



Juvenile Idiopathic Arthritis Pre-HSCT Data

Registry Use Only

Sequence
Number:

Date
Received:

CIBMTR Center Number:

CIBMTR Recipient ID:

Today's Date:
Month Day Year

Date of HSCT for which this form is
being completed:
Month Day Year

HSCT type: autologous allogeneic, allogeneic, syngeneic
unrelated related (identical twin)

Product type: marrow PBSC cord blood other product,
specify: _____

This form must be accompanied by Form 2000 – Recipient Baseline Data. All information in the box above, including the date, should be identical with the corresponding Form 2000. Information should come from an actual examination by the Transplant Center physician, or the physician who is following the recipient pre-HSCT, or abstraction of the recipient's medical records.

Questions followed by the symbol indicate additional information necessary to complete the question is referenced in the forms instruction manual.

If this is a report of a second or subsequent transplant, check here and continue with question 72.

Disease Assessment at Diagnosis

1. What was the date of diagnosis of Juvenile Idiopathic Arthritis?
Month Day Year

2. Specify the JIA subclass:

- 1 systemic JIA →
- 2 polyarticular rheumatoid arthritis with oligoarticular onset
- 3 polyarticular rheumatoid arthritis with polyarticular onset
- 4 other subtype →

3. Were the Schneider criteria (persistent thrombocytosis and corticosteroids to control fever) for systemic JIA fulfilled?
1 yes
2 no
3 unknown

4. Specify JIA subtype: _____

Specify the following laboratory studies performed at diagnosis of JIA:

If performed, specify lab study results:

- | | | |
|---|----------------------------------|--|
| 5. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no 3 <input type="checkbox"/> unknown | Anti-nuclear antibody → | 6. 1 <input type="checkbox"/> normal 2 <input type="checkbox"/> abnormal 3 <input type="checkbox"/> unknown |
| 7. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no 3 <input type="checkbox"/> unknown | C-reactive protein → | 8. 1 <input type="checkbox"/> normal 2 <input type="checkbox"/> abnormal 3 <input type="checkbox"/> unknown |
| 9. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no 3 <input type="checkbox"/> unknown | Erythrocyte sedimentation rate → | 10. 1 <input type="checkbox"/> normal 2 <input type="checkbox"/> abnormal 3 <input type="checkbox"/> unknown |
| 11. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no 3 <input type="checkbox"/> unknown | Rheumatoid factor → | 12. 1 <input type="checkbox"/> normal 2 <input type="checkbox"/> abnormal 3 <input type="checkbox"/> unknown |
| 13. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no 3 <input type="checkbox"/> unknown | Other lab study → | 14. 1 <input type="checkbox"/> normal 2 <input type="checkbox"/> abnormal 3 <input type="checkbox"/> unknown |
15. Specify lab study: _____

Mail this form to your designated campus (Milwaukee or Minneapolis). Retain the original at the transplant center.

CIBMTR Center Number:

CIBMTR Recipient ID:

Specify the presence of the following complications at any time from diagnosis to mobilization for stem cell collection (or high-dose therapy if mobilization was not done):

16. Corticosteroid dependency to control JIA

- 1 yes
- 2 no
- 3 unknown

17. Disease progression while on therapy

- 1 yes
- 2 no
- 3 unknown

18. Systemic JIA with polyarticular course

- 1 yes
- 2 no
- 3 unknown

19. Were the Schneider criteria (persistent thrombocytosis and corticosteroids to control fever) for systemic JIA fulfilled?

