NYSMSC Registry - Enrollment Form

Registry ID # 0000000

Hospital/Clinic # _____

1. Please indicate the relationship of the person completing the demographic portion of this questionnaire

○ Patient ○ Patient's Relative ○ Patient's Friend ○ Other ○ Staff Interviewer

2. First, Middle, Last Initial _____ **Registration Date** (mm/dd/yyyy) ___/___/_____ **Gender:** ○ Male ○ Female

City/Town of Residence _____ **State of Residence** _____ **ZIP Code** _____ **County** _____

3. Date of Birth (mm/dd/yyyy) ___/___/_____ **City/Town of Birth** _____ **State of Birth** _____ **Country of Birth (if not USA)** _____

Did you move out of state prior to age 15? If so, indicate to which state

a. State _____ **Age** _____ **b. State** _____ **Age** _____ **c. State** _____ **Age** _____

d. State _____ **Age** _____ **e. State** _____ **Age** _____ **f. State** _____ **Age** _____

4. Race* (fill in all that apply): Categories per US Census Bureau

○ White
○ Hispanic/Latino
○ Black/African American
○ Asian
○ American Indian/Alaskan Native
○ Other _____
○ Multiracial _____

5. Education:

○ Less than 12 years
○ High School Graduate
○ 1-3 years college/technical school degree
○ College/University Degree
○ Post Graduate Education

6. Ethnicity/Ancestry (15 largest categories, per US Census Bureau)

○ African American
○ American
○ American Indian
○ Dutch
○ English
○ French
○ German
○ Irish
○ Italian
○ Mexican
○ Norwegian
○ Polish
○ Scotch-Irish
○ Scottish
○ Swedish
○ Other

7. What is your current employment status (check only one):

○ Employed - Full time
○ Employed - Reduced hours due to disability
○ Employed - Adapted work due to disability
○ Employed at Home
○ Homemaker
○ Student
○ Volunteer
○ Workers' Compensation
○ Unemployed - not looking for work
○ Unemployed - looking for work
○ Retired, not disabled, under age 60
○ Retired, not disabled, over age 60
○ Disabled, under age 60 due to MS
○ Disabled, over age 60 due to MS

8. Who lives with you and where do you live (fill in all that apply):

○ Alone
○ With Spouse/Partner
○ With Sibling
○ With Friend/Companion
○ With Parent
○ With Children
○ With Domestic Help
○ With Health-Related Companion
○ With Other Relative
○ Nursing Home or Assisted Living Center
○ Other type of facility _____

9. Marital Status:

○ Single
○ Married/Cohabiting
○ Divorced/Separated
○ Widowed

Rev. 3/13/06

10. The following items are to be completed by **FEMALES ONLY**

Number of Pregnancies ___ **OR** ○ None **Are you pregnant now?** ○ Yes ○ No

Number of live births ___

Is your MS affected by your menstrual cycle? ○ Yes ○ No ○ Sometimes

11. **Do you have any children affected by Multiple Sclerosis?** ○ Yes ○ No **If Yes, how many?** ___

12. **Are you a twin?** ○ Fraternal ○ Identical ○ Not a twin

13. **Number of Full Siblings** ___ **Number of Half Siblings** ___

Your Birth Order Among Full Siblings (first=01, etc) ___

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

If yes, specify relative, confirmed by Neurologist and twin classification if applicable

Relative	Neurologist	Twin Classification
○ A ○ B ○ C ○ D ○ E ○ F ○ G ○ H ○ I ○ J ○ K ○ L ○ M	○ Yes ○ No	○ Identical ○ Fraternal ○ Not a Twin
○ A ○ B ○ C ○ D ○ E ○ F ○ G ○ H ○ I ○ J ○ K ○ L ○ M	○ Yes ○ No	○ Identical ○ Fraternal ○ Not a Twin
○ A ○ B ○ C ○ D ○ E ○ F ○ G ○ H ○ I ○ J ○ K ○ L ○ M	○ Yes ○ No	○ Identical ○ Fraternal ○ Not a Twin
○ A ○ B ○ C ○ D ○ E ○ F ○ G ○ H ○ I ○ J ○ K ○ L ○ M	○ Yes ○ No	○ Identical ○ Fraternal ○ Not a Twin
○ A ○ B ○ C ○ D ○ E ○ F ○ G ○ H ○ I ○ J ○ K ○ L ○ M	○ Yes ○ No	○ Identical ○ Fraternal ○ Not a Twin
○ A ○ B ○ C ○ D ○ E ○ F ○ G ○ H ○ I ○ J ○ K ○ L ○ M	○ Yes ○ No	○ Identical ○ Fraternal ○ Not a Twin

