: 50px;" type="text"/> age (Alzheimer's)	<input type="checkbox"/> Don't know
<input style="width: 50px;" type="text"/> age (Parkinson's)	<input type="checkbox"/> Don't know

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Figure 20: Survey 6, Page 2 of 9

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Survey 6

Relationship: Father

1. Is your father still living? Yes No Don't know
2. What is your father's current age or the age at his death? years old
3. Has your father ever been diagnosed by a physician with any of the following medical conditions?
- Amyotrophic lateral sclerosis: Yes No Don't know
- Alzheimer's disease: Yes No Don't know
- Parkinson's disease: Yes No Don't know
4. At what age was he diagnosed with the condition?
- age (ALS) Don't know
- age (Alzheimer's) Don't know
- age (Parkinson's) Don't know

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Figure 21: Survey 6, Page 3 of 9

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Survey 6

Relationship: Sibling (sister)

Please fill out information about each of your sisters and then click on "Save Sister" when finished. Repeat the process for each additional sister.

1. Is your sister still living? Yes No Don't know
2. What is your sister's current age or the age at her death? years old
3. Has your sister ever been diagnosed by a physician with any of the following medical conditions?
 - Amyotrophic lateral sclerosis: Yes No Don't know
 - Alzheimer's disease: Yes No Don't know
 - Parkinson's disease: Yes No Don't know
4. At what age was she diagnosed with the condition?

<input type="text"/>	age (ALS)	<input type="checkbox"/> Don't know
<input type="text"/>	age (Alzheimer's)	<input type="checkbox"/> Don't know
<input type="text"/>	age (Parkinson's)	<input type="checkbox"/> Don't know

Please add **1** sister(s):

No Data Found

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Figure 22: Survey 6, Page 4 of 9

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Survey 6

Relationship: Sibling (brother)

Please fill out information about each of your brothers and then click on "Save Brother" when finished. Repeat the process for each additional brother.

1. Is your brother still living? Yes No Don't know
2. What is your brother's current age or the age at his death? years old
3. Has your brother ever been diagnosed by a physician with any of the following medical conditions?
Amyotrophic lateral sclerosis: Yes No Don't know
Alzheimer's disease: Yes No Don't know
Parkinson's disease: Yes No Don't know
4. At what age was he diagnosed with the condition?
 age (ALS) Don't know
 age (Alzheimer's) Don't know
 age (Parkinson's) Don't know

Please add 1 brother(s):

No Data Found

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Figure 23: Survey 6, Page 5 of 9

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Survey 6

Relationship: Children

Please fill out information about each of your children and then click on "Save Child" when finished. Repeat the process for each additional child.

1. Relationship:
 - Daughter
 - Son

2. Is your child still living?
 - Yes
 - No
 - Don't know

3. What is your child's current age or the age at his death?
 years old

4. Has your child ever been diagnosed by a physician with any of the following medical conditions?
 - Amyotrophic lateral sclerosis:
 - Yes
 - No
 - Don't know
 - Alzheimer's disease:
 - Yes
 - No
 - Don't know
 - Parkinson's disease:
 - Yes
 - No
 - Don't know

5. At what age was she/he diagnosed with the condition?
 - age (ALS) Don't know
 - age (Alzheimer's) Don't know
 - age (Parkinson's) Don't know

Please add **2** child(ren):

No Data Found

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Figure 24: Survey 6, Page 6 of 9

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Survey 6

Survey Review

Thank you for taking the survey. Below are the answers you provided. Please take a minute to look over your answers. When you are finished, you can change your answers, save them to look at later, or submit them. If you would like a copy of your answers, please print them now. Once you submit your answers, you will not be able change or print them later.

Survey Responses:

- 1. Biological sisters (number) 1
- 2. Biological brothers (number) 1
- 3. Biological children (number) 2

Mother:

- 1. Still living:
- 2. Age (current/death):
- 3. Medical Condition:
- 4. Age (diagnosed): Does not apply

Father:

- 1. Still living: No
- 2. Age (current/death): 100
- 3. Medical Condition: Alzheimer's:Yes, Parkinson's:No
- 4. Age (diagnosed): Alzheimer's:99

Please Check Response:

Not answered
Not answered
Not answered

Change Answers

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Figure 25: Survey 6, Page 7 of 9

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Survey 6

Survey Review

Survey Responses: **Please Check Response:**

Sibling:

Sister(s): Not answered

Brother(s): Not answered

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Figure 26: Survey 6, Page 8 of 9

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Survey 6

Survey Review

Survey Responses: **Please Check Response:**

Children:

Child(ren): Not answered

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Contact CDC: 800-232-4636 / TTY: 888-232-6348



Figure 27: Survey 6, Page 9 of 9

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Disease Progression

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.

Compared with the time before you had symptoms of ALS or another 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 (e.g. 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.

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Figure 28: Disease Progression Survey, Page 1 of 8

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Disease Progression

Compared with the time before you had symptoms of ALS or another 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).

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.

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Figure 29: Disease Progression Survey, Page 2 of 8

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Disease Progression

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

The following question refers to your ability to cut foods and handle utensils (feed yourself).

5. How do you get most of your nutrition?

- Eat most of your meals by mouth.
- Get most of your nutrition through a feeding tube (PEG)

6. 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.

7. 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.