- 1 yes
- 2 no
- 3 unknown

20. Toxicity from conventional treatment(s)

- 1 yes
- 2 no
- 3 unknown

Specify the toxicities present between JIA diagnosis and prior to the start of the preparative regimen:

21. 1 yes 2 no Avascular necrosis of femoral head

22. 1 yes 2 no Cataracts

23. 1 yes 2 no Growth delay

24. 1 yes 2 no Hepatic dysfunction (≥ 3 fold increase in liver function tests)

25. 1 yes 2 no Renal insufficiency ($> 30\%$ increase in creatinine)

26. 1 yes 2 no Severe gastrointestinal (GI) toxicity

27. Specify GI toxicity:

28. 1 yes 2 no Severe hypertension

29. 1 yes 2 no Severe myelosuppression

30. 1 yes 2 no Other toxicity

31. Specify other toxicity:

Pre-HSCT Treatment for Juvenile Idiopathic Arthritis

32. Did the recipient receive any disease-modifying treatments between the time of diagnosis and prior to mobilization for stem cell collection (or high-dose therapy if mobilization was not done)?

- 1 yes → Continue with table below
- 2 no → Continue with question 65

Codes for Treatment Stopped			
1 Failure	2 Toxicity	3 Other reason	4 Reason unknown

Treatment Given?	Treatment Stopped?	Stopped Code	
33. Corticosteroids			
1 <input type="checkbox"/> yes	34. 1 <input type="checkbox"/> yes	35. <input type="text"/>	36. If code 3, specify other reason: _____
2 <input type="checkbox"/> no	2 <input type="checkbox"/> no		
3 <input type="checkbox"/> unknown	37. Was prednisone or other corticosteroid dosing changed between diagnosis and just prior to mobilization for stem cell collection?		
	1 <input type="checkbox"/> dose unchanged		
	2 <input type="checkbox"/> dose increased		
	3 <input type="checkbox"/> dose decreased		
	4 <input type="checkbox"/> unknown		

CIBMTR Center Number:

CIBMTR Recipient ID:

Treatment Given? **Treatment Stopped?** **Stopped Code**

Codes for Treatment Stopped			
1	2	3	4
Failure	Toxicity	Other reason	Reason unknown

38. Cyclophosphamide (CTX, Cytoxan, Neosar)

1 yes → 39. 1 yes → 40.
2 no 2 no
3 unknown

41. If code 3, specify other reason: _____

42. Cyclosporine (CsA, Neoral, Sandimmune)

1 yes → 43. 1 yes → 44.
2 no 2 no
3 unknown

45. If code 3, specify other reason: _____

46. Etanercept (Enbrel)

1 yes → 47. 1 yes → 48.
2 no 2 no
3 unknown

49. If code 3, specify other reason: _____

50. Methotrexate (MTX, Folex)

1 yes → 51. 1 yes → 52.
2 no 2 no
3 unknown

53. If code 3, specify other reason: _____

54. Specify the maximum weekly dose: mg dose unknown

55. Specify the duration of therapy: months duration unknown

56. Non-steroidal anti-inflammatory drugs (NSAIDs)

1 yes → 57. 1 yes → 58.
2 no 2 no
3 unknown

59. If code 3, specify other reason: _____

60. Other treatment

1 yes → 61. 1 yes → 62.
2 no 2 no
3 unknown

63. If code 3, specify other reason: _____

64. Specify other treatment: _____

65. Did the recipient stop receiving disease-modifying drugs (e.g., cyclophosphamide, methotrexate, etc.) or anti-TNF regimen (not NSAIDs) prior to mobilization for stem cell collection (or high-dose therapy if mobilization was not done)?

1 yes →
2 no
3 unknown

66. Specify the date that the recipient last received disease-modifying drugs or anti-TNF regimen: date unknown

67. Was the recipient receiving non-steroidal anti-inflammatory drugs (NSAIDs) within 4 weeks of mobilization for stem cell collection (or high-dose therapy if mobilization was not done)?

1 yes →
2 no
3 unknown

68. Were the NSAIDs discontinued prior to mobilization?

1 yes →
2 no
3 unknown

69. Specify the date NSAIDs were stopped: date unknown

70. Specify the reason for stopping (see Codes for Treatment Stopped above):

71. If code 3, specify other reason: _____

CIBMTR Center Number:

CIBMTR Recipient ID:

Disease Assessment Prior to Mobilization Therapy for Stem Cell Collection

Information for this section should come from the most recent evaluation prior to the initiation of mobilization therapy (≤ 4 weeks prior to mobilization for stem cell collection). If the recipient did not receive mobilization therapy, check here and continue with question 129.

