

INSERT XXVIII
Juvenile Idiopathic Arthritis (JIA)
(Previously JRA or JCA)

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.52*

1. Diagnosis:

- 1 Systemic JIA _____
- 2 Polyarticular Rheumatoid Arthritis with oligoarticular onset
- 3 Polyarticular Rheumatoid Arthritis with polyarticular onset
- 4 Other, specify: _____

2. Schneider criteria fulfilled?

- 1 Yes 0 No 8 Unknown
- persistent thrombocytosis
- corticosteroids to control fever

3. Date of diagnosis:
 Month Day Year

Indicate results of the following laboratory studies related to JIA diagnosis and mobilization (or high-dose therapy if mobilization not done):

	Always Normal	Very Normal	Not Done	Unknown
4. Anti-nuclear antibody	0 <input type="checkbox"/>	1 <input type="checkbox"/>	7 <input type="checkbox"/>	8 <input type="checkbox"/>
5. Rheumatoid factor	0 <input type="checkbox"/>	1 <input type="checkbox"/>	7 <input type="checkbox"/>	8 <input type="checkbox"/>
6. C-reactive protein	0 <input type="checkbox"/>	1 <input type="checkbox"/>	7 <input type="checkbox"/>	8 <input type="checkbox"/>
7. Erythrocyte sedimentation rate	0 <input type="checkbox"/>	1 <input type="checkbox"/>	7 <input type="checkbox"/>	8 <input type="checkbox"/>
8. Other, specify: _____	0 <input type="checkbox"/>	1 <input type="checkbox"/>	7 <input type="checkbox"/>	8 <input type="checkbox"/>

Indicate if patient had any of the following at any time prior to mobilization for stem cell collection (or high-dose therapy if mobilization not done):

Yes No Unknown

- 9. 1 0 8 Systemic JIA with polyarticular course _____
- 11. 1 0 8 Disease progression on therapy
- 12. 1 0 8 Corticosteroid dependency to control disease
- 13. 1 0 8 Toxicity from conventional treatment

10. Schneider criteria fulfilled?

- 1 Yes 0 No 8 Unknown
- persistent thrombocytosis
- corticosteroids to control fever

