



NARCOMS

North American Research Committee on Multiple Sclerosis

**NARCOMS
MULTIPLE SCLEROSIS
REGISTRY
A Long-Term Study**

ENROLLMENT QUESTIONNAIRE

Return completed survey to:

**NARCOMS REGISTRY
Global MS Patient Registry
RPHB 507
1530 3rd Ave South
Birmingham, Alabama 35294-0022**

For Office Use Only

Participant ID: _____

Date Received: _____

Source: _____

NARCOMS Multiple Sclerosis Registry

Information Page

The purpose of the NARCOMS Multiple Sclerosis (MS) Registry is to accelerate the process of informing patients of research projects for which they are eligible, and to use de-identified data for research purposes. This information may expedite the development of more effective treatments. If you do not have MS and have received this questionnaire, we apologize for the error.

Please read the following informative statements before you sign your consent:

- All information will be used for research purposes only and all responses will be kept private and confidential.
- Your personal information is kept strictly confidential and will not be released without your written consent, nor will it be sold for advertising or fundraising.
- The data you provide may be used in scientific publications, in summary form only.
- By being enrolled in the Registry, you agree to be notified of research studies for which you may be eligible, but you are not obligated to enter any additional studies.
- Participation in the Registry is completely voluntary and is of no cost to you.
- For research purposes we will need to update your information every six months. You will continue receiving these questionnaires and **agree to complete them in a timely manner.**
- If you have questions about your rights as a research subject or if you have questions, concerns or complaints about the research, you may contact: Western Institutional Review Board[®] (WIRB[®]), 3535 Seventh Avenue, SW Olympia, Washington 98502
Telephone: 1-800-562-4789 or 360-252-2500 E-mail: Help@wirb.com.
- This study is expected to continue until a cure for MS is found.
- **Please retain the enclosed copy of this page for your records.**

By signing below, I agree to the above statements.

Your signature is required for participation.

Date

You have to be at least **18 years** old to participate.

← Please be sure to read the Information Page and **sign your name.**

A. DEMOGRAPHICS

A1. Your **Legal** Name:

First _____ MI _____ Last _____

Preferred First Name _____

Other Legal Names (i.e. Maiden, prior legal name changes or other married names):

A2. Mailing Address:

Street _____ Apt. _____

City _____ State _____ Zip _____

Country _____

A3. Contact Information:

1. Home phone () _____ 2. Work phone () _____

3. Cell phone () _____ 4. Fax () _____

5. Email _____

Please include MSregistry@narcoms.org in your computer's address book and remember to let us know if your contact information changes.

A4. Please indicate how you prefer to be contacted in case we need to clarify any of your answers: (Check all that apply)

1. Email

2. Home

3. Work

4. Mail

5. Cell phone

6. Fax

A5. Gender: 1. Female 2. Male

A6. Height: _____ ft. _____ in. Weight: _____ lbs.

A7. Date of birth: _____ / _____ / _____
Month Day Year

A8. Birth Weight: _____ lbs. _____ oz. Unknown

A9. Place of birth: _____, _____

City

State/Province

Country (other than US)

A10. List below all the cities, states and countries where you lived continuously for **12 months or longer** when you were **under 25 years old** and indicate the **year** when you moved in and out.

City	State	Country	From year	To year

Note: Please answer both questions A11 and A12

A11. Are you of Hispanic, Latino or Spanish origin?

- 1. No, not of Hispanic, Latino, or Spanish origin
- 2. Yes, Mexican, Mexican American,
- 3. Yes, Puerto Rican
- 4. Yes, Cuban
- 5. Yes, of another Hispanic, Latino, or Spanish origin (i.e. Argentinean, Colombian, Dominican, Nicaraguan, Salvadoran, Spaniard, etc.)

A12. What is your race? (Check all that apply)

- 1. White
- 2. African American, Black
- 3. American Indian or Alaska Native (Tribe: _____)
- 4. Asian Indian
- 5. Japanese
- 6. Native Hawaiian
- 7. Chinese
- 8. Korean
- 9. Guamanian or Chamorro
- 10. Filipino
- 11. Vietnamese
- 12. Samoan
- 13. Other Asian (i.e. Thai, Pakistani, Cambodian) Specify: _____
- 14. Other Pacific Islander (i.e. Fijian, Tongan) Specify: _____
- 15. Other race Specify: _____

A13. What is your preferred language?

1. English
 2. Spanish
 3. French
 4. German
 5. Russian
 6. Japanese
 7. Other _____

A14. What is your **current** marital status?

1. Never Married
 2. Divorced
 3. Separated
 4. Married
 5. Widowed
 6. Cohabiting/Domestic Partner

A15. Do you have children?