72. Date of evaluation prior to mobilization for stem cell collection: / / 20
Month Day Year

73. Specify the number of painful / tender joints prior to mobilization: number unknown
Fuchs HA, Pincus T. Eular / ACR 28 joint count. Arthritis Rheum 1994, 37:470-475.
Joints included in 28 joint count are bilateral shoulders, elbows, wrists, MCPs, PIPs and knees.

74. Specify the number of swollen / effused joints prior to mobilization: number unknown
Fuchs HA, Pincus T. Eular / ACR 28 joint count. Arthritis Rheum 1994, 37:470-475.
Joints included in 28 joint count are bilateral shoulders, elbows, wrists, MCPs, PIPs and knees.

75. Specify the pediatric EPM Range of Motion final score (0.0-3.0): . score unknown
Len C., Ferraz M.B., Goldenberg J., et al. Pediatric Escola Paulista de Medicina Range of Motion Scale: A Reduced Joint Count Scale for General Use in JRA. J Rheumatol 1999, 26 (4) 909-913.

76. Was morning stiffness present just prior to mobilization?

- 1 yes
2 no
3 unknown

77. Specify the duration of morning stiffness: :
Hours Minutes

78. Specify the recipient's height at the time of mobilization:

- 1 known 1 inches
2 unknown centimeters

79. Specify the recipient's weight at the time of mobilization:

- 1 known 1 pounds
2 unknown kilograms

80. Specify the recipient's height one year prior to the time of mobilization:

- 1 known 1 inches
2 unknown centimeters

81. Specify the recipient's weight one year prior to the time of mobilization:

- 1 known 1 pounds
2 unknown kilograms

Laboratory Studies Prior to Mobilization Therapy for Stem Cell Collection

Specify if any of the following laboratory values were elevated prior to mobilization:

82. 1 yes 2 no 3 unknown Antinuclear antibody (ANA) titers
83. 1 yes 2 no 3 unknown C-reactive protein
84. 1 yes 2 no 3 unknown Erythrocyte sedimentation rate (ESR)
85. 1 yes 2 no 3 unknown Serum rheumatoid factor (RF) titers

86. Date CBC tested: / / 20
Month Day Year

87. WBC: .
1 known $\times 10^9/L$ ($\times 10^3/mm^3$)
2 not known $\times 10^6/L$

88. Segs: %
1 known
2 not known

CIBMTR Center Number:

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89. Bands:

1 known → %
2 not known

90. Lymphocytes:

1 known → %
2 not known

91. Monocytes:

1 known → %
2 not known

92. Eosinophils:

1 known → %
2 not known

93. Basophils:

1 known → %
2 not known

94. Hemoglobin:

1 known → .
2 not known

Specify units:

- 1 g/dL
2 g/L
3 mmol/L

95. Hematocrit:

1 known → %
2 not known

96. Platelets:

1 known → 1 $\times 10^9/L$ ($\times 10^3/mm^3$)
2 not known 2 $\times 10^6/L$

97. Creatinine:

1 known → . 1 mg/dL
2 not known 2 mmol/L
3 $\mu mol/L$

98. Alkaline phosphatase:

1 known → . 1 U/L
2 not known 2 $\mu kat/L$

99. AST:

1 known → . 1 U/L
2 not known 2 $\mu kat/L$

100. ALT:

1 known → . 1 U/L
2 not known 2 $\mu kat/L$

101. Total bilirubin:

1 known → . 1 mg/dL
2 not known 2 $\mu mol/L$

102. Albumin:

1 known → . 1 g/dL
2 not known 2 g/L

Specify the results of the following immune function studies performed just prior to mobilization:

Quantitative immunoglobulins:

103. IgG 1 normal 2 decreased 3 increased 4 unknown

104. IgA 1 normal 2 decreased 3 increased 4 unknown

105. IgM 1 normal 2 decreased 3 increased 4 unknown

106. IgE 1 normal 2 decreased 3 increased 4 unknown

CIBMTR Center Number:

CIBMTR Recipient ID:

Lymphocyte subsets:

- 107. CD3 1 normal 2 decreased 3 increased 4 unknown
- 108. CD4 1 normal 2 decreased 3 increased 4 unknown
- 109. CD8 1 normal 2 decreased 3 increased 4 unknown
- 110. CD16 1 normal 2 decreased 3 increased 4 unknown
- 111. CD19 1 normal 2 decreased 3 increased 4 unknown

Radiographic Assessment Prior to Mobilization Therapy for Stem Cell Collection

- 112. Were radiographic bone erosions present just prior to mobilization?
1 yes
2 no
3 unknown
- 113. Was advanced skeletal age of affected joints noted radiographically?
1 yes
2 no
3 unknown
- 114. Were osteoporotic fractures present at any time between diagnosis and mobilization?
1 yes
2 no
3 unknown

Functional Assessment Prior to Mobilization Therapy for Stem Cell Collection

- 115. Did the recipient complete a Childhood Health Assessment Questionnaire (CHAQ) prior to mobilization?
Singh G, Athreya B, Fries J, Goldsmith DP. Measurement of health status in children with rheumatoid arthritis. Arthritis Rheum 1994, 37:1761-69.

- 1 yes
- 2 no
- 3 unknown

Specify the following scores for the CHAQ pain sub-scale:

- 116. Recipient's pain assessment: .
- 117. Worst possible pain score: .
- 118. Best possible pain score: .

Specify the following scores for the CHAQ disability sub-scale:

- 119. Recipient's disability assessment: .
- 120. Worst possible disability score: .
- 121. Best possible disability score: .

Specify the following scores for the CHAQ severity sub-scale:

- 122. Recipient's severity assessment: .
- 123. Worst possible severity score: .
- 124. Best possible severity score: .

CIBMTR Center Number:

CIBMTR Recipient ID:

125. Did the physician complete a Global Assessment of Functioning of the recipient's health prior to mobilization?

- 1 yes →
2 no
3 unknown

126. Physician-rated Global Assessment score: .
127. Worst possible score: .
128. Best possible score: .

Most Recent Disease Assessment Prior to the Start of the Preparative Regimen

Information for this section should come from the most recent evaluation performed ≤ 2 weeks prior to the preparative regimen. If the recipient was not evaluated prior to the preparative regimen, check here and continue with the signature lines at question 176.

129. Date of evaluation prior to the preparative regimen: / / 20
Month Day Year

130. Specify the number of painful / tender joints prior to the preparative regimen: number unknown
Fuchs HA, Pincus T. Euler / ACR 28 joint count. Arthritis Rheum 1994, 37:470-475.
Joints included in 28 joint count are bilateral shoulders, elbows, wrists, MCPs, PIPs and knees.

131. Specify the number of swollen / effused joints prior to the preparative regimen: number unknown
Fuchs HA, Pincus T. Euler / ACR 28 joint count. Arthritis Rheum 1994, 37:470-475.
Joints included in 28 joint count are bilateral shoulders, elbows, wrists, MCPs, PIPs and knees.

132. Specify the pediatric EPM Range of Motion final score (0.0-3.0): . score unknown
Len C., Ferraz M.B., Goldenberg J., et al. Pediatric Escola Paulista de Medicina Range of Motion Scale: A Reduced Joint Count Scale for General Use in JRA. J Rheumatol 1999, 26 (4) 909-913.