Use the following relative legend to answer above:

A - Mother	H - Maternal Aunt
B - Father	I - Maternal Uncle
C - Son	J - Paternal Aunt
D - Daughter	K - Paternal Uncle
E - Maternal Grandparent	L - Maternal first degree cousin
F - Paternal Grandparent	M - Paternal first degree cousin
G - Sibling	

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

		A	B	C	D	E	F	G	H	I	J	K	L	M
Allergies - Specify _____	○ Myself	○	○	○	○	○	○	○	○	○	○	○	○	○
Asthma	○ Myself	○	○	○	○	○	○	○	○	○	○	○	○	○
Cancer	○ Myself	○	○	○	○	○	○	○	○	○	○	○	○	○
Chronic Respiratory Disorders	○ Myself	○	○	○	○	○	○	○	○	○	○	○	○	○
Crohn's Disease	○ Myself	○	○	○	○	○	○	○	○	○	○	○	○	○
Irritable Bowel Syndrome	○ Myself	○	○	○	○	○	○	○	○	○	○	○	○	○
Lupus erythematosus	○ Myself	○	○	○	○	○	○	○	○	○	○	○	○	○
Lymphoma	○ Myself	○	○	○	○	○	○	○	○	○	○	○	○	○
Migraines	○ Myself	○	○	○	○	○	○	○	○	○	○	○	○	○
Myasthenia gravis	○ Myself	○	○	○	○	○	○	○	○	○	○	○	○	○
Psoriasis	○ Myself	○	○	○	○	○	○	○	○	○	○	○	○	○
Rheumatoid disorders	○ Myself	○	○	○	○	○	○	○	○	○	○	○	○	○
Thyroid disease	○ Myself	○	○	○	○	○	○	○	○	○	○	○	○	○
Type I Juvenile diabetes mellitus	○ Myself	○	○	○	○	○	○	○	○	○	○	○	○	○
Other Illness	○ Myself	○	○	○	○	○	○	○	○	○	○	○	○	○

Use the following relative legend to answer above:

A - Mother	**H - Maternal Aunt**
B - Father	**I - Maternal Uncle**
C - Son	**J - Paternal Aunt**
D - Daughter	**K - Paternal Uncle**
E - Maternal Grandparent	**L - Maternal first degree cousin**
F - Paternal Grandparent	**M - Paternal first degree cousin**
G - Sibling	

16. Did you have exposure to the following risk factors before the onset of your disease (i.e., within 2 years)?

Fracture ○ Yes ○ No
Contact with dogs* ○ Yes ○ No
Contact with cats* ○ Yes ○ No
Contact with birds* ○ Yes ○ No
Spinal cord trauma ○ Yes ○ No
General anesthesia ○ Yes ○ No

*** Refers to frequent handling of animal and/or its feces**

Continual exposure to any chemical for over 1 year ○ Yes ○ No

Estimate your sun exposure (hours/day)

Winter ○ Less than 1 ○ 1-3 hours ○ 3+ hours
Summer ○ Less than 1 ○ 1-3 hours ○ 3+ hours

Smoking ○ Yes ○ No **No. of Years** ___ **Packs per day:** ○ 1 ○ 2 ○ 3 ○ 4 ○ 5+

17. Indicate if you had any of the following immunizations or the illness in the past

	Immunizations	Illness
Measles	○ Yes ○ No ○ Unknown/Can't Recall	○ Yes ○ No ○ Unknown/Can't Recall
German Measles	○ Yes ○ No ○ Unknown/Can't Recall	○ Yes ○ No ○ Unknown/Can't Recall
Mumps	○ Yes ○ No ○ Unknown/Can't Recall	○ Yes ○ No ○ Unknown/Can't Recall
Polio (oral)	○ Yes ○ No ○ Unknown/Can't Recall	○ Yes ○ No ○ Unknown/Can't Recall
Polio (injection)	○ Yes ○ No ○ Unknown/Can't Recall	○ Yes ○ No ○ Unknown/Can't Recall
Diphtheria	○ Yes ○ No ○ Unknown/Can't Recall	○ Yes ○ No ○ Unknown/Can't Recall
Pertussis (Whooping Cough)	○ Yes ○ No ○ Unknown/Can't Recall	○ Yes ○ No ○ Unknown/Can't Recall
Tetanus	○ Yes ○ No ○ Unknown/Can't Recall	○ Yes ○ No ○ Unknown/Can't Recall
Mumps	○ Yes ○ No ○ Unknown/Can't Recall	○ Yes ○ No ○ Unknown/Can't Recall
Chicken Pox	○ Yes ○ No ○ Unknown/Can't Recall	○ Yes ○ No ○ Unknown/Can't Recall
Hepatitis B	○ Yes ○ No ○ Unknown/Can't Recall	○ Yes ○ No ○ Unknown/Can't Recall
Hepatitis A	○ Yes ○ No ○ Unknown/Can't Recall	○ Yes ○ No ○ Unknown/Can't Recall
Smallpox	○ Yes ○ No ○ Unknown/Can't Recall	○ Yes ○ No ○ Unknown/Can't Recall