1. Yes →
 2. No

If Yes:

15a. How many biological children do you have? _____

15b. How many adopted or stepchildren do you have? _____

A16. The following questions are about your family background:

Family Member	Year of Birth (YYYY)	Month of Birth (MM)	Place of Birth (City, State/Province, Country if not USA)
1. Mother			
2. Father			
3. Maternal Grandmother (mother's mother)			
4. Maternal Grandfather (mother's father)			
5. Paternal Grandmother (father's mother)			
6. Paternal Grandfather (father's father)			

A17. Women Only (Men Skip to **A18**):

- Please indicate the number of medically confirmed pregnancies: _____
- Number of live births: _____
- Your age at first live birth: _____

A18. With whom do you currently live? Check all that apply:

- | | |
|--|--|
| <input type="checkbox"/> 1. Spouse/Partner | <input type="checkbox"/> 6. Domestic help |
| <input type="checkbox"/> 2. Sibling | <input type="checkbox"/> 7. Friend/Companion |
| <input type="checkbox"/> 3. Children | <input type="checkbox"/> 8. Health-related companion |
| <input type="checkbox"/> 4. Parent | <input type="checkbox"/> 9. Alone |
| <input type="checkbox"/> 5. Other relative | <input type="checkbox"/> 10. Nursing or sheltered home |

A19. Educational level:

What is the total number of years of formal education completed? _____
(Including primary, secondary or technical training)

A20. Please check the highest level completed.

- | | |
|---|--|
| <input type="checkbox"/> 1. High School Diploma/GED | <input type="checkbox"/> 4. Post Graduate Education
(Master's, Doctorate) |
| <input type="checkbox"/> 2. Associate's Degree | <input type="checkbox"/> 5. Technical Degree |
| <input type="checkbox"/> 3. Bachelor's Degree | |

A21. Are you currently employed?

1. Yes, Full Time 2. Yes, Part Time 3. No

21a. If NO → (check all that apply)

- 1. Unemployed (Seeking employment)
- 2. Unemployed (Not seeking employment)
- 3. Full time homemaker
- 4. Student
- 5. Disabled
- 6. Retired (Not due to medical reasons or disability)
- 7. Retired (Due to medical reasons or disability)
- 8. Other

A22. In the past 6 months, was your employment mostly:

1. Full time 2. Part time 3. Not Employed

→22a. If Full or Part Time in the past 6 months:

Hours per week worked: <20 20-30 31-35 36-40 >40

In the past 6 months, has your MS caused you to:

Cut back on the number of hours you work? 1. Yes 2. No

Did you miss any workdays? 1. Yes: # days missed _____ 2. No

A23. Household Income

To help us understand the health care resources that are available to persons with MS, we need to ask you about your income. Please indicate which of the following categories best represents your family's approximate annual income (from all sources and before taxes):

- | | |
|---|---|
| <input type="checkbox"/> 1. Less than \$15,000 | <input type="checkbox"/> 4. \$50,000 - \$100,000 |
| <input type="checkbox"/> 2. \$15,000 - \$29,999 | <input type="checkbox"/> 5. Over \$100,000 |
| <input type="checkbox"/> 3. \$30,000 - \$49,999 | <input type="checkbox"/> 6. I do not wish to answer |

C5. To confirm your diagnosis, have you had a spinal MRI? 1. Yes 2. No 3. Unsure

C6. To confirm your diagnosis, have you had a lumbar puncture (spinal tap)?

1. Yes 2. No 3. Unsure

C7. In retrospect, how old were you when you first experienced symptoms that you believe were from MS? || age

C8. What were your initial (first) symptoms? Please mark **all** that apply.

Initial Symptom	YES	NO
Visual loss (optic neuritis)		
Numbness/ tingling		
Impaired balance		
Dizziness (Vertigo)		
Double vision		
Difficulty walking/ running		
Weakness of one or more limbs (arm, leg)		
Facial weakness		
Other (specify):		

C9. Did you at some point seem to recover from all of your initial symptoms?

1. Yes 2. No 3. Unsure

C10. Have any of your **biological** (blood) relatives on your mother's **or** your father's side been diagnosed with MS?

Family Member	Diagnosed with MS? (Please circle)
1. Mother	Yes No Unsure
3. Brother(s) or sister(s)	Yes No Unsure
5. Maternal aunt(s), uncle(s), cousin(s)	Yes No Unsure
7. Maternal Grandfather (mother's father)	Yes No Unsure
9. Maternal Grandmother (mother's mother)	Yes No Unsure

Family Member	Diagnosed with MS? (Please circle)
2. Father	Yes No Unsure
4. Child(ren)	Yes No Unsure
6. Paternal aunt(s), uncle(s), cousin(s)	Yes No Unsure
8. Paternal Grandfather (father's father)	Yes No Unsure
10. Paternal Grandmother (father's mother)	Yes No Unsure

11. Adopted

12. No Siblings

13. No Children

C11. Are you a twin?

1. Yes 2. No 3. Unsure

11a. → **If Yes**, has your twin been diagnosed with MS?

1. Yes 2. No 3. Unsure

For the following set of questions, please indicate the answer that most generally applies to you and the course of your disease.