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Figure 30: Disease Progression Survey, Page 3 of 8

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Disease Progression

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

8. Has your ability to dress and perform self-care activities (e.g. 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 (e.g. 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.
9. Has your ability to turn in bed and adjust the bed clothes (e.g. 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.

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Figure 31: Disease Progression Survey, Page 4 of 8

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Disease Progression

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

10. Has your ability to walk changed?

- No change
- My walking has changed but I do not require any assistance or devices (e.g. foot brace, cane, or walker).
- I require assistance to walk (e.g. 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.

11. Has your ability to climb stairs changed?

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

12. 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 (e.g. 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.

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Figure 32: Disease Progression Survey, Page 5 of 8

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Disease Progression

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

13. 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.

14. 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.

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Figure 33: Disease Progression Survey, Page 6 of 8

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Disease Progression

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

15. 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.
16. What is your current weight?
 (lbs)
17. Have you been hospitalized in the past 6 months?
- Yes
 - No
18. If yes, how many times were you in the hospital?
 number of times
19. How many days were you hospitalized?
 total number of days
20. Have you gone to the Emergency Room in the past 6 months?
- Yes
 - No
21. If yes, how many times have you visited the Emergency Room?
 number of times

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Figure 34: Disease Progression Survey, Page 7 of 8

National Amyotrophic Lateral Sclerosis (ALS) Registry

Text size: [S](#) [M](#) [L](#) [XL](#)

Disease Progression

Survey Review

Thank you for taking the survey. Below are the answers you provided. Please take a minute to look over your answers. When you are finished, you can change your answers, save them to look at later, or submit them. If you would like a copy of your answers, please print them now. Once you submit your answers, you will not be able change or print them later.

Survey Responses:

1. Speech (change)
2. Salvia (increase)
3. Swallow (ability)
4. Handwriting (change)
5. Nutrition (change)
6. Utensils (handling) Does not apply
7. Feeding tube (PEG) Does not apply
8. Self-care (activities)
9. Bed clothes (adjustment)
10. Walking (ability)
11. Stair climbing (ability)
12. Breathing (difficulty)
13. Breathing (lying down)
14. Respiratory (support)
15. Who completed (indicate)
16. Current weight
17. Hospitalized (in 6 months)
18. Hospitalized (times) Does not apply
19. Hospitalized (days) Does not apply
20. Emergency room (in 6 months)
21. Emergency room (times) Does not apply

Please Check Response:

- Not Answered
- Not Answered
- Not Answered
- Not Answered
- Not Answered
- Not Answered
- Not Answered
- Not Answered
- Not Answered
- Not Answered
- Not Answered
- Not Answered
- Not Answered
- Not Answered
- Not Answered
- Not Answered
- Not Answered
- Not Answered
- Not Answered
- Not Answered

[Change Answers](#)

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Figure 35: Disease Progression Survey, Page 8 of 8



National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 8

Residence History

We are interested in the location of your residences for all the places where you lived for a period of 6 months or longer. Starting with the place where you were born, indicate the city and state (or country) of each place where you lived for 6 months or longer. If you lived on a farm, please give the nearest city or town. If you moved to a different residence within the same city, please include each home or dwelling as a separate entry.

1. At what age did you move to your next residence of **6 months or longer**? Years old
2. In what city or town was this residence?
3. In what state (or country) was this residence?
4. Was this residence a farm or a ranch?
 Yes No Don't know
5. Was your main source of drinking water at this residence a private well?
 Yes No Don't know
6. Was this residence within **1/4 mile** of an agricultural area that was sprayed with pesticides or herbicides?
 Yes No Don't know
 - a. How often did the pesticide or herbicide spraying happen?
 <1 time/year
 1-3 times/year
 ≥ 4 times/year
 Don't know
7. Was this your current or most recent residence?
 Yes No

Address(s):

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Figure 36: Survey 8, Page 1 of 2

National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 8

Survey Review

Thank you for taking the survey. Below are the answers you provided. Please take a minute to look over your answers. When you are finished, you can change your answers, save them to look at later, or submit them. If you would like a copy of your answers, please print them now. Once you submit your answers, you will not be able change or print them later.

Survey Responses:

Please Check Response:

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Figure 37: Survey 8, Page 2 of 2

National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 9

Lifetime Occupational History

The following questions ask about pesticides or chemicals that you may have used at work during at least 100 days or more during your lifetime.

Pesticides

We are interested in those pesticide products that you personally handled on the JOB, either by preparing them prior to application, by applying them yourself or by helping to clean up after they were applied.

1. Over your lifetime (at least 100 days or more), have you ever had a JOB where you handled HERBICIDES (to kill weeds)? Yes No Don't know
- a. At what age did you **FIRST** handle herbicides? Age
- b. At what age did you **LAST** handle herbicides? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** use herbicides? Years
2. Over your lifetime (at least 100 days or more), have you ever had a JOB where you handled FUNGICIDES (to control mildew, mold or rot)? Yes No Don't know
- a. At what age did you **FIRST** handle fungicides? Age
- b. At what age did you **LAST** handle fungicides? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** use fungicides? Years

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Figure 38: Survey 9, Page 1 of 11

