INSERT XXI
Multiple Sclerosis

FOR REGISTRY USE ONLY:
I.D. ☐ – ☐☐☐☐ – ☐☐☐☐☐☐
Date received:

TEAM: ☐☐☐☐ IUBMID: ☐☐☐☐☐☐
(Institutional Unique Blood or Marrow Transplant Identification Number)

Registry (circle one): IBMTR ABMTR EBMT

Date of transplant for which this form is being completed: ☐☐ ☐☐ ☐☐☐☐ (Month Day Year)

Date of report: ☐☐ ☐☐ ☐☐☐☐ (Month Day Year)

Pretransplant Information*

**** If this is a report of a second (or subsequent) transplant, check here ☐ and go to Q.46***

1. Date of diagnosis: ☐☐ ☐☐ ☐☐☐☐ (Month Day Year)

2. Did the patient meet the Poser criteria for clinically-definite Multiple Sclerosis *(see Appendix A)*?
1 ☐ Yes
0 ☐ No
8 ☐ Unknown

Appendix A
(Poser CM, Paty DW, Scheinber L, et al, Ann Neurol, 1983, 13:227-231)
Clinically definite MS:
- Two attacks and clinical evidence of two separate lesions
- Two attacks; clinical evidence of one lesion and paraclinical evidence of another, separate lesion

3. Did the patient meet the criteria for laboratory-supported Multiple Sclerosis?
1 ☐ Yes
0 ☐ No
8 ☐ Unknown

Family members affected:

	Yes	No	Unknown	
4.	1 ☐	0 ☐	8 ☐	Monozygotic twin
5.	1 ☐	0 ☐	8 ☐	Dizygotic twin
6.	1 ☐	0 ☐	8 ☐	Other first degree relative (sibling, parent, child)
7.	1 ☐	0 ☐	8 ☐	Second degree relative (grandparent, aunt, uncle, 1st cousin)
8.	1 ☐	0 ☐	8 ☐	Other, specify: _____

9. Indicate the disease course between diagnosis and mobilization for stem cell collection (or high-dose therapy if mobilization not done):
1 ☐ Relapsing/Remitting
2 ☐ Secondary progressive (may have had previous Relapsing/Remitting)
3 ☐ Primary progressive
4 ☐ Progressive relapsing (malignant)
7 ☐ Not evaluable, explain: _____

TEAM: ☐☐☐☐ IUBMID: ☐☐☐☐☐☐

10. Specify number of relapses of Multiple Sclerosis during the 2-year period prior to mobilization for stem cell collection (or high-dose therapy if mobilization not done): ☐☐ ❑ Unknown

11. Did the patient progress during the 2-year period prior to mobilization for stem cell collection (or high-dose therapy if mobilization not done)?

1 ❑ Yes
0 ❑ No
8 ❑ Unknown

Therapy History

Cite all disease-modifying treatments received by patient between time of diagnosis and prior to mobilization for stem cell collection (or high-dose therapy if mobilization not done):

	Yes	No	Unk	Treatment		Reason for Stopping *(use codes below)*
12.	1❑	0❑	8❑	α-interferon	**13.**	☐ If *Other*, specify: _____
14.	1❑	0❑	8❑	β-interferon	**15.**	☐ If *Other*, specify: _____
16.	1❑	0❑	8❑	Anti-lymphocyte antibodies	**17.**	☐ If *Other*, specify: _____
18.	1❑	0❑	8❑	Azathioprine	**19.**	☐ If *Other*, specify: _____
20.	1❑	0❑	8❑	Cop-I	**21.**	☐ If *Other*, specify: _____
22.	1❑	0❑	8❑	Corticosteroids – chronic low-dose	**23.**	☐ If *Other*, specify: _____
24.	1❑	0❑	8❑	Corticosteroids – pulse high-dose	**25.**	☐ If *Other*, specify: _____
26.	1❑	0❑	8❑	Craniospinal irradiation	**27.**	☐ If *Other*, specify: _____
28.	1❑	0❑	8❑	Cyclophosphamide	**29.**	☐ If *Other*, specify: _____
30.	1❑	0❑	8❑	Lymphocytopheresis	**31.**	☐ If *Other*, specify: _____
32.	1❑	0❑	8❑	Mitoxantrone	**33.**	☐ If *Other*, specify: _____
34.	1❑	0❑	8❑	Plasmapheresis	**35.**	☐ If *Other*, specify: _____
36.	1❑	0❑	8❑	Total lymph node irradiation (TLI)	**37.**	☐ If *Other*, specify: _____
38.	1❑	0❑	8❑	Other, specify: _____	**39.**	☐ If *Other*, specify: _____
40.	1❑	0❑	8❑	Other, specify: _____	**41.**	☐ If *Other*, specify: _____
42.	1❑	0❑	8❑	Other, specify: _____	**43.**	☐ If *Other*, specify: _____
44.	1❑	0❑	8❑	Other, specify: _____	**45.**	☐ If *Other*, specify: _____