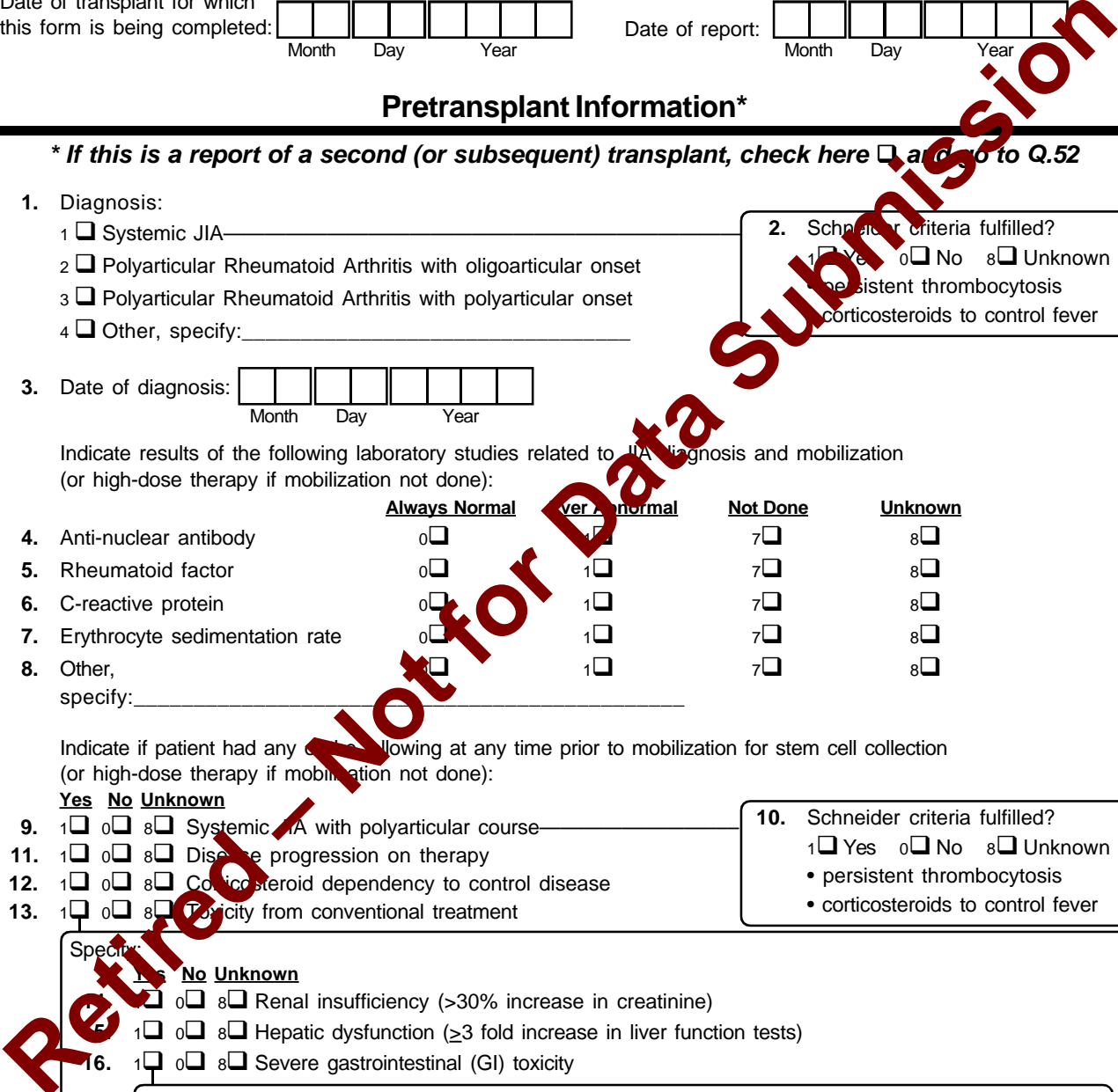
Specify:

Yes No Unknown

- 14. 1 0 8 Renal insufficiency (>30% increase in creatinine)
- 15. 1 0 8 Hepatic dysfunction (≥3 fold increase in liver function tests)
- 16. 1 0 8 Severe gastrointestinal (GI) toxicity

17. Specify GI toxicity: _____

- 18. 1 0 8 Severe myelosuppression
- 19. 1 0 8 Avascular necrosis of femoral head
- 20. 1 0 8 Cataracts
- 21. 1 0 8 Severe hypertension
- 22. 1 0 8 Growth delay
- 23. 1 0 8 Other, specify: _____



TEAM:

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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)

DRUGS:

24. Yes No Unk Corticosteroids

26. If Other, specify: _____

25. Was prednisone or other corticosteroid dosing changed between diagnosis and just prior to mobilization for stem cell collection?
1 No change 2 Increased 3 Decreased 8 Unknown

27. Yes No Unk Cyclophosphamide

28. If Other, specify: _____

29. Yes No Unk Cyclosporin-A

30. If Other, specify: _____

31. Yes No Unk Etanercept

32. If Other, specify: _____

33. Yes No Unk Methotrexate

36. If Other, specify: _____

Specify:
34. Maximum weekly dose: mg 8 Unknown
35. Duration of therapy: months 8 Unknown

37. Yes No Unk NSAIDS

38. If Other, specify: _____

39. Yes No Unk Other, specify: _____ 40. If Other, specify: _____

41. Yes No Unk Other, specify: _____ 42. If Other, specify: _____

43. Yes No Unk Other, specify: _____ 44. If Other, specify: _____

45. Yes No Unk Other, specify: _____ 46. If Other, specify: _____

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

47. Date patient last received a disease-modifying drug (e.g. cyclophosphamide, methotrexate, etc.) or anti-TNF regimen (not NSAIDS) prior to mobilization for stem cell collection (or high-dose therapy if mobilization not done):

7 Still receiving
Month Day Year 8 Unknown

48. Was patient receiving non-steroidal anti-inflammatory drugs (NSAIDS) just prior to mobilization for stem cell collection (or high-dose therapy if mobilization not done)?

