

## APPENDIX: SURVEY INSTRUMENT

This survey asks questions about your spinal cord disease or injury. It also asks about how you carry out your day to day activities. Please fill out the survey yourself or with the help of a friend.

Your Name: \_\_\_\_\_  
(PLEASE PRINT)

1. This question asks about the causes of your spinal cord condition. What is the cause(s) of your spinal cord condition and when did it happen? Please check the box(es) that best fits you and fill in the date when your condition began to the best of your knowledge.

| <u>Causes of spinal cord conditions</u>  | <u>Date of injury/trauma or diagnosis</u> |     |      |
|--|---|-----|------|
| <input type="checkbox"/> traumatic injury  | month                                     | day | year |
| <input type="checkbox"/> multiple sclerosis (MS)   | month                                     | day | year |
| <input type="checkbox"/> polio   | month                                     | day | year |
| <input type="checkbox"/> tumor   | month                                     | day | year |
| <input type="checkbox"/> syringomyelia (cavity in the spinal cord)                                     | month                                     | day | year |
| <input type="checkbox"/> infection or abscess of the spinal cord                                       | month                                     | day | year |
| <input type="checkbox"/> motor neuron disease (Lou Gehrig's disease or ALS)                            | month                                     | day | year |
| <input type="checkbox"/> arthritic disease of the spine or narrowing of spinal canal (spinal stenosis) | month                                     | day | year |
| <input type="checkbox"/> other disease → Please give name: _____                                       | month                                     | day | year |
| <input type="checkbox"/> not sure what the cause is  |   |     |      |
| <input type="checkbox"/> I don't have a spinal cord condition → Please END THE SURVEY.                 |   |     |      |

2. If you have a spinal cord injury, how did your injury happen: please check the one box that best fits the cause of your injury. (If you did not check the box for **traumatic injury** and fill in the date in the section above, please do so before going to the next page.)

- because of an act of violence (like a gunshot wound or explosion)  
 in a vehicle (like a car or motorcycle)  
 in a sports activity (like diving or water or snow skiing)  
 due to a fall  
 other traumatic cause, please describe: \_\_\_\_\_

3. Your doctor may have told you what your neurologic level is. Some examples of neurologic levels are C1, T5, or L3. Please check the correct box(es) and write in the exact level(s) if you know it.

- cervical → Please give level (C1...C7): \_\_\_\_\_  
 thoracic → Please give level (T1...T12): \_\_\_\_\_  
 lumbar → Please give level (L1...L5): \_\_\_\_\_  
 cauda equina → Please give level (S1...S5): \_\_\_\_\_  
 don't know

4. Spinal cord injury or disease can affect different areas of the body. Please check a box for each area of the body affected by your spinal condition:

- memory / thinking  
 eyes  
 one arm only  
 both arms  
 one leg only  
 both legs  
 bowel, bladder or sexual function  
 other → Please describe: \_\_\_\_\_  
 don't know

5. Sometimes spinal cord injury or disease causes loss of movement in the arms or legs. Have you lost movement in your arms or legs? Please check the box which best fits you.

- I have full useful movement in my arms and legs  
 I have some useful movement in the areas affected by my spinal cord condition  
 I have no useful movement in the areas affected by my spinal cord condition

6. Sometimes spinal cord injury or disease causes loss of feeling in the arms or legs. Have you lost feeling in your arms or legs? Please check the box which best fits you.

- I have full feeling in my body  
 I have some feeling in the areas affected by my spinal cord condition  
 I have no feeling in the areas affected by my spinal cord condition

7. Have you ever had an amputation?

- NO  
 YES

8. If you had a spinal cord injury, did you also have a head injury at the same time?

- NO  
 YES

Please go to next page ⇨

Please go to next page ⇨

9. The next set of questions asks about how much help you need with your day to day activities. Please answer the questions below based on an average day and your usual way of doing the activity. Please read the choices below before answering the questions. Then circle the number which best fits your need for help with each of these activities.

4 = NO EXTRA TIME OR HELP

-You do not need any extra time or help.

3 = EXTRA TIME, SPECIAL TOOL

-You need extra time or a special tool (like a raised toilet seat or wheelchair), BUT DO NOT need another person's help.

2 = SOME HELP

-You need some help from ANOTHER PERSON.

1 = TOTAL HELP

-You are UNABLE to do this activity and need total help.

| How much help do you need to.....                  | No Extra Time or Help | Extra Time or Special Tool | Some Help | Total Help or Never Do |
|--|-----------------------|----------------------------|-----------|------------------------|
| Move around inside your house?                     | 4                     | 3                          | 2         | 1                      |
| Go up and down a flight of stairs?                 | 4                     | 3                          | 2         | 1                      |
| Transfer to and from your bed or chair?            | 4                     | 3                          | 2         | 1                      |
| Get on and off the toilet?                         | 4                     | 3                          | 2         | 1                      |
| Transfer from the shower or tub?                   | 4                     | 3                          | 2         | 1                      |
| Eat?   | 4                     | 3                          | 2         | 1                      |
| Groom?<br>(combing hair, brushing teeth etc.)      | 4                     | 3                          | 2         | 1                      |
| Bathe?   | 4                     | 3                          | 2         | 1                      |
| Dress your upper body?                             | 4                     | 3                          | 2         | 1                      |
| Dress your lower body?                             | 4                     | 3                          | 2         | 1                      |
| Toilet?<br>(dressing and cleaning with toilet use) | 4                     | 3                          | 2         | 1                      |
| Manage your bladder?                               | 4                     | 3                          | 2         | 1                      |
| Manage your bowels?                                | 4                     | 3                          | 2         | 1                      |

Please go to next page ⇨

10. Think about your day to day mobility. To get around, do you usually walk or use a wheelchair? Please check the box which best fits your main way of getting around. If you use more than one way equally, mark both boxes.

- I walk **without help** of a special aide or tool
- I walk **with help** of a special aide or tool (like a cane or braces)
- I use a manual wheelchair
- I use a scooter or wheelchair with a motor
- I don't get out of bed

11. This next set of questions asks if you need help from someone else for certain activities. Please check the answer which best fits you.

a. You can get to places outside your own home....

- without help** (can travel alone on buses, taxis, or by car).
- with help** (need someone to help you or go with you when traveling).
- you are unable** to travel unless emergency plans are made for a special vehicle like an ambulance.

b. If you have a way to get to the store, you can shop for food or clothes....

- without help** (taking care of all shopping needs yourself).
- with help** (need someone to go with you).
- you are unable** to do any shopping.

c. You can plan and cook your own meals...

- without help**.
- with help** (can make some things but are unable to cook full meals yourself).
- you are unable** to cook at all.

d. You can do your housework...

- without help** (can scrub floors, etc.).
- with help** (do light housework but need help with heavy work).
- you are unable** to do any housework.

e. Can you handle your own money...

- without help** (write checks, pay bills, etc.).
- with help** (you can do day-to-day buying but need help with your checkbook with paying your bills).
- you are unable** to manage money.

12. In the last two weeks did you need help from another person for everyday activities? Please check the answer which best fits you.

- NO, I did not need help from another person
- YES → Please give the total number of hours of help (paid or unpaid) you usually use each day: \_\_\_\_\_ hours/day

Thank you for taking the time to complete the survey.