133. Was morning stiffness present prior to the preparative regimen?

- 1 yes →
2 no
3 unknown

134. Specify the duration of morning stiffness: :
Hours Minutes

135. Specify the recipient's height one year prior to the preparative regimen:

- 1 known → 1 inches
2 unknown 2 centimeters

136. Specify the recipient's weight one year prior to the preparative regimen:

- 1 known → 1 pounds
2 unknown 2 kilograms

Laboratory Studies Prior to the Start of the Preparative Regimen

Specify if any of the following laboratory values were elevated prior to the preparative regimen:

137. 1 yes 2 no 3 unknown Antinuclear antibody (ANA) titers

138. 1 yes 2 no 3 unknown C-reactive protein

139. 1 yes 2 no 3 unknown Erythrocyte sedimentation rate (ESR)

140. 1 yes 2 no 3 unknown Serum rheumatoid factor (RF) titers

141. Date tested: / / 20 (testing done within 30 days of start of preparative regimen)
Month Day Year

142. Segs: %
1 known →
2 not known

CIBMTR Center Number:

CIBMTR Recipient ID:

143. Bands:

- 1 known → %
2 not known

144. Monocytes:

- 1 known → %
2 not known

145. Eosinophils:

- 1 known → %
2 not known

146. Basophils:

- 1 known → %
2 not known

147. Alkaline phosphatase:

- 1 known → . 1 U/L
2 not known 2 μ kat/L

148. Albumin:

- 1 known → . 1 g/dL
2 not known 2 g/L

Specify the results of the following immune function studies performed just prior to the start of the preparative regimen:

Quantitative immunoglobulins:

149. IgG 1 normal 2 decreased 3 increased 4 unknown

150. IgA 1 normal 2 decreased 3 increased 4 unknown

151. IgM 1 normal 2 decreased 3 increased 4 unknown

152. IgE 1 normal 2 decreased 3 increased 4 unknown

Lymphocyte subsets:

153. CD3 1 normal 2 decreased 3 increased 4 unknown

154. CD4 1 normal 2 decreased 3 increased 4 unknown

155. CD8 1 normal 2 decreased 3 increased 4 unknown

156. CD16 1 normal 2 decreased 3 increased 4 unknown

157. CD19 1 normal 2 decreased 3 increased 4 unknown

Radiographic Assessment Prior to the Start of the Preparative Regimen

158. Were radiographic bone erosions present prior to the start of the preparative regimen?

- 1 yes
2 no
3 unknown

159. Was advanced skeletal age of affected joints noted radiographically prior to the start of the preparative regimen?

- 1 yes
2 no
3 unknown

160. Was osteoporosis present prior to the start of the preparative regimen?

- 1 yes →
2 no
3 unknown

161. Were osteoporotic fractures present?

- 1 yes
2 no
3 unknown

CIBMTR Center Number:

CIBMTR Recipient ID:

Functional Assessment Prior to the Start of the Preparative Regimen

162. Did the recipient complete a Childhood Health Assessment Questionnaire (CHAQ) prior to the start of the preparative regimen?
Singh G, Athreya B, Fries J, Goldsmith DP. Measurement of health status in children with rheumatoid arthritis. Arthritis Rheum 1994, 37:1761-69.

- 1 yes
- 2 no
- 3 unknown

Specify the following scores for the CHAQ pain sub-scale:

163. Recipient's pain assessment: .

164. Worst possible pain score: .

165. Best possible pain score: .

Specify the following scores for the CHAQ disability sub-scale:

166. Recipient's disability assessment: .

167. Worst possible disability score: .

168. Best possible disability score: .

Specify the following scores for the CHAQ severity sub-scale:

169. Recipient's severity assessment: .

170. Worst possible severity score: .

171. Best possible severity score: .

172. Did the physician complete a Global Assessment of Functioning of the recipient's health prior to the preparative regimen?

- 1 yes
- 2 no
- 3 unknown

173. Physician-rated Global Assessment score: .

174. Worst possible score: .

175. Best possible score: .

176. Signed: _____

Person completing form

Please print name: _____

Phone: (_____) _____

Fax: (_____) _____

E-mail address: _____