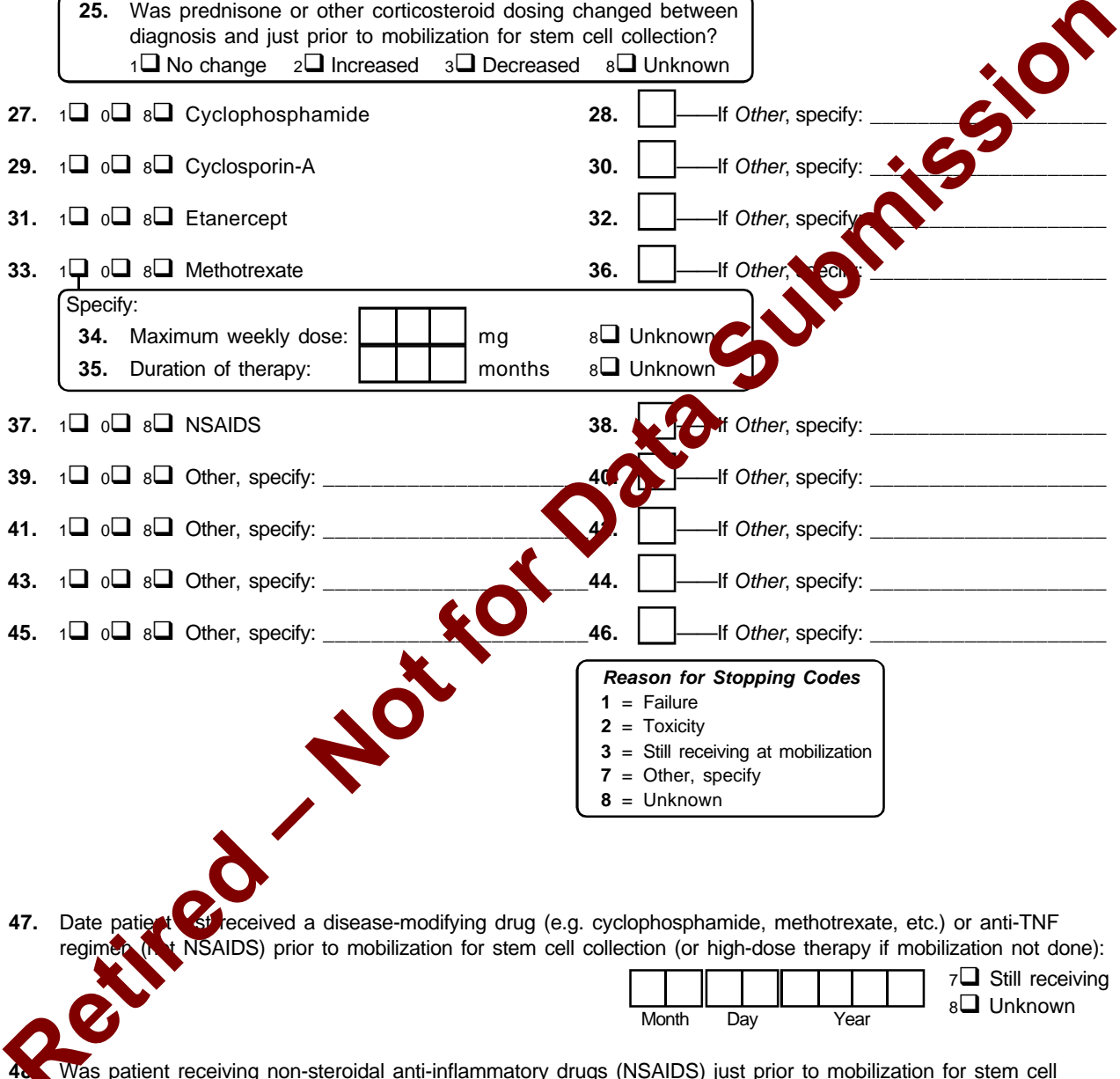
1 Yes
0 No
8 Unknown

49. Were the NSAIDS discontinued prior to mobilization?

1 Yes
0 No
8 Unknown

Specify:
50. Reason for stopping (see Codes above): If Other, specify: _____

51. Date stopped: 8 Unknown
Month Day Year



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Pre-Mobilization Evaluation*

*** 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.108**

52. Date of evaluation prior to mobilization for stem cell collection:
Month Day Year

53. Number of painful/tender joints prior to mobilization
(Eular/ACR 28 joint count, Appendix A): Unknown

54. Number of swollen/effused joints prior to mobilization
(Eular/ACR 28 joint count, Appendix A): Unknown

Appendix A