Reason for Stopping Codes
1 = Failure
2 = Toxicity
3 = Still receiving at mobilization
7 = Other, specify
8 = Unknown

TEAM: ☐☐☐☐ IUBMID: ☐☐☐☐☐☐

Pre-Mobilization Evaluation*

**** Provide data on most recent evaluation prior to the initiation of mobilization therapy (evaluation should be performed ≤4 weeks prior to mobilization for stem cell collection); if patient did not receive mobilization therapy, check here ❑ and go to Q.74***

46. Date of evaluation prior to mobilization for stem cell collection: ☐☐ ☐☐ ☐☐☐☐ (Month Day Year)

47. Scripps neurological rating scale score prior to mobilization: ☐☐☐ ❑ Unknown

Kurtze functional systems scores prior to mobilization:

48.	Pyramidal ☐☐	❑ Unknown
49.	Cerebellar ☐☐	❑ Unknown
50.	Brain stem ☐☐	❑ Unknown
51.	Sensory ☐☐	❑ Unknown
52.	Bowel/Bladder ☐☐	❑ Unknown
53.	Visual ☐☐	❑ Unknown
54.	Cerebral ☐☐	❑ Unknown
55.	Other functions ☐☐	❑ Unknown
56.	Others, specify: ☐☐	❑ Unknown

_____

57. Kurtze Expanded Disability Status Scale (EDSS) prior to mobilization: ☐☐.☐ ❑ Unknown

Composite Scale

Timed 25-foot Walk prior to mobilization:

58. Assistive device used? 1❑ Yes 0❑ No ❑ Unknown

59. Specify:
1❑ Unilateral assistance (cane or crutch)
2❑ Bilateral assistance (canes or crutches)
3❑ Walker or similar device

60.	Time for Trial 1:	☐☐☐.☐ sec.	1❑ Did not complete	❑ Unknown
61.	Time for Trial 2:	☐☐☐.☐ sec.	1❑ Did not complete	❑ Unknown

9-hole Peg Test prior to mobilization:

62.	Dominant Hand, Time for Trial 1:	☐☐☐.☐ sec.	1❑ Did not complete	❑ Unknown
63.	Dominant Hand, Time for Trial 2:	☐☐☐.☐ sec.	1❑ Did not complete	❑ Unknown
64.	Non-dominant Hand, Time for Trial 1:	☐☐☐.☐ sec.	1❑ Did not complete	❑ Unknown
65.	Non-dominant Hand, Time for Trial 2:	☐☐☐.☐ sec.	1❑ Did not complete	❑ Unknown

Paced Auditory Serial Addition Test (PASAT) prior to mobilization:

66.	PASAT 3 Score: ☐☐	Range (0-60)	❑ Unknown
67.	PASAT 2 Score: ☐☐	Range (0-60)	❑ Unknown

TEAM: ☐☐☐☐ IUBMID: ☐☐☐☐☐☐

68. Date of most recent MRI scan of brain prior to mobilization: ☐☐ ☐☐ ☐☐☐☐ (Month Day Year) 7❑ MRI not done 8❑ Date unknown

MRI scan:

69. Are gadolinium-enhancing lesions present on the MRI? 1❑ Yes 0❑ No 8❑ Unknown

70. Number of gadolinium-enhancing lesions: ☐☐ 8❑ Unknown

Did the MRI meet the following criteria:

71. Criteria of Paty? 1❑ Yes 0❑ No 8❑ Unknown

Definition: 3 or more T2-hyperintensities with 1 bordering the lateral ventricle

72. Criteria of Fazekas? 1❑ Yes 0❑ No 8❑ Unknown

Definition: 3 or more T2-hyperintensities with at least 2 of the following lesion characteristics:
- Size >5 mm
- Abutting the ventricular wall
- Infratentorial location

73. Criteria of Barkhof? 1❑ Yes 0❑ No 8❑ Unknown

Definition:
- Gadolinium-enhancing lesion (at least 1)
- Juxtacortical location (at least 1)
- Periventricular location (at least 3)
- Infratentorial location (at least 1)