National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 9

Lifetime Occupational History

Pesticides

3. Over your lifetime (at least 100 days or more), have you ever had a JOB where you handled INSECTICIDES (to control insects or pests)?
- Yes No Don't know
- a. At what age did you **FIRST** handle insecticides? Age
- b. At what age did you **LAST** handle insecticides? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** use insecticides? Years
4. Over your lifetime (at least 100 days or more), have you ever had a JOB where you handled RODENTICIDES (to kill rats or mice)?
- Yes No Don't know
- a. At what age did you **FIRST** handle rodenticides? Age
- b. At what age did you **LAST** handle rodenticides? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** use rodenticides? Years

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Figure 39: Survey 9, Page 2 of 11

National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 9

Lifetime Occupational History

Pesticides

5. Over your lifetime (at least 100 days or more), have you ever had a JOB where you handled FUMIGANTS (gas used to kill fungus, mold or insects)? Yes No Don't know
- a. At what age did you **FIRST** handle fumigants? Age
- b. At what age did you **LAST** handle fumigants? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** use fumigants? Years

Solvents

6. Over your lifetime (at least 100 days or more), have you ever had a JOB where you used GLUES OR ADHESIVES? Yes No Don't know
- a. At what age did you **FIRST** use glues or adhesives? Age
- b. At what age did you **LAST** use glues or adhesives? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** use glues or adhesives? Years

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Figure 40: Survey 9, Page 3 of 11

National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 9

Lifetime Occupational History

Solvents

7. Over your lifetime (at least 100 days or more), have you ever had a JOB where you used SOLVENTS AND DEGREASERS? Yes No Don't know

- a. At what age did you **FIRST** use solvents and degreasers? Age
- b. At what age did you **LAST** use solvents and degreasers? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** use solvents and degreasers? Years

8. Over your lifetime (at least 100 days or more), have you ever had a JOB where you worked with UNLEADED GASOLINE? Yes No Don't know

- a. At what age did you **FIRST** work with unleaded gasoline? Age
- b. At what age did you **LAST** work with unleaded gasoline? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** use unleaded gasoline? Years

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Figure 41: Survey 9, Page 4 of 11



National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 9

Lifetime Occupational History

Solvents

9. Over your lifetime (at least 100 days or more), have you ever had a JOB where you worked with LEADED GASOLINE? Yes No Don't know
- a. At what age did you **FIRST** work with leaded gasoline? Age
- b. At what age did you **LAST** work with leaded gasoline? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** use leaded gasoline? Years
10. Over your lifetime (at least 100 days or more), have you ever had a JOB where you used UNLEADED PAINT? Yes No Don't know
- a. At what age did you **FIRST** use unleaded paint? Age
- b. At what age did you **LAST** use unleaded paint? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** use unleaded paint? Years

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Figure 42: Survey 9, Page 5 of 11

National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 9

Lifetime Occupational History

Solvents

11. Over your lifetime (at least 100 days or more), have you ever had a JOB where you used LEADED PAINT? Yes No Don't know
- a. At what age did you **FIRST** use leaded paint? Age
 - b. At what age did you **LAST** use leaded paint? Age
 - c. This is a total of Years
 - d. For how many of those years did you **NOT** use leaded paint? Years
12. Over your lifetime (at least 100 days or more), have you ever had a JOB where you used FORMALDEHYDE? Yes No Don't know
- a. At what age did you **FIRST** use formaldehyde? Age
 - b. At what age did you **LAST** use formaldehyde? Age
 - c. This is a total of Years
 - d. For how many of those years did you **NOT** use formaldehyde? Years

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Figure 43: Survey 9, Page 6 of 11

National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 9

Lifetime Occupational History

Metals

13. Over your lifetime (at least 100 days or more), have you ever had a JOB where you **SOLDERED**? Yes No Don't know

- a. At what age did you **FIRST** solder? Age
- b. At what age did you **LAST** solder? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** solder? Years

14. What specific metals or materials did you solder?

Tin Yes No Don't know

Silver Yes No Don't know

Other metals or Alloy Yes No Don't know

IF OTHER: Specify

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Figure 44: Survey 9, Page 7 of 11

National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 9

Lifetime Occupational History

Metals

15. Over your lifetime (at least 100 days or more), have you ever had a JOB where you WELDED, BRAZED OR FLAME CUT METALS? Yes No Don't know

a. At what age did you **FIRST** weld, braze or flame cut metals? Age

b. At what age did you **LAST** weld, braze or flame cut metals? Age

c. This is a total of Years

d. For how many of those years did you **NOT** weld, braze or flame cut metals? Years

16. What specific metals or materials did you weld, braze or flame cut?

Steel Yes No Don't know

Iron, copper or aluminum Yes No Don't know

Brass or bronze Yes No Don't know

Lead Yes No Don't know

Other metals or Alloy Yes No Don't know

IF OTHER: Specify

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Figure 45: Survey 9, Page 8 of 11

National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 9

Lifetime Occupational History

Metals

17. Over your lifetime (at least 100 days or more), have you ever had a JOB where you were exposed to METAL DUST OR METAL FUMES? Yes No Don't know

- a. At what age were you **FIRST** exposed to metal dust or metal fumes? Age
- b. At what age were you **LAST** exposed to metal dust or metal fumes? Age
- c. This is a total of Years
- d. For how many of those years were you **NOT** exposed to metal dust or metal fumes? Years

18. To which specific metal dust or metal fumes were you exposed?

- Steel Yes No Don't know
- Iron, copper or aluminum Yes No Don't know
- Brass or bronze Yes No Don't know
- Lead Yes No Don't know
- Other metals or Alloy Yes No Don't know