Definition of a relapse or exacerbation of MS:

Development of new symptoms or worsening of old symptoms that last longer than 48 hours. In a relapse or exacerbation, MS symptoms generally worsen over a period of days to several weeks. They then improve partially or completely over several weeks or months. A relapse can be associated with several different symptoms getting worse at the same time.

For our purposes here, the change in symptoms cannot be due to heat or illness (i.e., flu, cold or urinary tract infection) to be called a relapse or exacerbation.

C12. Based on the definition above, have you **ever** had a relapse?

1. Yes 2. No 3. Unsure

The following questions aim to establish a timeline of your relapse history.

C13. Have you had any relapses **within the last 2 years**?

1. Yes → how many? ___ 2. No 3. Unsure

C14. Have you had any relapses **within the last year**?

1. Yes → how many? ___ 2. No 3. Unsure

C15. Have you had any relapses within the **last 6 months**?

1. Yes → how many? ___ 2. No 3. Unsure

C16. How many relapses over the **past 2 years** required treatment with steroids?

- 0 (none) 1 2 3 4 5 6 or more

C17. Compare your overall MS symptoms now with what you experienced **6 months ago**.

Is your MS.... (Circle one)

1	2	3	4	5	6	7
Much Worse	Worse	A Little Worse	No Change	A Little Better	Better	Much Better

C18. For each condition listed below, please indicate with an “X” Yes, No, or Don’t Know as appropriate. If you **DO** have the condition, please give the **YEAR** you were diagnosed.

Condition	Don't Know	No	Yes →	Year Diagnosed
High cholesterol (Dyslipidemia)				<input type="checkbox"/> Unsure
High blood pressure (hypertension)				<input type="checkbox"/> Unsure
Heart trouble (such as angina, congestive heart failure, or coronary artery disease, atrial fibrillation)				<input type="checkbox"/> Unsure
Lung trouble (Asthma, emphysema, chronic bronchitis, or COPD)				<input type="checkbox"/> Unsure
Diabetes mellitus				<input type="checkbox"/> Unsure
Autoimmune thyroid disease (Grave’s disease, Hashimoto’s Thyroiditis)				<input type="checkbox"/> Unsure
Inflammatory bowel disease (Crohn’s disease, ulcerative colitis)				<input type="checkbox"/> Unsure
Lupus (Systemic lupus erythematosus, SLE)				<input type="checkbox"/> Unsure
Rheumatoid Arthritis				<input type="checkbox"/> Unsure
Epilepsy (seizure disorder)				<input type="checkbox"/> Unsure
Psoriasis				<input type="checkbox"/> Unsure
Uveitis (inflammation of the eye)				<input type="checkbox"/> Unsure
Fibromyalgia (fibromyositis)				<input type="checkbox"/> Unsure
Irritable bowel syndrome				<input type="checkbox"/> Unsure
Depression				<input type="checkbox"/> Unsure
Anxiety				<input type="checkbox"/> Unsure
Cancer (specify type): _____				<input type="checkbox"/> Unsure
Other: _____				<input type="checkbox"/> Unsure

C19. Please indicate for each of the therapies listed below, which ones you are **currently taking (and start date)**, which ones you have **taken in the past**, and which ones you have **never taken**. Check **unsure** as appropriate. **Medications are listed in alphabetical order by generic name followed by the registered trade name in parentheses.**

Immunological Therapies	Currently Taking	When started mm/yyyy	Took only in the Past for a total of ___ months	Never Taken	Unsure
1. ACTH –Adrenocorticotrophic hormone (Acthar®)	<input type="checkbox"/>	___/___	___ mos.		
2. Alemtuzumab (Campath®)	<input type="checkbox"/>	___/___	___ mos.		
3. Azathioprine (Imuran®)	<input type="checkbox"/>	___/___	___ mos.		
4. BG-12 (Oral Fumurate)	<input type="checkbox"/>	___/___	___ mos.		
5. Cladribine (Leustat®)	<input type="checkbox"/>	___/___	___ mos.		
6. Cyclophosphamide (Cytosan®)	<input type="checkbox"/>	___/___	___ mos.		
7. Daclizumab (Zenapax®)	<input type="checkbox"/>	___/___	___ mos.		
8. Fingolimod (FTY-720, Gilenya®)	<input type="checkbox"/>	___/___	___ mos.		
9. Gamma Globulin (IVIG)	<input type="checkbox"/>	___/___	___ mos.		
10. Glatiramer Acetate (Copaxone®)	<input type="checkbox"/>	___/___	___ mos.		
11. Interferon Beta-1a (Avonex®)	<input type="checkbox"/>	___/___	___ mos.		
12. Interferon Beta-1a (Rebif®)	<input type="checkbox"/>	___/___	___ mos.		
13. Interferon Beta-1b (Extavia®, Betaseron/Betaferon®)	<input type="checkbox"/>	___/___	___ mos.		
14. Laquinimod	<input type="checkbox"/>	___/___	___ mos.		
15. Methotrexate (Trexall®, Rheumatrex®, Matrex®)	<input type="checkbox"/>	___/___	___ mos.		
16. Mitoxantrone (Novantrone)	<input type="checkbox"/>	___/___	___ mos.		
17. Mycophenolate Mofetil (Cellcept®)	<input type="checkbox"/>	___/___	___ mos.		
18. Natalizumab (Tysabri®)	<input type="checkbox"/>	___/___	___ mos.		
19. Plasmapheresis / Plasma Exchange	<input type="checkbox"/>	___/___	___ mos.		
20. Prednisone (Oral)	<input type="checkbox"/>	___/___	___ mos.		
21. Rituximab (Rituxan®)/ Ocrelizumab	<input type="checkbox"/>	___/___	___ mos.		
22. Teriflunomide	<input type="checkbox"/>	___/___	___ mos.		

