The New York State Multiple Sclerosis Consortium Registry

-Please use black pen (felt type or roller ball preferred).
-Write legibly and place only one number or letter per box.
-When filling in circles, completely darken the circle.
Do not circle around the outside of the circle.

Registry ID Number
1 2 3 4 5 6 7
Three-digit site code, followed by sequential unique identifier code.

Hospital or clinic number
Please provide hospital or department chart number for cross-referencing purposes.

Registration Date
M M / D D / Y Y Y Y
Date of patient visit used for registration.

1. Please indicate the relation of the person completing these Pages (1-3):
○ Myself (patient) ○ Relative of patient ○ Friend of patient ○ Other

2. Patient's First, Middle, and Last Initials

City of residence

State

Zip Code -

County

3. Social Security Number (Last 4 digits only)
XXX-XX-

4. Date of Birth:
M M / D D / Y Y Y Y

5. Gender
○ Male ○ Female

6. Place of birth (City or town)

State of birth

Country of birth (Abbreviate)
(If other than U.S.)

7. Race
○ Caucasian (includes Hispanic)
○ Black
○ Asian / Pacific Islander
○ American Indian /Alaskan
○ Other(specify)

8. Education
○ Less than 12 years
○ High school graduate
○ 1-3 years college or technical school
○ College or technical school graduate
○ Post-graduate education

9. What is your current employment status (check only one):
○ Employed
○ Sheltered
○ Cannot find work
○ Disabled, currently age <60
○ Retired not disabled age <60
○ Retired age 60+
○ Homebound employment
○ Volunteer
○ Student
○ Workers' comp.
○ Homemaker
○ Unemployed

10. Females Only
Please indicate the number of medically confirmed pregnancies

Number of Pregnancies

Are you pregnant now? ○ Yes ○ No

Number of live births

Date of first live birth
M M / D D / Y Y Y Y

11. Are you a member of the National Multiple Sclerosis Society?
○ No ○ Yes

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12. Please indicate your present living situation

Private residence (including apartments)

Indicate those who live with you at the present time at your residence. (Check all that apply)

- ○ Spouse
- ○ Children
- ○ Parent(s)
- ○ No one (living alone)
- ○ Friend(s)
- ○ Other Relative

Institutional setting

Indicate the type of facility that describes your situation.

- ○ Nursing home
- ○ Other type of facility

13. Marital Status

- ○ Never married
- ○ Divorced
- ○ Married
- ○ Widow/er
- ○ Separated
- ○ Cohabitating

14. Do you have a family history of MS in blood relatives? ○ **No** ○ **Yes**

Specify

Is relative listed above a twin?

○ Not a twin ○ Fraternal ○ Identical

15. Are you a twin? ○ Not a twin ○ Fraternal ○ Identical

16. Do you or any blood relatives have any of the following conditions? (Check all that apply and specify relation of afflicted family member).

Lupus erythematosus	○ Myself	○ Relative	○ Both	Specify
Rheumatoid arthritis	○ Myself	○ Relative	○ Both	Specify
Crohn's (inflammatory bowel) disease	○ Myself	○ Relative	○ Both	Specify
Juvenile diabetes mellitus	○ Myself	○ Relative	○ Both	Specify
Manic depressive illness	○ Myself	○ Relative	○ Both	Specify
Psoriasis	○ Myself	○ Relative	○ Both	Specify
Allergies	○ Myself	○ Relative	○ Both	Specify
Thyroiditis	○ Myself	○ Relative	○ Both	Specify
Myasthenia gravis	○ Myself	○ Relative	○ Both	Specify
Other Illness	○ Myself	○ Relative	○ Both	Specify

17. For each of the following activities, please check each response indicating your level of difficulty:

(4) No difficulty (and you can easily perform the activity)

(3) Some difficulty (but you can perform the actvity well enough)

(2) A lot of difficulty (but you can still do the activity)

(1) Unable (you cannot do this activity or else someone helps you with it)

(0) Not applicable (you choose not to do this activity)

Getting up from a low seat like a sofa	○ 4	○ 3	○ 2	○ 1	
Climbing a flight of stairs	○ 4	○ 3	○ 2	○ 1	
Standing a long time, like for 30 minutes	○ 4	○ 3	○ 2	○ 1	
Driving an automobile	○ 4	○ 3	○ 2	○ 1	○ 0

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18. Are you having any pain? ○ No ○ Yes

What was the extent of your pain during the past 3 days including today?