(Fuchs and Pincus, *Arthritis Rheum*, 1994, 37:470)
Joints included in 28 joint count are bilateral shoulders,
elbows, wrists, MCPs, PIPs and knees

55. Indicate pediatric EPM-Range of motion final score (0-3)
(Len C, et al, *J Rheum*, 1999, 26(4):909-913): Unknown

56. Was morning stiffness present just prior to mobilization?
1 Yes
0 No
8 Unknown

57. Specify duration: hours minutes

58. Specify patient's height at time of mobilization: Specify unit: 1 cm 2 in

59. Specify patient's weight at time of mobilization: Specify unit: 1 kg 2 lb

60. Specify patient's height one year prior to time of mobilization: Specify unit: 1 cm 2 in

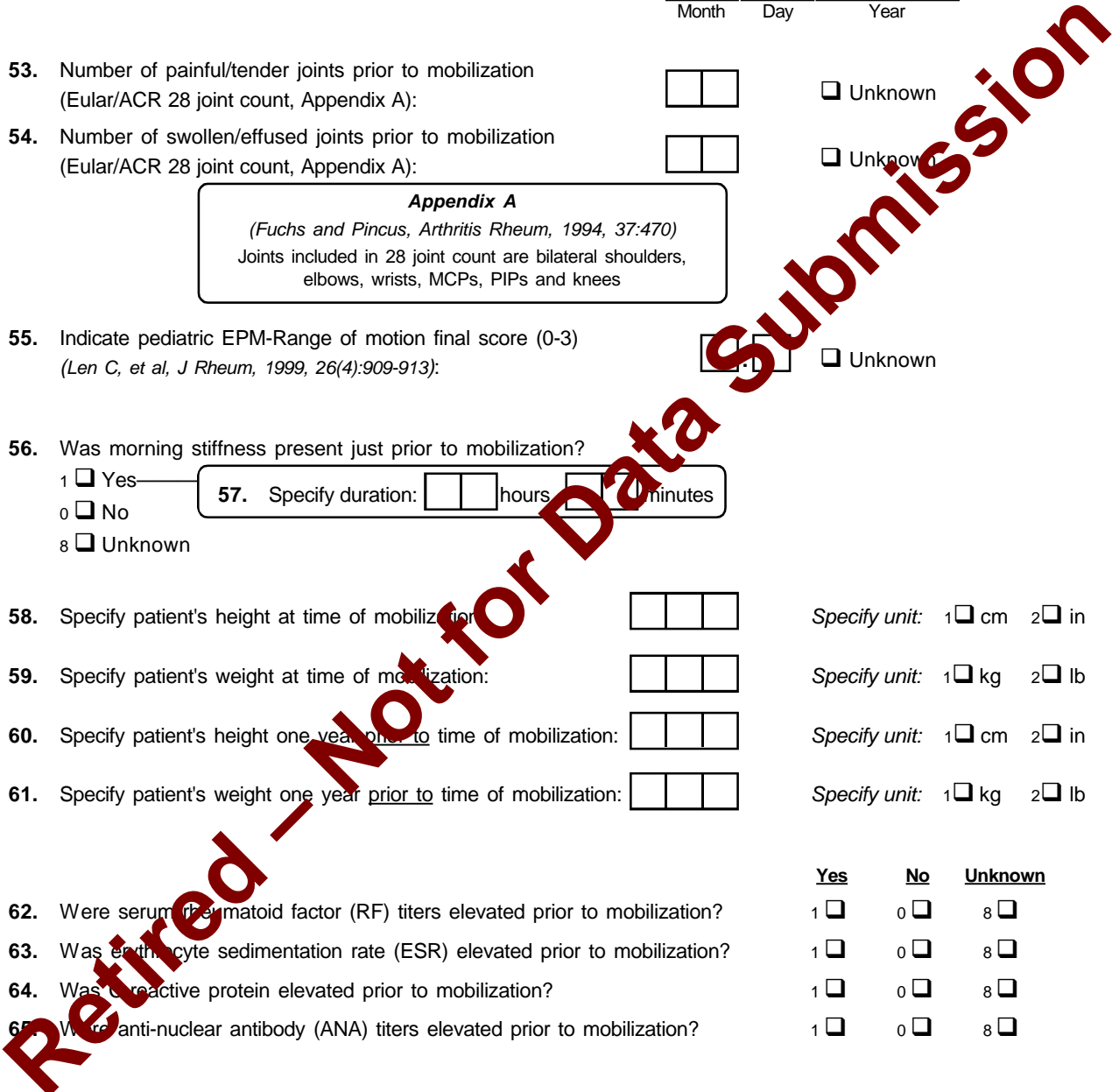
61. Specify patient's weight one year prior to time of mobilization: Specify unit: 1 kg 2 lb