C24. Are you CURRENTLY taking ANY of the therapies below?

1. Yes 2. No 3. Unsure

→ **If Yes or Unsure**, please indicate for each of the symptomatic therapies listed below which ones you are **currently** taking by checking **Yes** or **Unsure**, as appropriate. Medications are in alphabetical order by generic name (® registered name).

Symptomatic Therapy	Yes	Unsure	Symptomatic Therapy	Yes	Unsure
1. 4-aminopyridine (4-AP, compounded medication)	<input type="checkbox"/>	<input type="checkbox"/>	18. Fluoxetine (Prozac)	<input type="checkbox"/>	<input type="checkbox"/>
2. Dalfampridine (Ampyra)	<input type="checkbox"/>	<input type="checkbox"/>	19. Gabapentin (Neurontin)	<input type="checkbox"/>	<input type="checkbox"/>
3. Alprazolam (Xanax)	<input type="checkbox"/>	<input type="checkbox"/>	20. Intrathecal Baclofen Pump	<input type="checkbox"/>	<input type="checkbox"/>
4. Amantadine (Symmetrel)	<input type="checkbox"/>	<input type="checkbox"/>	21. Lorazepam (Ativan)	<input type="checkbox"/>	<input type="checkbox"/>
5. Amitriptyline (Elavil)	<input type="checkbox"/>	<input type="checkbox"/>	22. Methylphenidate (Ritalin, Concerta, Metadate)	<input type="checkbox"/>	<input type="checkbox"/>
6. Armodafinil (Nuvigil)	<input type="checkbox"/>	<input type="checkbox"/>	23. Modafinil (Provigil)	<input type="checkbox"/>	<input type="checkbox"/>
7. Baclofen (Lioresal)	<input type="checkbox"/>	<input type="checkbox"/>	24. Oxybutynin (Ditropan, Ditropan XL, Oxytrol)	<input type="checkbox"/>	<input type="checkbox"/>
8. Botulinum toxin type A/B (Botox, Myobloc, BTA/B, BoNT-A/B)	<input type="checkbox"/>	<input type="checkbox"/>	25. Paroxetine (Paxil)	<input type="checkbox"/>	<input type="checkbox"/>
9. Bupropion (Wellbutrin, Wellbutrin SR, Wellbutrin XL)	<input type="checkbox"/>	<input type="checkbox"/>	26. Pregabalin (Lyrica)	<input type="checkbox"/>	<input type="checkbox"/>
10. Carbamazepine (Tegretol, Tegretol XR, Carbatrol)	<input type="checkbox"/>	<input type="checkbox"/>	27. Sertraline (Zoloft)	<input type="checkbox"/>	<input type="checkbox"/>
11. Citalopram (Celexa)	<input type="checkbox"/>	<input type="checkbox"/>	28. Sildenafil (Viagra)	<input type="checkbox"/>	<input type="checkbox"/>
12. Clonazepam (Klonopin)	<input type="checkbox"/>	<input type="checkbox"/>	29. Tizanidine (Zanaflex)	<input type="checkbox"/>	<input type="checkbox"/>
13. Dextroamphetamine (Dexedrine)	<input type="checkbox"/>	<input type="checkbox"/>	30. Tolterodine (Detrol, Detrol LA)	<input type="checkbox"/>	<input type="checkbox"/>
14. Donepezil (Aricept)	<input type="checkbox"/>	<input type="checkbox"/>	31. Topiramate (Topamax)	<input type="checkbox"/>	<input type="checkbox"/>
15. Duloxetine (Cymbalta)	<input type="checkbox"/>	<input type="checkbox"/>	32. Venlafaxine (Effexor, Effexor XR)	<input type="checkbox"/>	<input type="checkbox"/>
16. Escitalopram (Lexapro)	<input type="checkbox"/>	<input type="checkbox"/>	33. Zolpidem (Ambien)	<input type="checkbox"/>	<input type="checkbox"/>
17. Other (Specify): _____	<input type="checkbox"/>	<input type="checkbox"/>	34. Other (Specify): _____	<input type="checkbox"/>	<input type="checkbox"/>

C25. Have you had an appointment with ANY of the following healthcare providers **in the last year, not seen them within the last year** for the treatment of your MS? Please Mark with an “X” for each of the providers listed below.

