

Attachment 6a
Screen Shots Previously Approved Surveys

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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.

National Amyotrophic Lateral Sclerosis (ALS) Registry

ALS Registry Home

- About
- Frequently Asked Questions
- News
- Resources and Links
- Publications and Reports
- Order Registry Materials
- Conferences and Events
- ALS Research Notification
- State-Metro ALS Surveillance
- ALS Bioregistry
- Registry Testimonials
- Contact the System Administrator

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
24 Hours/Every Day
- cdcinfo@cdc.gov

[ATSDR](#)

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



[My Account](#) | [Logout](#)

Persons with ALS (PALS) Account

The persons with ALS account are 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.



Page last reviewed: May 10, 2012
Page last updated: May 10, 2012
Content source: [Centers for Disease Control and Prevention](#)


Figure 1: PALS Login Landing Page to Access Surveys


National Amyotrophic Lateral Sclerosis (ALS) Registry

- ALS Registry Home**
- About
- Frequently Asked Questions
- News
- Resources and Links
- Publications and Reports
- Order Registry Materials
- Conferences and Events
- ALS Research Notification
- State-Metro ALS Surveillance
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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 1-6 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.

[General Instructions](#)

Surveys

Survey	Status	Date Completed
Survey 1	Completed	1/14/2013
Survey 2	Completed	1/14/2013
Survey 3	In Progress	
Survey 4	In Progress	
Survey 5	In Progress	
Survey 6	Completed	1/14/2013
Disease Progression	Completed	1/14/2013

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)



Page last reviewed: May 10, 2012
Page last updated: May 10, 2012
Content source: Centers for Disease Control and Prevention

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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[Next](#)

[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	

[Previous](#) Page 2 / 4 [Next](#) [Save & Quit](#)

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)

[Previous](#)

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[Save & Quit](#)

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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Save & Submit

Save & Quit

Print Page



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
 Marines
 Coast Guard
 Navy
 Air Force
 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
 Korean Conflict
 Vietnam War
 Other (specify):
 Persian Gulf
 Persian Gulf II
 Afghanistan War

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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](#)

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[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? number of cigarettes per day
One pack contains 20 cigarettes.

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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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[Save & Quit](#)

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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[Save & Submit](#)

[Save & Quit](#)

[Print Page](#)

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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[Save & Quit](#)

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 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

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[Save & Quit](#)

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?

<input type="text"/>	age (ALS)	<input type="checkbox"/> Don't know
<input type="text" value="99"/>	age (Alzheimer's)	<input checked="" type="checkbox"/> Don't know
<input type="text"/>	age (Parkinson's)	<input type="checkbox"/> Don't know

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[Save & Quit](#)

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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Save & Quit

Print Page

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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Figure 27: Survey 6, Page 9 of 9

National Amyotrophic Lateral Sclerosis (ALS) Registry

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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