IF OTHER: Specify

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Figure 46: Survey 9, Page 9 of 11

National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 9

Lifetime Occupational History

Other occupational exposure

19. Over your lifetime (at least 100 days or more), have you ever had a JOB where you worked with ANY OTHER CHEMICAL? Yes No Don't know

Specify

- a. At what age did you **FIRST** work with this chemical? Age
- b. At what age did you **LAST** work with this chemical? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** use this chemical? Years

20. Over your lifetime (at least 100 days or more), have you ever had a JOB where you worked with ANY OTHER CHEMICAL? Yes No Don't know

Specify

- a. At what age did you **FIRST** work with this chemical? Age
- b. At what age did you **LAST** work with this chemical? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** use this chemical? Years

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Figure 47: Survey 9, Page 10 of 11

National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 9

Survey Review

Thank you for taking the survey. Below are the answers you provided. Please take a minute to look over your answers. When you are finished, you can change your answers, save them to look at later, or submit them. If you would like a copy of your answers, please print them now. Once you submit your answers, you will not be able change or print them later.

Survey Responses:

Please Check Response:

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Figure 48: Survey 9, Page 11 of 11

National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 10

Home Pesticide Use

The following questions are about chemicals or home pesticides that you used to kill insects, plants, weeds, mold or mildew, or other pests in or around any house or apartment where you lived. We are interested only in those products that you personally handled, either by preparing them prior to application, by applying them yourself, or by helping to clean up after they were applied. Please consider products that you have personally handled at any time in your life. Please consider only the time from 10 years of age to the present.

1. Have you ever personally handled insecticides to control insects and pests in your home? Yes No Don't know

- a. At what age did you **FIRST** handle insecticides in the home? Age
- b. At what age did you **LAST** handle insecticides in the home? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** handle insecticides in your home? Years
- e. During the periods when you did use insecticides in the home, how many days per year did you use them? Days per year

2. Have you ever personally handled insecticides to control insects and pests in your lawn or garden? Yes No Don't know

- a. At what age did you **FIRST** handle insecticides in the lawn or garden? Age
- b. At what age did you **LAST** handle insecticides in the lawn or garden? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** handle insecticides in the lawn or garden? Years
- e. During the periods when you did use insecticides in the lawn or garden, how many days per year did you use them? Days per year

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National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 10

Home Pesticide Use

3. Have you ever used herbicides or weed killers to control weeds or plants in your lawn, garden, or other areas around the home? Yes No Don't know
- a. At what age did you **FIRST** handle herbicides in your lawn, garden, or other areas around the home? Age
- b. At what age did you **LAST** handle herbicides in your lawn, garden, or other areas around the home? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** use herbicides in your lawn, garden, or other areas around the home? Years
- e. During the periods when you did use herbicides in your lawn, garden, or other areas around the home, how many days per year did you use them? Days per year
4. Have you ever used fungicides to control mildew or rot in your home or plant mold in the garden? Yes No Don't know
- a. At what age did you **FIRST** handle fungicides in the home or garden? Age
- b. At what age did you **LAST** handle fungicides in the home or garden? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** use fungicides? Years
- e. During the periods when you did use fungicides in the home or garden, how many days per year did you use them? Days per year
5. Have you ever personally applied chemical soaps, shampoos, dips or powders to kill fleas, ticks or other insects on a pet, such as a dog or a cat? Yes No Don't know
- a. At what age did you **FIRST** apply these substances to your pet(s)? Age
- b. At what age did you **LAST** apply these substances to your pet(s)? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** apply these substances to your pets? Years
- e. During the periods when you did use these substances, how many days per year did you apply them to your pet(s)? Days per year

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Survey 10

Survey Review

Thank you for taking the survey. Below are the answers you provided. Please take a minute to look over your answers. When you are finished, you can change your answers, save them to look at later, or submit them. If you would like a copy of your answers, please print them now. Once you submit your answers, you will not be able change or print them later.

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Survey 11

Hobbies

The following questions are about home activities and hobbies you have performed on a regular basis, that is, for at least one hour each month for at least one year or more. Please consider only the time from when you were 10 years old to the present.

1. Have you ever done leather work (such as making belts, purses, etc.)? Yes No Don't know

- a. At what age did you **FIRST** do leather work? Age
- b. At what age did you **LAST** do leather work? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** do leather work? Years
- e. During the period when you did leather work, how many **hours each month** did you perform the activity? Hours/Month

2. Have you ever lead glazed pottery or other ceramics? Yes No Don't know

- a. At what age did you **FIRST** glaze pottery or other ceramics? Age
- b. At what age did you **LAST** glaze pottery or other ceramics? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** glaze pottery or other ceramics? Years
- e. During the period when you did glaze pottery or other ceramics, how many **hours each month** did you perform the activity? Hours/Month

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Survey 11

Hobbies

3. Have you ever painted pictures or furniture with oil-based paint? Yes No Don't know

- a. At what age did you **FIRST** paint pictures or furniture with oil-based paint? Age
- b. At what age did you **LAST** paint pictures or furniture with oil-based paint? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** paint pictures or furniture with oil-based paint? Years
- e. During the period when you did paint pictures or furniture with oil-based paint, how many **hours each month** did you perform the activity? Hours/Month

4. Have you ever done home remodeling projects that involved scraping, stripping, burning and sanding paint? Please count only houses built before 1960. Yes No Don't know