Providers	Never	In the last year	Not Seen Within the last year	Unsure
1. Acupuncturist				
2. Allergist				
3. Chiropractor				
4. Herbalist				
5. Holistic Medicine Practitioner				
6. Home Health Aide				
7. Hypnotist				
8. Internal Medicine Provider				
9. Massage Therapist				
10. Neurologist MS Specialist				
11. Neurologist Non-MS Specialist				
12. Neuropsychologist				
13. Nurse Clinician/Advanced Practice Nurse				
14. Nurse – MS Specialist				
15. Nurse – Non-MS Specialist				
16. Nutritionist				
17. OB/GYN				
18. Occupational Therapist				
19. Ophthalmologist				
20. Optometrist				
21. Orthopedic Surgeon				
22. Pharmacist (medication therapy management)				
23. Physical Therapist				
24. Physician’s Assistant (PA)				
25. Podiatrist				
26. Primary Health Care Provider				
27. Psychiatrist				
28. Psychologist				
29. Rehab. Spec. (Physiatrist) MS Specialist				
30. Rehab. Spec. (Physiatrist) Non-MS Specialist				
31. Social Worker/Counselor				
32. Speech Therapist				
33. Urologist				
34. Visiting Nurse				
35. Other Practitioner (please specify):				

PDDS

Patient-determined Disease Steps

C26. Please read the choices listed below and choose the one that best describes your own situation. **This scale focuses mainly on how well you walk.** You might not find a description that reflects your condition exactly, but please mark the **one** category that describes your situation the closest.

- 0 **Normal:** I may have some mild symptoms, mostly sensory due to MS but they do not limit my activity. If I do have an attack, I return to normal when the attack has passed.
- 1 **Mild Disability:** I have some noticeable symptoms from my MS but they are minor and have only a small effect on my lifestyle.
- 2 **Moderate Disability:** I don't have any limitations in my walking ability. However, I do have significant problems due to MS that limit daily activities in other ways.
- 3 **Gait Disability:** MS does interfere with my activities, especially my walking. I can work a full day, but athletic or physically demanding activities are more difficult than they used to be. I usually don't need a cane or other assistance to walk, but I might need some assistance during an attack.
- 4 **Early Cane:** I use a cane or a single crutch or some other form of support (such as touching a wall or leaning on someone's arm) for walking all the time or part of the time, especially when walking outside. I think I can walk 25 feet in 20 seconds without a cane or crutch. I always need some assistance (cane or crutch) if I want to walk as far as 3 blocks.
- 5 **Late Cane:** To be able to walk 25 feet, I have to have a cane, crutch or someone to hold onto. I can get around the house or other buildings by holding onto furniture or touching the walls for support. I may use a scooter or wheelchair if I want to go greater distances.
- 6 **Bilateral Support:** To be able to walk as far as 25 feet I must have 2 canes or crutches or a walker. I may use a scooter or wheelchair for longer distances.
- 7 **Wheelchair / Scooter:** My main form of mobility is a wheelchair. I may be able to stand and/or take one or two steps, but I can't walk 25 feet, even with crutches or a walker.
- 8 **Bedridden:** Unable to sit in a wheelchair for more than one hour.

PERFORMANCE SCALES (Pages 16 – 21)

Instructions: These scales are meant to describe some of the different kinds of disabilities people with MS may have. Some of these problems may have to do with MS, and for some you may not be so sure. Do not be concerned by this. We are interested in any problem you have with each aspect of your functioning, regardless of whether it is due to MS, medication or some other health problem. By "normal" we mean the way you were before you developed MS. **Please describe your condition in the past 4 weeks.**

MOBILITY

C27. Below are categories of mobility disability. Each category has some examples included to help you decide. All of the examples within a category may not apply to you. Please read all of the categories; *check the single category* that best describes your average condition **in the past 4 weeks. Compare your current condition to your mobility before you developed MS.**