62. Were serum rheumatoid factor (RF) titers elevated prior to mobilization? Yes No Unknown
1 0 8

63. Was erythrocyte sedimentation rate (ESR) elevated prior to mobilization? Yes No Unknown
1 0 8

64. Was C-reactive protein elevated prior to mobilization? Yes No Unknown
1 0 8

65. Were anti-nuclear antibody (ANA) titers elevated prior to mobilization? Yes No Unknown
1 0 8



TEAM:

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Laboratory Values Prior to Mobilization for Stem Cell Collection

		<u>Specify Units</u>	<u>Unknown</u>
66. Hemoglobin:	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/> <input type="text"/>	1 <input type="checkbox"/> g/dL 2 <input type="checkbox"/> g/L 3 <input type="checkbox"/> mmol/L	<input type="checkbox"/>
67. Hematocrit:	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> %		<input type="checkbox"/>
68. WBC:	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/>	1 <input type="checkbox"/> x10 ⁹ /L (x10 ³ /mm ³) 2 <input type="checkbox"/> x10 ⁶ /L	<input type="checkbox"/>
Differential			
69. Segs:	<input type="text"/> <input type="text"/> %		<input type="checkbox"/>
70. Bands:	<input type="text"/> <input type="text"/> %		<input type="checkbox"/>
71. Lymphocytes:	<input type="text"/> <input type="text"/> %		<input type="checkbox"/>
72. Monocytes:	<input type="text"/> <input type="text"/> %		<input type="checkbox"/>
73. Eosinophils:	<input type="text"/> <input type="text"/> %		<input type="checkbox"/>
74. Basophils:	<input type="text"/> <input type="text"/> %		<input type="checkbox"/>
75. Platelets:	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	1 <input type="checkbox"/> x10 ⁹ /L (x10 ³ /mm ³) 2 <input type="checkbox"/> x10 ⁶ /L	<input type="checkbox"/>
76. Creatinine:	<input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/> <input type="text"/>	1 <input type="checkbox"/> mg/dL 2 <input type="checkbox"/> mmol/L 3 <input type="checkbox"/> μmol/L	<input type="checkbox"/>
77. Alkaline phosphatase:	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/> <input type="text"/>	1 <input type="checkbox"/> U/L 2 <input type="checkbox"/> kat/L	<input type="checkbox"/>
78. AST:	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/> <input type="text"/>	1 <input type="checkbox"/> U/L 2 <input type="checkbox"/> μkat/L	<input type="checkbox"/>
79. ALT:	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/> <input type="text"/>	1 <input type="checkbox"/> U/L 2 <input type="checkbox"/> μkat/L	<input type="checkbox"/>
80. Total Bilirubin:	<input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/> <input type="text"/>	1 <input type="checkbox"/> mg/dL 2 <input type="checkbox"/> μmol/L	<input type="checkbox"/>
81. Albumin:	<input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/> <input type="text"/>	1 <input type="checkbox"/> g/dL 2 <input type="checkbox"/> g/L	<input type="checkbox"/>