- a. At what age did you **FIRST** do home remodeling projects that involved scraping, stripping, burning and sanding paint on houses built before 1960? Age
- b. At what age did you **LAST** do home remodeling projects that involved scraping, stripping, burning and sanding paint on houses built before 1960? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** do home remodeling projects that involved scraping, stripping, burning and sanding paint on houses built before 1960? Years
- e. During the period when you did home remodeling projects that involved scraping, stripping, burning and sanding paint on houses built before 1960, how many **hours each month** did you perform the activity? Hours/Month

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Survey 11

Hobbies

5. Have you ever done woodworking? Yes No Don't know

- a. At what age did you **FIRST** do woodworking? Age
- b. At what age did you **LAST** do woodworking? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** do woodworking? Years
- e. During the period when you did wood working, how many **hours each month** did you perform the activity? Hours/Month

6. Have you ever painted, repaired or restored old cars, other than fixing a flat tire or changing oil? Yes No Don't know

- a. At what age did you **FIRST** paint, repair or restore old cars, other than fixing a flat tire or changing oil? Age
- b. At what age did you **LAST** paint, repair or restore old cars, other than fixing a flat tire or changing oil? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** paint, repair or restore old cars, other than fixing a flat tire or changing oil? Years
- e. During the period when you did paint, repair or restore old cars, other than fixing a flat tire or changing oil, how many **hours each month** did you perform the activity? Hours/Month

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Survey 11

Hobbies

7. Have you ever built wooden or plastic models using glue? Yes No Don't know

- a. At what age did you **FIRST** build wooden or plastic models using glue? Age
- b. At what age did you **LAST** build wooden or plastic models using glue? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** build wooden or plastic models using glue? Years
- e. During the period when you did build wooden or plastic models using glue, how many **hours each month** did you perform the activity? Hours/Month

8. Have you ever developed photographs? Yes No Don't know

- a. At what age did you **FIRST** develop photographs? Age
- b. At what age did you **LAST** develop photographs? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** develop photographs? Years
- e. During the period when you did develop photographs, how many **hours each month** did you perform the activity? Hours/Month

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Survey 11

Hobbies

9. Have you ever done gardening? Yes No Don't know

a. At what age did you **FIRST** do gardening? Age

b. At what age did you **LAST** do gardening? Age

c. This is a total of Years

d. For how many of those years did you **NOT** do gardening? Years

e. During the period when you did gardening, how many **hours each month** did you perform the activity? Hours/Month

10. Have you done soldering, welding, or metal work (such as sculpting, garden structures, etc.)? Yes No Don't know

a. At what age did you **FIRST** solder, weld, or do metal work? Age

b. At what age did you **LAST** solder, weld, or do metal work? Age

c. This is a total of Years

d. For how many of those years did you **NOT** solder, weld, or do metal work? Years

e. During the period when you did solder, weld, or do metal work, how many **hours each month** did you perform the activity? Hours/Month

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Survey 11

Hobbies

11. Have you ever done outdoor hunting or shooting with guns, including animals, skeet, trap or targets? Yes No Don't know

- a. At what age did you **FIRST** do outdoor hunting or shooting with guns, including animals, skeet, trap or targets? Age
- b. At what age did you **LAST** do outdoor hunting or shooting with guns, including animals, skeet, trap or targets? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** do outdoor hunting or shooting with guns, including animals, skeet, trap or targets? Years
- e. During the period when you did outdoor hunting or shooting with guns, including animals, skeet, trap or targets, how many **hours each month** did you perform the activity? Hours/Month

12. Have you ever done gun shooting in an indoor pistol or rifle range? Yes No Don't know

- a. At what age did you **FIRST** do gun shooting in an indoor pistol or rifle range? Age
- b. At what age did you **LAST** do gun shooting in an indoor pistol or rifle range? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** do gun shooting in an indoor pistol or rifle range? Years
- e. During the period when you did gun shooting in an indoor pistol or rifle range, how many **hours each month** did you perform the activity? Hours/Month

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Survey 11

Hobbies

13. Have you ever done casting of bullets or reloading of ammunition? Yes No Don't know

- a. At what age did you **FIRST** do casting of bullets or reloading of ammunition? Age
- b. At what age did you **LAST** do casting of bullets or reloading of ammunition? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** do casting of bullets or reloading of ammunition? Years
- e. During the period when you did casting of bullets or reloading of ammunition, how many **hours each month** did you perform the activity? Hours/Month

14. Have you ever done fishing using lead weights or sinkers? Yes No Don't know

- a. At what age did you **FIRST** do fishing using lead weights or sinkers? Age
- b. At what age did you **LAST** do fishing using lead weights or sinkers? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** do fishing using lead weights or sinkers? Years
- e. During the period when you did fishing using lead weights or sinkers, how many **hours each month** did you perform the activity? Hours/Month

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Survey 11

Hobbies

15. Have you ever done any other HOBBY, such as knitting, making jewelry? Please DO NOT consider physical activity, electronic games, writing as hobbies. Yes No Don't know

Please specify hobby:

- a. At what age did you **FIRST** do this HOBBY? Age
- b. At what age did you **LAST** do this HOBBY? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** do this HOBBY? Years
- e. During the period when you did this HOBBY, how many **hours each month** did you perform the activity? Hours/Month

16. Have you ever done any other HOBBY, such as knitting, making jewelry? Please DO NOT consider physical activity, electronic games, writing as hobbies. Yes No Don't know

Please specify hobby:

- a. At what age did you **FIRST** do this HOBBY? Age
- b. At what age did you **LAST** do this HOBBY? Age
- c. This is a total of Years
- d. For how many of those years did you **NOT** do this HOBBY? Years
- e. During the period when you did this HOBBY, how many **hours each month** did you perform the activity? Hours/Month

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Survey 11

Survey Review

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Survey 12

Hormonal and Reproductive History (Women only)

The following questions are about your menstrual periods.