18. For each of the following activities, please fill in one response indicating your level of difficulty:

No difficulty (and you can easily perform the activity)
Some difficulty (but you can still perform the activity well enough)
A lot of difficulty (but you can still do the activity)
Unable (you cannot do this activity or someone else helps you with it)
Not applicable (you choose not to do this activity)

○ ○ ○ ○ ○ **Getting up from a low seat like a sofa**
○ ○ ○ ○ ○ **Climbing a flight of stairs**
○ ○ ○ ○ ○ **Standing a long time, like for 30 minutes**
○ ○ ○ ○ ○ **Driving an automobile**

19. Are you having any pain? (fill in only one): ○ No ○ Yes

If YES, what was the extent of your pain during the past 3 days including today (fill in only one)?

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

20. How satisifed are you with life in general (fill in only one)?

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

21. How much are you limited in each of the following areas:

	No limitation	None to mild limitation	Mild limitation	Mild to moderate limitation	Moderate limitation	Moderate to severe limitation	Severe limitation
Right upper limb	○	○	○	○	○	○	○
Left upper limb	○	○	○	○	○	○	○
Right lower limb	○	○	○	○	○	○	○
Left lower limb	○	○	○	○	○	○	○

	No limitation	None to mild limitation	Mild limitation	Mild to moderate limitation	Moderate limitation	Moderate to severe limitation	Severe limitation
Bowel continence	○	○	○	○	○	○	○
Bladder continence	○	○	○	○	○	○	○
Fatiguability	○	○	○	○	○	○	○
Vision	○	○	○	○	○	○	○

22. For each of the following feelings or moods, please fill in one response indicating how much you have been bothered or worried during the last 7 days:

Are you feeling...	Not bothered or worried	Mildly	Moderately	Quite a bit	Extremely
Lonesome or isolated	○	○	○	○	○
Pessimistic about future	○	○	○	○	○
Uptight, tense or stressed	○	○	○	○	○
Panic attacks	○	○	○	○	○

Are you feeling...	Not bothered or worried	Mildly	Moderately	Quite a bit	Extremely
Easily irritated or annoyed	○	○	○	○	○
Morbid or gloomy thoughts	○	○	○	○	○
Blaming yourself or guilt	○	○	○	○	○

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

Bone Density Test Results ○ Normal ○ Abnormal

24. Are you presently using complementary therapies or non-traditional medicine?

○ Acupuncture ○ Herbs ○ Chiropractic ○ Vitamins ○ Massage ○ Supplements ○ Exercise Program

○ Other _____

25. Insurance (fill in all that apply):

○ Self-pay ○ Medicare ○ Medicaid ○ Research Funding

○ Managed care or health maintenance organization (HMO)

○ Uniformed services insurance (CHAMPUS)

○ Commercial Insurance/ fee for service/ or indemnity plan

○ None

PATIENT QUESTIONS END HERE

THE FOLLOWING PAGES ARE TO BE ANSWERED BY MEDICAL PERSONNEL

26. Date of MS Onset

Symptom (mm/yyyy) ___/____ ○ Unknown

MS Diagnosis (mm/yyyy) ___/____ ○ Unknown

27. Symptomatology of the episode:

	MS Onset (mm/yyyy)	MS Diagnosis (mm/yyyy)
Unknown	___/____	___/____
Walking Difficulties	___/____	___/____
Upper Extremity Dysfunction	___/____	___/____
Lower Extremity Dysfunction	___/____	___/____
Paroxysmal/sensory symptoms (pain, paresthesia, Lhermitte)	___/____	___/____
Bladder/bowel/sexual dysfunction	___/____	___/____
Vertigo/hypoacusia (hearing loss)	___/____	___/____
Speech/swallowing impairment	___/____	___/____
Oculomotor impairment	___/____	___/____
Facial motor/sensory	___/____	___/____
Mental deterioration/psychiatric symptoms	___/____	___/____
Fatigue	___/____	___/____
Optic Neuritis	___/____	___/____
Other	___/____	___/____