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

	<u>Normal</u>	<u>Decreased</u>	<u>Increased</u>	<u>Unknown</u>
Quantitative Immunoglobulins:				
82. IgG:	<input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	8 <input type="checkbox"/>
83. IgA:	<input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	8 <input type="checkbox"/>
84. IgM:	<input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	8 <input type="checkbox"/>
85. IgE:	<input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	8 <input type="checkbox"/>
Lymphocyte subsets				
86. CD3:	<input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	8 <input type="checkbox"/>
87. CD4:	<input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	8 <input type="checkbox"/>
88. CD8:	<input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	8 <input type="checkbox"/>
89. CD19:	<input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	8 <input type="checkbox"/>
90. CD16:	<input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	8 <input type="checkbox"/>

Retired - Not for Data Submission

TEAM:

IUBMID:

Radiographic Evaluation Prior to Mobilization for Stem Cell Collection

91. Were radiographic bone erosions present just prior to mobilization?

1 Yes 0 No 8 Unknown

92. Was advanced skeletal age of affected joints noted radiographically?

1 Yes 0 No 8 Unknown

93. Did patient have osteoporotic fractures at any time between diagnosis and mobilization?

1 Yes 0 No 8 Unknown

94. Did the patient complete a Childhood Health Assessment Questionnaire (CHAQ) prior to mobilization (see Appendix B)?

1 Yes
0 No
8 Unknown

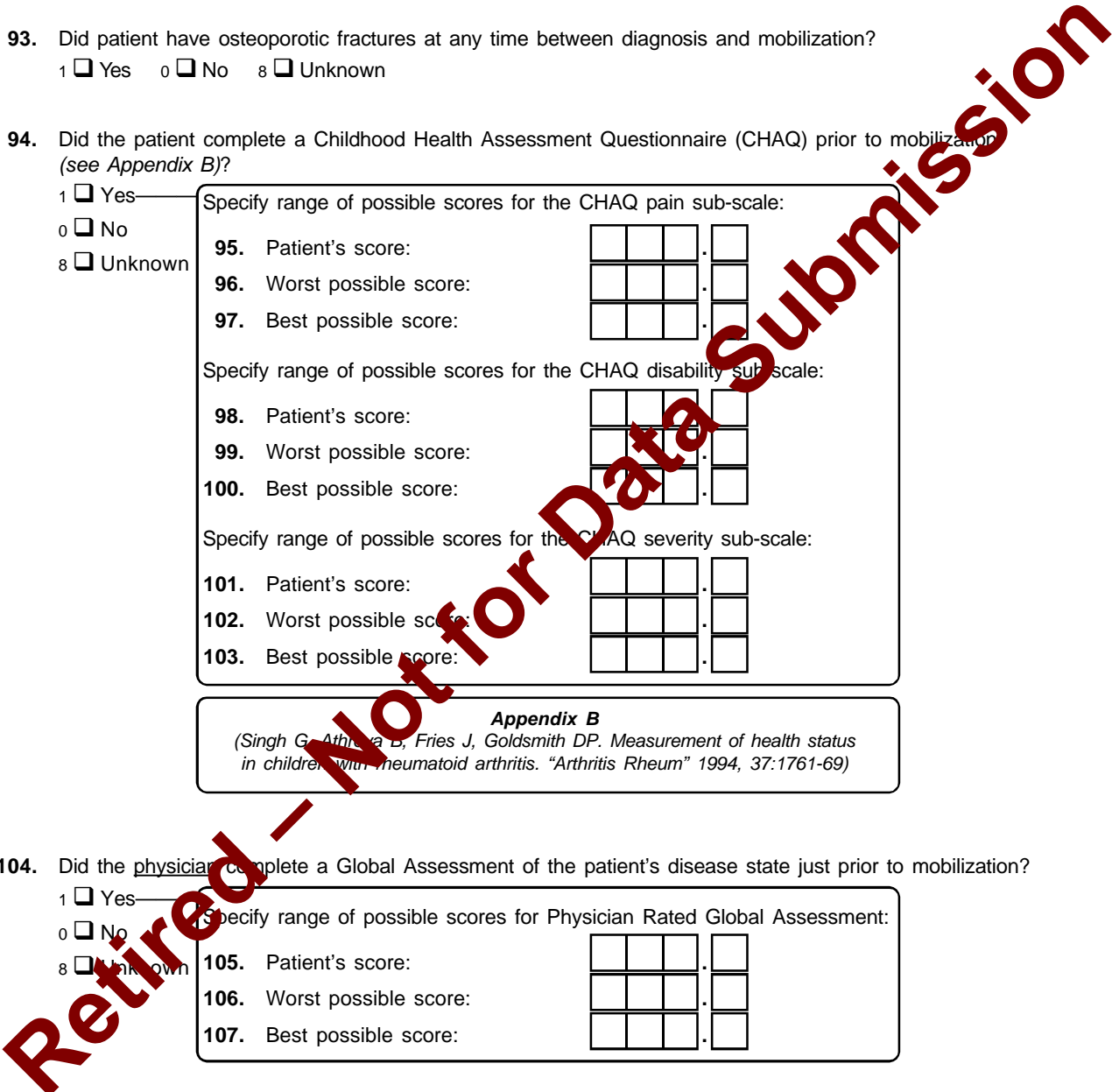
Specify range of possible scores for the CHAQ pain sub-scale:	
95. Patient's score:	<input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/>
96. Worst possible score:	<input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/>
97. Best possible score:	<input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/>
Specify range of possible scores for the CHAQ disability sub-scale:	