TEAM: ☐☐☐☐ IUBMID: ☐☐☐☐☐☐

Evaluation Prior to Conditioning (High-dose Therapy)*

**** Evaluation should be performed ≤2 weeks prior to conditioning***

74. Was an assessment performed after mobilization and prior to starting conditioning (high-dose therapy)?
1 ❑ Yes 0 ❑ No 8 ❑ Unknown
Go to ***Q.102***

75. Date of evaluation prior to conditioning: ☐☐ ☐☐ ☐☐☐☐
Month Day Year

76. Scripps neurological rating scale score prior to conditioning: ☐☐☐ ❑ Unknown

Kurtze functional systems scores prior to conditioning:

77.	Pyramidal	☐☐	❑ Unknown
78.	Cerebellar	☐☐	❑ Unknown
79.	Brain stem	☐☐	❑ Unknown
80.	Sensory	☐☐	❑ Unknown
81.	Bowel/Bladder	☐☐	❑ Unknown
82.	Visual	☐☐	❑ Unknown
83.	Cerebral	☐☐	❑ Unknown
84.	Other functions	☐☐	❑ Unknown
85.	Others, specify: _____	☐☐	❑ Unknown

86. Kurtze Expanded Disability Status Scale (EDSS) prior to conditioning: ☐☐.☐ ❑ Unknown

Composite Scale
Timed 25-foot Walk prior to conditioning:

87. Assistive device used? 1❑ Yes 0❑ No ❑ Unknown

88. Specify:
1❑ Unilateral assistance (cane or crutch)
2❑ Bilateral assistance (canes or crutches)
3❑ Walker or similar device

89.	Time for Trial 1:	☐☐☐.☐ sec.	1❑ Did not complete	❑ Unknown
90.	Time for Trial 2:	☐☐☐.☐ sec.	1❑ Did not complete	❑ Unknown

9-hole Peg Test prior to conditioning:

91.	Dominant Hand, Time for Trial 1:	☐☐☐.☐ sec.	1❑ Did not complete	❑ Unknown
92.	Dominant Hand, Time for Trial 2:	☐☐☐.☐ sec.	1❑ Did not complete	❑ Unknown
93.	Non-dominant Hand, Time for Trial 1:	☐☐☐.☐ sec.	1❑ Did not complete	❑ Unknown
94.	Non-dominant Hand, Time for Trial 2:	☐☐☐.☐ sec.	1❑ Did not complete	❑ Unknown

Paced Auditory Serial Addition Test (PASAT) prior to conditioning:

95.	PASAT 3 Score:	☐☐	Range (0-60)	❑ Unknown
96.	PASAT 2 Score:	☐☐	Range (0-60)	❑ Unknown

TEAM: ☐☐☐☐ IUBMID: ☐☐☐☐☐☐

97. Date of most recent MRI scan of brain prior to conditioning:

☐☐ ☐☐ ☐☐☐☐
Month Day Year

7❑ MRI not done between mobilization and conditioning
8❑ Date unknown

MRI scan:

98. Are gadolinium-enhancing lesions present on the MRI? 1❑ Yes 0❑ No 8❑ Unknown

99. Number of gadolinium-enhancing lesions: ☐☐ 8❑ Unknown

100. Are new lesions present on the MRI? 1❑ Yes 0❑ No 8❑ Unknown

101. Indicate new lesions present *(check only one)*:
1❑ Gadolinium-enhancing
2❑ Unenhancing
3❑ Both
8❑ Unknown

TEAM: ☐☐☐☐ IUBMID: ☐☐☐☐☐☐

Posttransplant Information*

To be completed 100 days posttransplant, or at time of death if death occurred <100 days posttransplant, or immediately prior to start of high-dose therapy (conditioning) for second transplant if second transplant done <100 days after first transplant.

102. Did patient receive treatment for multiple sclerosis posttransplant?

1 ❑ Yes
0 ❑ No
8 ❑ Unknown

Reason for Therapy Codes
1 = Planned per protocol
2 = Continued from pretransplant
3 = Relapse/Progression of MS
7 = Other, specify
8 = Unknown

Cite regimens:

	Yes	No	Unk		Reason for Therapy (use codes above)	Start Date Month Day Year	Still Receiving
103.	1❑	0❑	8❑	α-interferon			1❑
104.					☐ If *Other*, specify:		
105.	1❑	0❑	8❑	ß-interferon			1❑
106.					☐ If *Other*, specify:		
107.	1❑	0❑	8❑	Anti-lymphocyte antibodies			1❑
108.					☐ If *Other*, specify:		
109.	1❑	0❑	8❑	Azathioprine			1❑
110.					☐ If *Other*, specify:		
111.	1❑	0❑	8❑	Cop-I			1❑
112.					☐ If *Other*, specify:		
113.	1❑	0❑	8❑	Corticosteroids – chronic low-dose			1❑
114.					☐ If *Other*, specify:		
115.	1❑	0❑	8❑	Corticosteroids – pulse high-dose			1❑
116.					☐ If *Other*, specify:		
117.	1❑	0❑	8❑	Craniospinal irradiation			1❑
118.					☐ If *Other*, specify:		
119.	1❑	0❑	8❑	Cyclophosphamide			1❑
120.					☐ If *Other*, specify:		
121.	1❑	0❑	8❑	Lymphocytopheresis			1❑
122.					☐ If *Other*, specify:		
123.	1❑	0❑	8❑	Mitoxantrone			1❑
124.					☐ If *Other*, specify:		
125.	1❑	0❑	8❑	Plasmapheresis			1❑
126.					☐ If *Other*, specify:		
127.	1❑	0❑	8❑	Total lymph node irradiation (TLI)			1❑
128.					☐ If *Other*, specify:		
				Other(s), specify:			
129.	1❑	0❑	8❑	_____			1❑
130.					☐ If *Other*, specify:		

TEAM: ☐☐☐☐ IUBMID: ☐☐☐☐☐☐

Disease Status at Current Evaluation

131. Scripps neurological rating scale score: ☐☐☐ ❑ Unknown

Kurtze functional systems scores:

132. Pyramidal ☐☐ ❑ Unknown

133. Cerebellar ☐☐ ❑ Unknown

134. Brain stem ☐☐ ❑ Unknown

135. Sensory ☐☐ ❑ Unknown

136. Bowel/Bladder ☐☐ ❑ Unknown

137. Visual ☐☐ ❑ Unknown

138. Cerebral ☐☐ ❑ Unknown

139. Other functions ☐☐ ❑ Unknown

140. Others, specify: ☐☐ ❑ Unknown

_____

141. Kurtze Expanded Disability Status Scale (EDSS): ☐☐.☐ ❑ Unknown

Composite Scale

Timed 25-foot Walk:

142. Assistive device used? 1❑ Yes 0❑ No ❑ Unknown

143. Specify:
1❑ Unilateral assistance (cane or crutch)
2❑ Bilateral assistance (canes or crutches)
3❑ Walker or similar device

144. Time for Trial 1: ☐☐☐.☐ sec. 1❑ Did not complete ❑ Unknown

145. Time for Trial 2: ☐☐☐.☐ sec. 1❑ Did not complete ❑ Unknown

9-hole Peg Test:

146. Dominant Hand, Time for Trial 1: ☐☐☐.☐ sec. 1❑ Did not complete ❑ Unknown

147. Dominant Hand, Time for Trial 2: ☐☐☐.☐ sec. 1❑ Did not complete ❑ Unknown

148. Non-dominant Hand, Time for Trial 1: ☐☐☐.☐ sec. 1❑ Did not complete ❑ Unknown

149. Non-dominant Hand, Time for Trial 2: ☐☐☐.☐ sec. 1❑ Did not complete ❑ Unknown

Paced Auditory Serial Addition Test (PASAT):

150. PASAT 3 Score: ☐☐ Range (0-60) ❑ Unknown

151. PASAT 2 Score: ☐☐ Range (0-60) ❑ Unknown

TEAM: ☐☐☐☐ IUBMID: ☐☐☐☐☐☐

152. Date of most recent MRI scan of brain ≤100 days posttransplant:

☐☐ ☐☐ ☐☐☐☐ Month Day Year

7❑ MRI not done
8❑ Date unknown

MRI scan:

153. Are gadolinium-enhancing lesions present on the MRI? 1❑ Yes 0❑ No 8❑ Unknown

154. Number of gadolinium-enhancing lesions: ☐☐ 8❑ Unknown

155. Are new lesions present on the MRI? 1❑ Yes 0❑ No 8❑ Unknown

156. Indicate new lesions present *(check only one)*
1❑ Gadolinium-enhancing
2❑ Unenhancing
3❑ Both
8❑ Unknown

157. Was there evidence of disease activity present at current evaluation? 1❑ Yes 0❑ No 8❑ Unknown

158. Date of first evidence of disease activity posttransplant:

☐☐ ☐☐ ☐☐☐☐ Month Day Year

8❑ Unknown