1. How old were you when you had your first menstrual period? Age
2. Have you had at least one menstrual period in the past 12 months? Please do not include bleedings caused by medical conditions, hormone therapy, or surgeries.
 - a. What is the reason that you have **not had a period** in the past 12 months?
 - Yes
 - No
 - Don't know
 - Pregnancy
 - Breast feeding
 - Menopause/Hysterectomy
 - Medical conditions/Treatments
 - Don't know
 - Other: Please specify
3. How old were you when you had your **LAST** menstrual period? Age

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Survey 12

Hormonal and Reproductive History (Women only)

The next questions are about your pregnancy and childbirth history.

4. Have you ever been pregnant? Yes No Don't know
- a. How many times have you been pregnant? Please count all pregnancies including (live births, miscarriages, stillbirths, tubal pregnancies or abortions). Number of pregnancies
5. Are you currently pregnant? Yes No Don't know
6. How many deliveries resulted in a live birth? Number of live births
7. How old were you at the time of your **FIRST** live birth? Age
8. How old were you at the time of your **LAST** live birth? Age

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Survey 12

Survey Review

Thank you for taking the survey. Below are the answers you provided. Please take a minute to look over your answers. When you are finished, you can change your answers, save them to look at later, or submit them. If you would like a copy of your answers, please print them now. Once you submit your answers, you will not be able change or print them later.

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Survey 13

Caffeine

The next questions pertain to your usual caffeine habits as an adult. By usual, we mean drinking the beverage at least once a month for six months or more.

1. Did you ever drink espresso or espresso drinks (Latte, Mocha, Americano)? A serving of espresso is 1 shot.
 - Yes No Don't know
 - a. At what age did you **FIRST** drink espresso or espresso drinks at least once per month? Age
 - b. Are you still drinking espresso or espresso drinks at least once per month? Yes No Don't know
 - c. At what age did you **LAST** drink espresso or espresso drinks at least once per month? Age
 - d. This is a total of Years
 - e. Were there any periods of time during these years when you did **NOT** drink espresso or espresso drinks? If no, then record as (00 years). Years
 - f. During the periods when you did drink espresso, how often (per day, week, month **or** year) did you drink them? Number of drinks per day week month year

2. Did you ever drink caffeinated coffee? A serving of coffee is 8 ounces.
 - Yes No Don't know
 - a. At what age did you **FIRST** drink caffeinated coffee at least once per month? Age
 - b. Are you still drinking caffeinated coffee at least once per month? Yes No Don't know
 - c. At what age did you **LAST** drink caffeinated coffee at least once per month? Age
 - d. This is a total of Years
 - e. For how many of those years did you **NOT** drink caffeinated coffee? Years
 - f. During the periods when you did drink caffeinated coffee, how often (per day, week, month **or** year) did you drink it? Number of drinks per day week month year

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Survey 13

Caffeine

3. Did you ever drink caffeinated tea (green or black), hot or iced? A serving of tea is 8 oz. Yes No Don't know

a. At what age did you **FIRST** drink caffeinated tea at least once per month? Age

b. Are you still drinking caffeinated tea at least once per month? Yes No Don't know

c. At what age did you **LAST** drink caffeinated tea at least once per month? Age

d. This is a total of Years

e. For how many of those years did you **NOT** drink caffeinated tea? Years

f. During the periods when you did drink caffeinated tea, how often (per day, week, month **or** year) did you drink them? Number of drinks per day week month year

4. Did you ever drink highly caffeinated drinks, including Jolt®, Surge®, Mountain Dew MDX®, Red Bull®? A serving of these drinks is a 12 oz can. Yes No Don't know

a. At what age did you **FIRST** drink highly caffeinated drinks at least once per month? Age

b. Are you still drinking highly caffeinated drinks at least once per month? Yes No Don't know

c. At what age did you **LAST** drink highly caffeinated drinks at least once per month? Age

d. This is a total of Years

e. For how many of those years did you **NOT** drink highly caffeinated drinks? Years

f. During the periods when you did drink highly caffeinated drinks, how often (per day, week, month **or** year) did you drink them? Number of drinks per day week month year

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Survey 13

Caffeine

5. Did you ever drink caffeinated soda, including colas, Barq's Root Beer® or regular Mountain Dew®? A serving of colas or root beer is a 12 oz can. Yes No Don't know
- a. At what age did you **FIRST** drink caffeinated soda at least once per month? Age
- b. Are you still drinking caffeinated soda at least once per month? Yes No Don't know
- c. At what age did you **LAST** drink caffeinated soda at least once per month? Age
- d. This is a total of Years
- e. For how many of those years did you **NOT** drink caffeinated soda? Years
- f. During the periods when you did drink caffeinated soda, how often (per day, week, month **or** year) did you drink them? Number of drinks per day week month year

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Survey 13

Survey Review

Thank you for taking the survey. Below are the answers you provided. Please take a minute to look over your answers. When you are finished, you can change your answers, save them to look at later, or submit them. If you would like a copy of your answers, please print them now. Once you submit your answers, you will not be able change or print them later.