- 0 Normal:** Functionally normal walking and running
 - Although I have MS and some symptoms, my walking or running is not limited.
- 1 Minimal Gait Disability:** Minor but noticeable effects on mobility.
 - I am making minor adjustments in my work or lifestyle because of some difficulty in walking.
 - I have given up some particularly strenuous activities because of walking problems.
- 2 Mild Gait Disability:** Noticeable effects on mobility.
 - I have to park closer to my destination because of difficulty in walking.
 - I have given up some activities, such as long shopping trips, dancing, hiking, or other activities that require a lot of walking.
- 3 Occasional Use of Cane or Unilateral Support:** May use cane or unilateral support (e.g., spouse's arm) for greater distances outside.
 - I find myself using the wall, other people's arms, or furniture, to help support my walking at times, but I can walk at least 25 feet (i.e., 2 car lengths) without any support.
 - I do not use a cane or similar support around the house, but do use it when I leave the house. I use a cane or similar support to avoid looking like I am drunk.
 - I carry a cane even if I do not use it, because it makes me feel more secure.
- 4 Frequent Use of Cane:** Unable to walk 25 feet (i.e., 2 car lengths) without a cane/unilateral support.
 - I need a cane or similar support to get around in the house, as well as outside. I need to use a wall, furniture, or other people's arms to allow me to walk short distances (i.e., less than 25 feet). I do not walk anywhere without using some support on one side (e.g., wall, furniture, pushing shopping cart, cane, someone's arm).
- 5 Severe Gait Disability Bilateral Support:** Requires bilateral support (e.g., crutches, walker) to walk 25 feet (i.e., 2 car lengths).
 - I need to hold onto something with both hands in order to walk 25 feet or more. I have to use two crutches, walker or a pushcart in order to walk most of the time.
- 6 Total Gait Disability or Bedridden:** Essentially confined to a wheelchair; may be able to take 1 or 2 steps.
 - Even though I can take a step or two on my own, I need to use a wheelchair for any distances greater than 25 feet (i.e., 2 car lengths).

HAND FUNCTION

C28. Please read all of the categories and *check the single category* which best describes your *worst* hand function condition in the past month. **Compare your current condition to your hand function before you developed MS.**

- 0 **Normal**
 - Although I have MS and some symptoms, my hands have not been affected.
- 1 **Minimal Hand Disability**
 - I have some problems with my hands, but it has not changed my activities.
 - I do not write as well as I used to.
- 2 **Mild Hand Disability**
 - I am making a few adjustments in my activities because of some difficulty with coordination, shaking and strength in my hands.
 - I have reduced some activities requiring fine hand control, such as handicrafts, typing, etc.
- 3 **Moderate Hand Disability**
 - I am making many adjustments in my activities due to hand problems.
- 4 **Severe Hand Disability**
 - I have given up important activities due to hand problems.
 - I am still able to do my activities, but they take me much longer.
- 5 **Total Hand Disability**
 - *Every day*, difficulty with my hands *prevents* me from doing many of my activities

VISION

C29. Please read all of the categories, and *check the single category* which best describes your overall visual condition (with glasses if you use them) over the past month. **Compare your current condition to your vision before you developed MS.**

- 0 **Normal Vision:** Functionally normal; no limitations on activity or lifestyle.
 - MS has not affected my vision
 - I wear glasses but otherwise my vision is normal.
- 1 **Minimal Visual Disability**
 - My vision is normal, but it has been affected in the past by MS.
- 2 **Mild Visual Disability**
 - I have visual symptoms of either blurred or double vision, but I am still able to do all of my usual activities.
- 3 **Moderate Visual Disability**
 - Because of my visual problems, I have been forced to give up some of my usual activities, but after a period of rest I can usually return to these activities.
- 4 **Severe Visual Disability**
 - I am no longer able to maintain my original lifestyle because of my vision and rest does not seem to help my vision.
 - I can no longer drive a car because of my vision.
- 5 **Total Visual Disability**
 - I am essentially blind.
 - I cannot read, even with aids.

FATIGUE

C30. Please read all of the categories, and *check the single category* that best describes your fatigue condition in the past month. **Compare your current condition to your fatigue level before you developed MS.**

- 0 **Normal Fatigue:** Functionally normal; no limitations on activity or lifestyle.
 - I do not notice being fatigued.
- 1 **Minimal Fatigue Disability**
 - I experience fatigue for no apparent reason, but it has not changed my activities.
- 2 **Mild Fatigue Disability**
 - *Occasionally*, fatigue forces me to change some of my activities (e.g., once a week or less).
- 3 **Moderate Fatigue Disability**
 - *Frequently*, fatigue forces me to change some of my activities (e.g., several times a week)
- 4 **Severe Fatigue Disability**
 - *Every day*, fatigue forces me to modify my daily activities.
 - I am always tired.
- 5 **Total Fatigue Disability**
 - *Every day*, fatigue *prevents* me from doing many of my daily activities.

COGNITIVE SYMPTOMS

Problems with remembering, thinking, difficulties with calculations, confusion, difficulty remembering what you read, word recall, etc., compared to before you developed MS.

C31. Please read all of the categories, and *check the single category* which best describes your cognitive symptoms in the past month. **Compare your current condition to your level of cognition before you developed MS.**

- 0 **Normal Cognition:** Functionally normal; no limitations on activity or lifestyle.
 - I have not noticed any problems with memory or confusion.
- 1 **Minimal Cognitive Disability**
 - I notice some problems with memory or confusion, but they do not interfere with my activities.
- 2 **Mild Cognitive Disability**
 - *Occasionally*, memory problems or confusion affect some of my activities (e.g., once a week or less).
- 3 **Moderate Cognitive Disability**
 - *Frequently*, memory problems or confusion affect some of my activities (e.g., several times a week).
- 4 **Severe Cognitive Disability**
 - I *constantly* need to allow for problems with memory or confusion in my daily activities.
- 5 **Total Cognitive Disability**
 - *Every day*, memory problems or confusion *prevent* me from doing many of my daily activities.