28. Disease status at time of visit:

○ Two attacks with objective clinical evidence of two or more lesions

○ Two attacks with objective clinical evidence of one lesion

Dissemination in space demonstrated by:

- ○ MRI according to International Panel Criteria (IPC) OR
- ○ Two or more MRI-detected lesions consistent with MS plus positive CSF OR
- ○ Await further clinical attack implicating a different site

○ One attack with objective clinical evidence of two or more lesions

Dissemination in time demonstrated by:

- ○ MRI according to International Panel Criteria (IPC) OR
- ○ Second clinical attack

○ One attack with objective clinical evidence of one lesion (monosymptomatic presentation; clinically isolated syndrome)

Dissemination in space demonstrated by:

- ○ MRI according to International Panel Criteria (IPC) OR
- ○ Two or more MRI-detected lesions consistent with MS plus positive CSF

Dissemination in time demonstrated by:

- ○ MRI according to International Panel Criteria (IPC) OR
- ○ Second clinical attack

○ Insidious neurological progression suggestive of MS

One year of disease progression (retrospectively or prospectively determined) AND TWO of the following:

- ○ Positive brain MRI (nine T2 lesions or four or more T2 lesions with positive VEP)
- ○ Positive spinal cord MRI (two focal T2 lesions)
- ○ Positive CSF

Is the diagnosis of MS clinically definite according to Poser criteria ○ Yes ○ No

Is the diagnosis of MS clinically definite according to McDonald criteria ○ MS ○ Possible MS ○ Not MS

29. A relapse or exacerbation is defined as the development of neurological symptoms or worsening of preexisting neurological symptoms lasting for at least 24 hours, accompanied by objective changes on neurological examination. Choose 1 option from Column A below and fill in the corresponding information in Column B.

A	B
○ Relapsing/Remitting ○ Secondary Progressive ○ Progressive Relapsing	Indicate the number of years the patient has had relapses ○ 0-5 Years ○ 6-10 Years ○ 11-15 Years ○ 15+ Years ○ Unknown Indicate the number of relapses in the last year ___ Indicate the number of months from the last relapse ___ Is the patient exacerbating at time of visit? ○ Yes ○ No

○ Primary Progressive
○ Devic's Disease
○ Clinically Isolated Syndrome
○ Optic Neuritis ○ Brainstem Syndrome ○ Transverse Myelitis
○ ADEM
○ Other _____

30. MRI DATA

Brain
Date (mm/dd/yyyy) ___/___/_____

○ Normal
○ Abnormal
○ No MRI

If Abnormal, is it:
○ Typical
○ Suggestive
○ Atypical

PATY Criteria ○ Yes ○ No

Modified Barkhof Criteria ○ Yes ○ No

Comparison with previous brain MRI, if available

○ Worsened ○ New T2 Lesions ○ New black holes ○ Unchanged ○ Improved
○ New Gd-enhancing lesions ○ Not Available

Is brain MRI supportive of MS diagnosis? ○ Yes ○ No ○ Test not performed/unknown

Spinal Cord

Cervical Date (mm/dd/yyyy) ___/___/_____

○ Normal
○ Abnormal
○ No MRI

Thoracic/lumbar Date (mm/dd/yyyy) ___/___/_____

○ Normal
○ Abnormal
○ No MRI

Is spinal cord MRI supportive of MS diagnosis? ○ Yes ○ No ○ Test not performed/unknown

Comparison with previous spinal cord MRI, if available

○ Worsened ○ New T2 Lesions ○ New black holes ○ Unchanged ○ Improved
○ New Gd-enhancing lesions ○ Not Available

31. Cerebral Spinal Fluid

Date (mm/dd/yyyy)

__/__/____ ○ No CSF Tested

Are CSF IgG parameters supportive of MS diagnosis ○ Yes ○ No ○ Test not performed/unknown

Are oligoclonal bands present in CSF ○ Yes ○ No ○ Test not performed/unknown

IgG Index ___.__

32. Evoked Potentials

Date (mm/dd/yyyy)

__/__/____

○ No Evoked Potentials

	RIGHT			LEFT		
	Not Done	**Normal**	**Abnormal**	**Not Done**	**Normal**	**Abnormal**
Visual	○	○	○	○	○	○
Brain Stem Auditory	○	○	○	○	○	○
Somatosensory Upper Limbs	○	○	○	○	○	○
Somatosensory Lower Limbs	○	○	○	○	○	○
Motor	○	○	○	○	○	○