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National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 14

Head and Neck Injuries

The next questions are about injuries to your head and/or neck that you may have had at anytime in your life. These may have occurred during sporting activities, from falls, violence, car accidents or other accidents. Please include injuries from both childhood and adulthood.

1. Have you ever had an injury to your head or neck? Think about any childhood injuries you remember or were told about. Yes No Don't know
- a. How many head or neck injuries have you had? Num
- b. At what age did the **FIRST** injury occur? Age
- c. Did you lose consciousness from this injury? Yes No Don't know
- d. How long were you unconscious?
 Less than 5 minutes
 5-59 minutes
 1-24 hours
 Longer than a day
 Don't know
- e. Did you go to the emergency room or were you hospitalized for this injury? Yes No Don't know
- f. From this injury, did you have any of the following (check all that apply)?
 Skull fracture
 Seizure
 Memory loss, amnesia
 None of the above
 Don't know

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National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 14

Head and Neck Injuries

2. Have you ever injured your head or neck in a car accident or from some other moving vehicle accident (e.g. motorcycle, ATV)? Yes No Don't know
- a. How many accidents have you had? Num
- b. At what age did the **FIRST** accident occur? Age
- c. Did you lose consciousness from this accident? Yes No Don't know
- d. How long were you unconscious? Less than 5 minutes 5-59 minutes 1-24 hours Longer than a day Don't know
- e. Did you go to the emergency room or were you hospitalized for this injury? Yes No Don't know
- f. From this injury, did you have any of the following (check all that apply)?
- Skull fracture
 - Seizure
 - Memory loss, amnesia
 - None of the above
 - Don't know

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National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 14

Head and Neck Injuries

3. Have you ever injured your head or neck in a fall or from being hit by something (e.g., falling from a bike, horse, or rollerblades, falling on ice, being hit by a rock)? Have you ever injured your head or neck playing sports or on the playground? Yes No Don't know
- a. How many head or neck injuries from a fall or being hit by something have you had? Num
- b. At what age did the **FIRST** head or neck injury from a fall or being hit by something occur? Age
- c. Did you lose consciousness from this injury? Yes No Don't know
- d. How long were you unconscious? Less than 5 minutes 5-59 minutes 1-24 hours Longer than a day Don't know
- e. Did you go to the emergency room or were you hospitalized for this injury? Yes No Don't know
- f. From this injury, did you have any of the following (check all that apply)? Skull fracture Seizure Memory loss, amnesia None of the above Don't know

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National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 14

Head and Neck Injuries

4. Have you ever injured your head or neck in a fight, from being hit by someone, or from being shaken violently? Have you ever been shot in the head? Yes No Don't know
- a. How many head or neck injuries have you had in a fight or from other violence? Num
- b. At what age did the **FIRST** head or neck injury in a fight or from other violence occur? Age
- c. Did you lose consciousness from this injury? Yes No Don't know
- d. How long were you unconscious? Less than 5 minutes 5-59 minutes 1-24 hours Longer than a day Don't know
- e. Did you go to the emergency room or were you hospitalized for this injury? Yes No Don't know
- f. From this injury, did you have any of the following (check all that apply)?
- Skull fracture
 - Seizure
 - Memory loss, amnesia
 - None of the above
 - Don't know

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Survey 14

Head and Neck Injuries

5. Have you ever been nearby when an explosion or blast occurred? If you served in the military, think about any combat, or training related incidents? Yes No Don't know
- a. How many times were you near an explosion or blast? Num
- b. At what age did the **FIRST** head or neck injury from an explosion or blast occur? Age
- c. Did you lose consciousness from this injury? Yes No Don't know
- d. How long were you unconscious? Less than 5 minutes 5-59 minutes 1-24 hours Longer than a day Don't know
- e. Did you go to the emergency room or were you hospitalized for this injury? Yes No Don't know
- f. From this injury, did you have any of the following (check all that apply)? Skull fracture Seizure Memory loss, amnesia None of the above Don't know

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Survey 14

Electrical Shocks

6. Have you ever received a severe electrical shock that resulted in unconsciousness? Yes No Don't know
- a. How many shocks of this type have you received? Num
- b. At what age did you **FIRST** receive a shock that resulted in unconsciousness? Age
- c. Have you ever received a severe electrical shock that resulted in a burn? Yes No Don't know
- d. How many shocks of this type have you received? Num
- e. At what age did you **FIRST** receive a shock that resulted in a burn? Age
- f. Have you ever received a severe electrical shock that did not result in unconsciousness or a burn? Yes No Don't know
- g. How many shocks of this type have you received? Num
- h. At what age did you **FIRST** receive a shock that did not result in unconsciousness or a burn? Age

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Survey 14

Survey Review

Thank you for taking the survey. Below are the answers you provided. Please take a minute to look over your answers. When you are finished, you can change your answers, save them to look at later, or submit them. If you would like a copy of your answers, please print them now. Once you submit your answers, you will not be able change or print them later.

Survey Responses:

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National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 15

Health Insurance

What kind of health insurance or health care coverage do you have? Exclude private plans that only provide extra cash while hospitalized. If you have more than one kind of health insurance, please check the box next to each plan that you have.

Please mark all that apply.