○ Mild pain ○ Discomforting pain ○ Distressing pain ○ Horrible pain ○ Excruciating pain

19. How satisfied are you with life in general? (Check only one)

○ Not satisfied ○ More satisfied than not satisfied ○ Fairly well satisfied ○ Very well satisfied

20. For each of the following areas, please check each response indicating your level of limitation:

	(7) No limitation	(6) None to mild limitation	(5) Mild limitation	(4) Mild to moderate limitation	(3) Moderate limitation	(2) Moderate to severe limitation	(1) Severe limitation
Left upper limb	○ 7	○ 6	○ 5	○ 4	○ 3	○ 2	○ 1
Right upper limb	○ 7	○ 6	○ 5	○ 4	○ 3	○ 2	○ 1
Right lower limb	○ 7	○ 6	○ 5	○ 4	○ 3	○ 2	○ 1
Left lower limb	○ 7	○ 6	○ 5	○ 4	○ 3	○ 2	○ 1
Bowel continence	○ 7	○ 6	○ 5	○ 4	○ 3	○ 2	○ 1
Bladder continence	○ 7	○ 6	○ 5	○ 4	○ 3	○ 2	○ 1
Fatigability	○ 7	○ 6	○ 5	○ 4	○ 3	○ 2	○ 1
Vision	○ 7	○ 6	○ 5	○ 4	○ 3	○ 2	○ 1

21. How much have you been bothered or worried during the past 7 days by the following moods? Please check each response:

	(5) Not bothered or worried	(4) Mildly	(3) Moderately	(2) Quite a bit	(1) Extremely
Feeling lonesome	○ 5	○ 4	○ 3	○ 2	○ 1
Feeling pessimistic about your future	○ 5	○ 4	○ 3	○ 2	○ 1
Feeling uptight, tense or stressed out	○ 5	○ 4	○ 3	○ 2	○ 1
Having panic attacks	○ 5	○ 4	○ 3	○ 2	○ 1
Feeling easily irritated or annoyed	○ 5	○ 4	○ 3	○ 2	○ 1
Having morbid or gloomy thoughts	○ 5	○ 4	○ 3	○ 2	○ 1
Blaming yourself	○ 5	○ 4	○ 3	○ 2	○ 1

22. Have you suffered a fracture since being diagnosed with MS? ○ Yes ○ No

23. Are you presently using complementary therapies (non-traditional medicine; i.e., acupuncture, herbs, chiropractic, massage)?

○ Yes ○ No

Patient questions end here.

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[ ][ ][ ]

23. Date of first MS Symptom: M M / D D / Y Y Y Y

Indicate date of first onset of MS symptoms.

24. First MS Medical Diagnosis: M M / D D / Y Y Y Y

List the date of first medical diagnosis of MS.

25. Please indicate method of payment for services: (Check all that apply)

- ○ Self-pay
- ○ Medicare
- ○ Medicaid
- ○ None
- ○ Research funding
- ○ Commercial insurance / Fee for service / or indemnity plan
- ○ Managed care or health maintenance organization (HMO)
- ○ Uniformed services insurance (CHAMPUS)

26. MS disease status and relapse characteristics:

Relapse or exacerbation is defined as the development of new neurologic symptoms or worsening of pre-existing neurologic symptoms, lasting 48 hours, accompanied by objective changes on examination, indicating deterioration when the course had been stationary, or improving during the previous month.

- ○ Relapsing/Remitting →
- ○ Secondary progressive →
- ○ Progressive relapsing →

a. Please indicate the number of relapses or exacerbations the patient has experienced in the past 3 years. Number of events [ ]

b. If the patient has been exacerbating for less then 3 years, indicate the number of months from their first relapse until the time of this visit.

