Attachment 6b
Screen Shots New Surveys

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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 **¼ 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): [Save Address]

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Figure 1: Survey 8, Page 1 of 2

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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 2: Survey 8, Page 2 of 2

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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 3: Survey 9, Page 1 of 11

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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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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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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 6: Survey 9, Page 4 of 11

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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 7: Survey 9, Page 5 of 11

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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 8: Survey 9, Page 6 of 11

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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 9: Survey 9, Page 7 of 11

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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 10: Survey 9, Page 8 of 11

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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 11: Survey 9, Page 9 of 11

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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 12: Survey 9, Page 10 of 11

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Survey 9

Survey Review

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Survey Responses: **Please Check Response:**

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Figure 13: Survey 9, Page 11 of 11

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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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Figure 14: Survey 10, Page 1 of 3

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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

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Figure 16: Survey 10, Page 3 of 3

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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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National Amyotrophic Lateral Sclerosis (ALS) Registry

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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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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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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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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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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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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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 Responses: **Please Check Response:**

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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. ○ Yes ○ No ○ Don't know
   a. What is the reason that you have **not had a period** in the past 12 months?
   - ○ 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

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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 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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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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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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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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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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National Amyotrophic Lateral Sclerosis (ALS) Registry

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.

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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

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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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National Amyotrophic Lateral Sclerosis (ALS) Registry

Survey 16

Survey Review

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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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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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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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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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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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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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