- HMO
- Private health insurance (non-HMO employer-sponsored)
- MEDICARE
- MEDI-GAP (private insurance that supplements Medicare)
- MEDICAID
- VA (Veteran's Administration)
- Other military health care (CHAMP, TRICARE, Department of Defense health plans)
- Indian Health Service
- State-sponsored health plan
- Other government program
(specify):
- Other health insurance plan
(specify):
- No health care coverage of any type
- Don't know

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Survey 15

Survey Review

Thank you for taking the survey. Below are the answers you provided. Please take a minute to look over your answers. When you are finished, you can change your answers, save them to look at later, or submit them. If you would like a copy of your answers, please print them now. Once you submit your answers, you will not be able change or print them later.

Survey Responses:

Please Check Response:

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National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 16

Supplemental Questions

1. Please enter your ideas or thoughts regarding the factors that may have caused your ALS.

2. Please enter any ideas about factors that may cause ALS in general.

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Figure 77: Survey 16, Page 1 of 2

National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 16

Survey Review

Thank you for taking the survey. Below are the answers you provided. Please take a minute to look over your answers. When you are finished, you can change your answers, save them to look at later, or submit them. If you would like a copy of your answers, please print them now. Once you submit your answers, you will not be able change or print them later.

Survey Responses:

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Figure 78: Survey 16, Page 2 of 2

National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 17

Clinical Module

1. When did you first notice weakness that was later diagnosed as ALS? Month / Year Don't Know
2. In what part of the body did you first notice weakness that was diagnosed as ALS?
 - Speech and/or swallowing muscles
 - Arm or hand
 - Neck, back or abdominal area
 - Leg or foot
 - Breathing muscles
 - All over my body

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National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 17

Clinical Module

3. Before you noticed weakness that turned out to be ALS, did you experience any of the following?

a. Cramps or muscle spasms? Yes No Don't know

In what month and year did you first experience **cramps or muscle spasms**? Month / Year Don't Know

b. Scattered muscle twitching? Yes No Don't know

In what month and year did you first experience **scattered muscle twitching**? Month / Year Don't Know

c. Difficulty swallowing? Yes No Don't know

In what month and year did you first experience **difficulty swallowing**? Month / Year Don't Know

d. Problems with speech? Yes No Don't know

In what month and year did you first experience **problems with speech**? Month / Year Don't Know

e. Difficulty controlling bowels or bladder? Yes No Don't know

In what month and year did you first experience **difficulty controlling bowels or bladder**? Month / Year Don't Know

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National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 17

Clinical Module

4. Have you taken the drug riluzole (Rilutek®)?

- I have never taken riluzole
- I used to take riluzole but discontinued it
- I am currently taking riluzole
- Don't know

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Figure 81: Survey 17, Page 3 of 7

National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 17

Clinical Module

5. The following questions are about assistive devices or programs you may have used.

- a. Have you ever used a power wheelchair or electric scooter? Yes No Don't know
In what month and year did you first use a **power wheelchair or electric scooter**? Month / Year Don't Know
- b. Have you ever used noninvasive breathing equipment, such as Bi-Pap (Bi-level Positive Airway Pressure)? Yes No Don't know
In what month and year did you first use **noninvasive breathing equipment such as Bi-Pap**? Month / Year Don't Know
- c. Have you ever had a tracheostomy? Yes No Don't know
In what month and year did you have the **tracheostomy**? Month / Year Don't Know
- d. Have you ever used an augmentative and alternative communication device? Yes No Don't know
In what month and year did you first use an **augmentative and alternative communication device**? Month / Year Don't Know
- e. Have you ever been enrolled in a hospice program? Yes No Don't know
In what month and year did you first enroll in a **hospice program**? Month / Year Don't Know

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National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 17

Clinical Module

6. Since you developed ALS, have you had any of the following (mark all that apply)

a. Pneumonia that required treatment with prescription medication

Yes No Don't know

b. Falls that caused injury significant enough that you were seen by a physician

Yes No Don't know

c. A blood clot in an arm, leg or in the lung that required treatment with blood thinner medication

Yes No Don't know

7. Have you participated in any ALS research studies?

Yes No Don't know

a. Would you potentially be interested in participating in ALS research studies?

Yes No Don't know

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National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 17

Clinical Module

8. A multidisciplinary ALS clinic is a clinic in which specialized medical care is provided at a medical facility by a team of healthcare professionals. This team may include a neurologist, nurse, physical therapist, occupational therapist, respiratory therapist, speech-language pathologist, nutritionist or dietitian and social worker.
Have you attended an ALS multidisciplinary clinic?
- I have never attended a multidisciplinary ALS clinic
 - I currently attend a multidisciplinary ALS clinic
 - I previously attended a multidisciplinary ALS clinic but do not plan to attend any further visits
 - Don't know
- 9 Which hand do/did you write with?
- Right
 - Left
 - Can use either equally well
- 10 Do you have advance directives established, such as a living will?
- Yes
 - No
 - Don't know
11. Have you had genetic test for inherited traits that can cause ALS?
- Yes
 - No
 - Don't know

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National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 17

Survey Review

Thank you for taking the survey. Below are the answers you provided. Please take a minute to look over your answers. When you are finished, you can change your answers, save them to look at later, or submit them. If you would like a copy of your answers, please print them now. Once you submit your answers, you will not be able change or print them later.

Survey Responses:

Please Check Response:

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