BLADDER / BOWEL

C32. Please read all of the categories, and *check the single category* which best describes your bladder/bowel symptoms in the past month even if you use a catheter or have had surgical procedures. **Compare your current condition to your bladder/bowel function before you developed MS.**

- 0 **Normal Bladder/Bowel:** Functionally normal; no limitations on activity or lifestyle.
 - I have not noticed any problems with my bladder or bowel control.
- 1 **Minimal Bladder/Bowel Disability**
 - I have some problems with bladder or bowel control (e.g., urinary frequency, urgency or hesitancy), but it does not interfere with my activities.
 - I am aware of needing to control my bladder and bowel, and I do not have any problem with wetting or soiling.
- 2 **Mild Bladder/Bowel Disability**
 - *Occasionally*, bladder or bowel control problems affect some of my activities (e.g., once a week or less).
 - I have trouble controlling my bladder or bowel once a week or less (e.g., dribbling).
- 3 **Moderate Bladder/Bowel Disability**
 - *Frequently*, bladder or bowel control problems affect some of my activities (e.g., several times a week). I have trouble controlling my bladder or bowel several times a week (e.g., wet or soil).
- 4 **Severe Bladder/Bowel Disability**
 - *Every day*, bladder or bowel control problems force me to modify my daily activities.
- 5 **Total Bladder/Bowel Disability**
 - *Every day*, bladder or bowel control problems *prevent* me from doing many of my daily activities.

SENSORY SYMPTOMS

Problems with numbness, tingling, odd sensations, electric shock, burning, band-like sensation around trunk or extremities. Do not include aching pain or headaches.

C33. Please read all of the categories, and *check the single category* that best describes your sensory symptoms in the past month. **Compare your current condition to your level of sensory function before you developed MS.**

- 0 **Normal Sensory:** Functionally normal; no limitations on activity or lifestyle.
 - I have not noticed any problems with numbness or tingling.
- 1 **Minimal Sensory Disability**
 - I have some problems with numbness or tingling, but it does not interfere with my activities.
- 2 **Mild Sensory Disability**
 - *Occasionally*, numbness or tingling forces me to change some of my activities (e.g., once a week or less).
- 3 **Moderate Sensory Disability**
 - *Frequently*, numbness or tingling affects some of my activities (e.g., several times a week).
- 4 **Severe Sensory Disability**
 - *Every day*, numbness or tingling problems force me to modify my daily activities.
- 5 **Total Sensory Disability**
 - *Every day* numbness or tingling *prevents* me from doing many of my daily activities.

SPASTICITY SYMPTOMS

Unusual tightening of muscles that feels like leg stiffness, jumping of legs, a repetitive bouncing of the foot, muscle cramping in legs or arms or legs going out tight and straight or drawing up.

C34. Please read all the categories, and *check the single category* that most accurately describes your spasticity symptoms in the past month. **Compare your current condition to your level of spasticity before you developed MS.**

- 0 **Normal Spasticity:** No symptoms of spasticity.
 - I have not noticed any problems with spasticity.
 - 1 **Minimal Spasticity Disability**
 - I notice some problems with spasticity, but they do not interfere with my activities.
 - 2 **Mild Spasticity Disability**
 - *Occasionally*, spasticity forces me to change some of my activities (e.g., once a week or less).
 - 3 **Moderate Spasticity Disability**
 - *Frequently*, spasticity affects some of my activities (e.g., several times a week).
 - 4 **Severe Spasticity Disability**
 - *Every day*, spasticity problems force me to modify my daily activities.
 - 5 **Total Spasticity Disability**
 - *Every day*, spasticity problems *prevent* me from doing many of my daily activities.
-

PAIN

C35. Please read all the categories, and *check the single category* that most accurately describes your pain (regardless of cause) in the past month. **Compare your current condition to your experience before you developed MS.**

- 0 **Normal:** No symptoms of pain.
 - I have not noticed any problems with pain.
- 1 **Minimal Pain**
 - I notice some problems with pain, but they do not interfere with my activities.
- 2 **Mild Pain**
 - *Occasionally*, pain forces me to change some of my activities (e.g., once a week or less).
- 3 **Moderate Pain**
 - *Frequently*, pain affects some of my activities (e.g., several times a week).
- 4 **Severe Pain**
 - *Every day*, pain problems force me to modify my daily activities.
- 5 **Total Disabling Pain**
 - *Every day*, pain problems *prevent* me from doing many of my daily activities.