Number of months [ ] Or ○ Patient has been relapsing for 3 or more years.

c. Is patient exacerbating at the time of this visit? ○ No ○ Yes

- ○ Primary progressive → **Go to question 27**
- ○ Other (specify) [ ]

27. Functional Scores

Pyramidal	Cerebellar	Brain Stem	Sensory	Bowel and bladder	Visual	Cerebral	Other functions
○ 0	○ 0	○ 0	○ 0	○ 0	○ 0	○ 0	○ 0
○ 1	○ 1	○ 1	○ 1	○ 1	○ 1	○ 1	○ 1
○ 2	○ 2	○ 2	○ 2	○ 2	○ 2	○ 2	○ V
○ 3	○ 3	○ 3	○ 3	○ 3	○ 3	○ 3	
○ 4	○ 4	○ 4	○ 4	○ 4	○ 4	○ 4	
○ 5	○ 5	○ 5	○ 5	○ 5	○ 5	○ 5	
○ 6	○ V	○ V	○ 6	○ 6	○ 6	○ V	
○ V	○ X		○ V	○ V	○ V		
					○ X		

28. Kurtzke EDSS at registration visit

○ Zero	○ 5.5
○ 1.0	○ 6.0
○ 1.5	○ 6.5
○ 2.0	○ 7.0
○ 2.5	○ 7.5
○ 3.0	○ 8.0
○ 3.5	○ 8.5
○ 4.0	○ 9.0
○ 4.5	○ 9.5
○ 5.0	

29. **a.** Timed ambulation for twenty-five (25) feet in seconds. **(Please address both parts of this test: time and assistance)**

[ ][ ][ ] . [ ]

b. Assistance: (Indicate level of assistance necessary to complete 25 ft. walk.)

○ Unassisted ○ Assist of one ○ Assist of two ○ Unable to perform test

30. **Optional Supplement** 9-hole peg test: indicate the number of seconds it takes to complete the test for each hand, and indicate the dominant hand.

a. Right hand [ ][ ][ ] . [ ]

b. Left hand [ ][ ][ ] . [ ]

c. Indicate dominant hand

○ Right ○ Left ○ Ambidextrous ○ Unable to perform test

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31. **a.** Magnetic Resonance Imaging

		/			/				
M	M		D	D		Y	Y	Y	Y

Indicate date of last neurologic MRI scan

b. Is brain MRI ...

- ○ Not performed
- ○ Normal?
- ○ Abnormal?

c. Is MRI supportive of diagnosis of MS?

- ○ Yes
- ○ No
- ○ Test inconclusive
- ○ Test not performed/unknown if test performed

32. Cerebrospinal Fluid Parameters

a. Are CSF IgG parameters supportive of diagnosis of MS?

○ Yes ○ No ○ Test inconclusive ○ Test not performed/unknown if test performed

b. Are oligoclonal bands present in the CSF but not in the blood?

○ Yes ○ No ○ Test inconclusive ○ Test not performed/unknown if test performed

c. Are free kappa light chains elevated in the CSF?

○ Yes ○ No ○ Test inconclusive ○ Test not performed/unknown if test performed

33. Indicate the types of MS therapies the patient has received in the past or whether the patient is presently receiving the therapy: (Choose all that apply.) Also indicate the number of months the patient has received the therapy, combining past and present use (i.e., if the patient was taking the therapy for 3 months, had a break in treatment and now has been taking the therapy for 6 months, the total duration of use is 9 months).

Duration of use (months)	Past use	Present use	
	○	○	Azathioprine (Imuran)
	○	○	Glatiramer acetate (Copaxone)
	○	○	Cyclophosphamide (Cytoxan)
	○	○	Interferon beta-1a (Avonex)
	○	○	Interferon beta-1b (Betaseron)
	○	○	Methotrexate
	○	○	IVIg
	○	○	Other (specify)
	○	○	Other (specify)

34. Please indicate the patient's past and present use of Steroids (Prednisone, Solumedrol, Decadron, ACTH), the type of therapy regimen and the duration of use.

Past use	Present use	
○	○	Steroids

If the patient has been treated with steroids:

a. Has the treatment been episodic during **past year** (i.e., for exacerbation symptoms only)?

○ Yes ○ No → **Go to part b**

→ **No further questions**

b. Has the patient been treated with regular pulses during **past year** (i.e., monthly doses)?

○ Yes ○ No

If so, for how many months? | | |

35. One-time consultation ○