The New York State Multiple Sclerosis Consortium Registry

FOLLOW-UP VISIT DATE

Hospital or clinic number: [ ][ ][ ][ ][ ][ ][ ][ ]
Please provide hospital or department chart number for cross referencing purposes.

M M / D D / Y Y Y Y
Date of patient visit for follow-up evaluation

Registry ID Number [ ][ ][ ][ ][ ][ ][ ]
Three-digit site code followed by sequential unique identifier

1. Indicate the relation of the person completing these Pages (1-3):
(i.e., the person providing the answers to these questions)

- ○ Myself (patient)
- ○ Relative of patient
- ○ Friend of patient
- ○ Other

Indicate by darkening the circle.

INSTRUCTIONS:

- Please use black pen (felt type or roller ball preferred).

- Write legibly and place only one number or letter per box.

- If you make a mistake, place a line through the incorrect response, and write the correct response near the space for that answer.

2. Patient's First and Last Initials [ ][ ]

Street (Do not Fill in)
X X X X X X X X X X X X

City of residence [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

State [ ][ ]

Zip Code [ ][ ][ ][ ][ ] - [ ][ ][ ][ ]

County [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

3. Social Security Number (Last 4 digits only)
X X X - X X - [ ][ ][ ][ ]

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

5. Gender
○ Male ○ Female

6. What is your current employment status (mark all that apply):

Indicate by darkening the circle.

- ○ Employed
- ○ Sheltered
- ○ Cannot find work
- ○ Disabled age <60
- ○ Retired not disabled age <60
- ○ Retired age 60+
- ○ Disabled age 60+
- ○ Homebound employment
- ○ Volunteer
- ○ Student
- ○ Worker's Comp.
- ○ Homemaker
- ○ Unemployed

7. Education (mark highest level of education)

- ○ Less than 12 years
- ○ High School Graduate
- ○ 1-3 years college or technical school
- ○ College or technical school graduate
- ○ Post graduate education

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

9. Females Only
Please indicate the number of medically confirmed pregnancies you have had during the **past year** (since completing last year's form).

Number of Pregnancies in the last year: [ ][ ]

Number of live births in the last year: [ ][ ]

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Indicate by darkening the circle.

Patient's First and Last Initials

10. Please indicate your present living situation

Private residence (including apartments)

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

- O Spouse
- O Children
- O Parent(s)
- O No one (living alone)
- O Friend(s)
- O Other relative

Institutional setting

Indicate the type of facility which describes your situation.

- O Nursing home
- O Other type of facility

11. Marital Status

O Never married O Married O Separated O Divorced O Widow/er O Cohabitating

12. Do you have a family history of MS in blood relatives (living or deceased)?

O No —— **Go to question 14**

O Yes -Specify relation

13. Is relative listed above a twin? O Not a twin O Fraternal O Identical

14. Do you or any blood relatives (living or deceased) have any of the following conditions? **-If No, go to question 15**

(Check all that apply & specify relation of afflicted family member).

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

15. 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 activity 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)

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

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16. Are you having **ANY** (not limited to MS) pain? ○ No ○ Yes — If yes, please check only one response for the following question

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

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

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

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

18. 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 (shoulder to hand)	○ 7	○ 6	○ 5	○ 4	○ 3	○ 2	○ 1
Right upper limb (shoulder to hand)	○ 7	○ 6	○ 5	○ 4	○ 3	○ 2	○ 1
Right lower limb (hip to foot)	○ 7	○ 6	○ 5	○ 4	○ 3	○ 2	○ 1
Left lower limb (hip to foot)	○ 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 (Tiredness)	○ 7	○ 6	○ 5	○ 4	○ 3	○ 2	○ 1
Vision	○ 7	○ 6	○ 5	○ 4	○ 3	○ 2	○ 1

If you use a catheter, do not score a 7 for the bladder question.

19. 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 or isolated	○ 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

Patient questions end here.

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

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

21. MS disease status and relapse characteristics:

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

a. Has patient exacerbated during the **past year**?
- ○ No **- Go to question 22**
- ○ Yes. Indicate number of event

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

- ○ Primary progressive → **Go to question 22**
- ○ Other (specify)

DEFINITION:
Relapse or exacerbation is defined as the development of new neurologic symptoms or worsening of preexisting 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.

22. 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		

23. Kurtzke EDSS at follow-up 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	

24. Timed ambulation for twenty-five (25) feet in seconds. ___ ___ ___ . ___

(Please address both parts of this test, time and assistance)

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

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

25. **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

Right hand ___ ___ ___ . ___

Left hand ___ ___ ___ . ___

Indicate dominant hand
- ○ Right
- ○ Left
- ○ Ambidextrous

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26. Magnetic Resonance Imaging

M M / D D / Y Y Y Y

Indicate date of last neurologic MRI scan in the **past year**. If not performed, please indicate in section a.

a. Is MRI...

- ○ Not performed in last year or unknown if performed.
- ○ Normal?
- ○ Abnormal?

b. Has MRI changed since previous registration visit MRI or previous follow-up visit MRI?

○ Worse ○ Same ○ Better ○ No comparison made

27. Cerebrospinal Fluid Parameters obtained in the **past year**

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

28. Indicate the types of MS therapies the patient has received in the **past year** 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)
	○	○	Copolymer-1 (Copaxone)
	○	○	Cyclophosphamide (Cytoxan)
	○	○	Interferon Beta-1A (Avonex)
	○	○	Interferon Beta-1B (Betaseron)
	○	○	Linomide
	○	○	Methotrexate
	○	○	Oral Myelin (Myloral)
	○	○	Other (specify)
	○	○	Other (specify)

29. Please indicate the patient's past and present use of Steroids (Prednisone, Solumedrol, Decadron, ACTH) in the **past year**, 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**

Yes → **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?