DEPRESSION

C36. Please read all the categories, and *check the single category* which most accurately describes symptoms of depression in the past month. **Compare your current condition to what you felt before you developed MS.**

- 0 **Normal:** No symptoms of depression.
 - I have not noticed any problems with depression.
 - 1 **Minimal Depression**
 - I notice some problems with depression, but they do not interfere with my activities.
 - 2 **Mild Depression**
 - Depression *occasionally* forces me to change some of my activities (e.g., once a week or less).
 - 3 **Moderate Depression**
 - Depression *frequently* affects some of my activities (e.g., several times a week).
 - 4 **Severe Depression**
 - *Every day*, depression problems force me to modify my daily activities.
 - 5 **Total Depression**
 - *Every day*, depression problems *prevent* me from doing many of my daily activities.
-

TREMOR AND COORDINATION

Tremor is the rhythmic shaking of the head, hands or legs. Loss of coordination is clumsiness or imbalance (e.g., staggering gait or unsteady gait like being drunk)

C37. Please read all the categories, and *check the single category* that most accurately describes your tremor and loss of coordination symptoms in the past month. **Compare your current condition to your experience before you developed MS.**

- 0 **Normal:** No tremor or loss of coordination.
 - I do not have any tremor or loss of coordination.
 - I have not noticed any problems with tremor or loss of coordination.
- 1 **Minimal Tremor or Loss of Coordination**
 - *Sometimes* I have some tremor or loss of coordination, but it does not interfere with my activities.
- 2 **Mild Tremor or Loss of Coordination**
 - Tremor or loss of coordination *occasionally* forces me to change some of my activities (e.g., once a week or less).
- 3 **Moderate Tremor or Loss of Coordination**
 - Tremor or loss of coordination *frequently* forces me to change some of my activities (e.g., several times a week).
- 4 **Severe Tremor or Loss of Coordination**
 - *Every day*, tremor or loss of coordination problems force me to modify my daily activities.
- 5 **Total Disabling Tremor or Loss of Coordination**
 - *Every day*, tremor or loss of coordination problems *prevent* me from doing many of my daily activities.

D.**LIFESTYLE**

D1. Have you smoked at least 100 cigarettes in your ENTIRE LIFE?

1. Yes 2. No (SKIP TO QUESTION **D8** below)

D2. Do you NOW smoke ?

1. Not at all 2. Some days 3. Every day

D3. On the average, how many cigarettes do you **now** smoke a day? _____ cigarettes

D4. On how many of the PAST 30 DAYS did you smoke a cigarette? _____ days

Smoking History

D5. How old were you when you FIRST started to smoke fairly regularly? _____ years

D6. How old were you when you quit smoking cigarettes? _____ years

D7. On the average, **during the years** that you have smoked, about how many cigarettes did you smoke a day? _____ cigarettes and/or _____ cigars

Alcohol Use

D8. How often did you have a drink containing alcohol in the **past year**? Consider a "drink" to be a can or bottle of beer, a glass of wine, a wine cooler, or one cocktail, or a shot of hard liquor (like scotch, gin, or vodka).

1. Never 2. Monthly or less 3. Two to four times a month
 4. Two to three times per week 5. Four or more times a week

D9. How many drinks did you have on a **typical day** when you were drinking in the past year?
_____ drinks (Please put 0 if you never had a drink in the past year.)

D10. How often did you have five or more drinks on one occasion in the past year?

1. Never 2. Less than monthly 3. Monthly
 4. Weekly 5. Daily or almost daily

D11. During the **past month**, other than your regular job, did you participate in **any** physical activity or exercise such as running, calisthenics, golf, gardening or walking for exercise?

1. Yes

 2. No

If **YES** → Did you engage in moderate or high level of physical activity for at least 30 minutes 5 or more times a week?

1. Yes 2. No

E.**MISCELLANEOUS**

E1. Do you have access to the Internet?

1. Yes 2. No

E2. Would you like to complete the next survey online at a secure website rather than getting a survey form in the mail? To switch to this faster and more cost-effective online option, check the Yes box below. Please add MSregistry@narcoms.org in your computer's address book so that we can email you a confirmation and further instructions.

1. Yes, E-mail address: _____ 2. No

E3. How did you learn about NARCOMS (check all that apply):

1. Consortium of Multiple Sclerosis Centers (CMSC) 2. Internet
 3. Book, publication 4. Doctor's Office 5. Word of Mouth
 6. National MS Society or Chapter 7. Rocky Mountain MS Center
 8. Newspaper 9. Radio 10. TV 11. MS Event
 12. Other _____

Have you signed your name on the inside of the front cover and made sure all pages are completed? Please keep the enclosed copy of the signature page for your records. Thank you.

E4. We appreciate your time in completing this questionnaire. We invite you to make any comments below:

Please direct any questions, concerns and/or comments you may have on the Registry to:

Robert Fox, M.D.
 Managing Director, NARCOMS Registry

Desiree Mitchell
 Project Manager, NARCOMS Registry

Ruth Ann Marrie, M.D., PhD.
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