33. Functional Scores and EDSS

Pyramidal	Cerebellar	Brain Stem	Sensory	Bowel & Bladder	Visual	Cerebral	Other functions
0	0	0	0	0	0	0	0
1	1	1	1	1	1	1	
2	2	2	2	2	2	2	
3	3	3	3	3	3	3	1
4	4	4	4	4	4	4	
5	5	5	5	5	5	5	
6	6	6	6	6	6	6	
	V				V		V
V	X	V	V	V	X	V	

Kurtzke EDSS at registration

○ 0.0	○ 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	

34. Timed Ambulation for 25 feet in seconds

□□□.□

0 ○○○○
1 ○○○○
2 ○○○○
3 ○○○○
4 ○○○○
5 ○○○○
6 ○○○○
7 ○○○○
8 ○○○○
9 ○○○○

Level of Assistance

○ Unassisted ○ Assist of one ○ Assist of two ○ Unable

Is the patient wearing an AFO?

○ Yes ○ No

35. ****OPTIONAL** 9-Hole peg test - Indicate the number of seconds it takes to complete the test for each hand, and indicate the dominant hand

RIGHT	LEFT
☐☐☐.☐	☐☐☐.☐
0 ○○○ ○	0 ○○○ ○
1 ○○○ ○	1 ○○○ ○
2 ○○○ ○	2 ○○○ ○
3 ○○○ ○	3 ○○○ ○
4 ○○○ ○	4 ○○○ ○
5 ○○○ ○	5 ○○○ ○
6 ○○○ ○	6 ○○○ ○
7 ○○○ ○	7 ○○○ ○
8 ○○○ ○	8 ○○○ ○
9 ○○○ ○	9 ○○○ ○

Indicate Dominant Hand

○ Right ○ Left ○ Ambidextrous

OR

○ Unable to perform test

○ Test not done

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36. ****OPTIONAL** Tests**

PASAT Test A___ **OR** **PASAT Test B**___ **OR** ○ Test not done

value:0-60 **value: 0-60**

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37. **Mental Deterioration (OPTIONAL)**

General disease in mentation:	○ None	○ Mild	○ Moderate	○ Severe
Memory:	○ None	○ Mild	○ Moderate	○ Severe
Abstract/Conceptual Reasoning:	○ None	○ Mild	○ Moderate	○ Severe
Attention/Concentration/Processing speed:	○ None	○ Mild	○ Moderate	○ Severe
Visuoperceptual abilities:	○ None	○ Mild	○ Moderate	○ Severe
Language skills:	○ None	○ Mild	○ Moderate	○ Severe
Other Cognitive Domain: specify _____	○ None	○ Mild	○ Moderate	○ Severe

Was the patient emotionally evaluated? ○ Yes ○ No

If yes to above, which test was performed?

MSNQ ○ Yes ○ No ○ By patient ○ By informant

Neuropsychiatric Assessment ○ Yes ○ No

Lability of affect ○ Yes ○ No

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38. **Psychiatric Symptoms**

○ None
○ Mood alteration - Depression
○ Mood alteration - Euphoria
○ Mood alteration - Anxiety
○ Delusions
○ Hallucinations
○ Other_____

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39. **Has the patient ever been in a clinical trial?** ○ Yes ○ No **If yes,** ○ Past ○ Present

Was the study of an FDA approved treatment? ○ Yes ○ No

Specify trial (OPTIONAL) _____

40. DISEASE MODIFYING THERAPIES ONLY: Indicate the types of MS therapies the patient has received in the past and/or whether the patient is presently receiving the therapy

Drug	PRESENT USE	Duration (mos.)	Duration Unknown	PAST USE	Duration (mos.)
Avonex	○		○	○	
Betaseron	○		○	○	
Cellcept	○		○	○	
Copaxone	○		○	○	
Cytoxan	○		○	○	
Imuran	○		○	○	
IVIg	○		○	○	
Methotrexate	○		○	○	
Novantrone	○		○	○	
Rebif 22 mcg	○		○	○	
Rebif 44 mcg	○		○	○	
Tysabri	○		○	○	
Combination therapy Specify:	○		○	○	
Combination therapy Specify:	○		○	○	
Other/Experimental disease modifying therapy Specify:	○		○	○	
Other/Experimental disease modifying therapy Specify:	○		○	○	
Pulse steroid Specify:	○		○	○	
Episodic steroid Specify:	○		○	○	

MEDICAL PERSONNEL QUESTIONS END HERE