98. Patient's score:	<input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/>
99. Worst possible score:	<input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/>
100. Best possible score:	<input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/>
Specify range of possible scores for the CHAQ severity sub-scale:	
101. Patient's score:	<input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/>
102. Worst possible score:	<input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/>
103. Best possible score:	<input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/>

Appendix B
(Singh G, Athanasia D, Fries J, Goldsmith DP. Measurement of health status in children with rheumatoid arthritis. "Arthritis Rheum" 1994, 37:1761-69)

104. Did the physician complete a Global Assessment of the patient's disease state just prior to mobilization?

1 Yes
0 No
8 Unknown

Specify range of possible scores for Physician Rated Global Assessment:	
105. Patient's score:	<input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/>
106. Worst possible score:	<input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/>
107. Best possible score:	<input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/>



TEAM:

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Evaluation Prior to Conditioning (High-dose Therapy)*

* Evaluation should be performed ≤ 2 weeks prior to conditioning

108. Was an assessment performed after mobilization and prior to starting conditioning (high-dose therapy)?

1 Yes

0 No — Go to Q.155

109. Date of evaluation prior to conditioning:
Month Day Year

110. Number of painful/tender joints prior to mobilization (Eular/ACR 28 joint count, Appendix A): Unknown

111. Number of swollen/effused joints prior to mobilization (Eular/ACR 28 joint count, Appendix A): Unknown

Appendix A
(Fuchs and Pincus, *Arthritis Rheum*, 1994, 37:470)
Joints included in 28 joint count are bilateral shoulders, elbows, wrists, MCPs, PIPs and knees

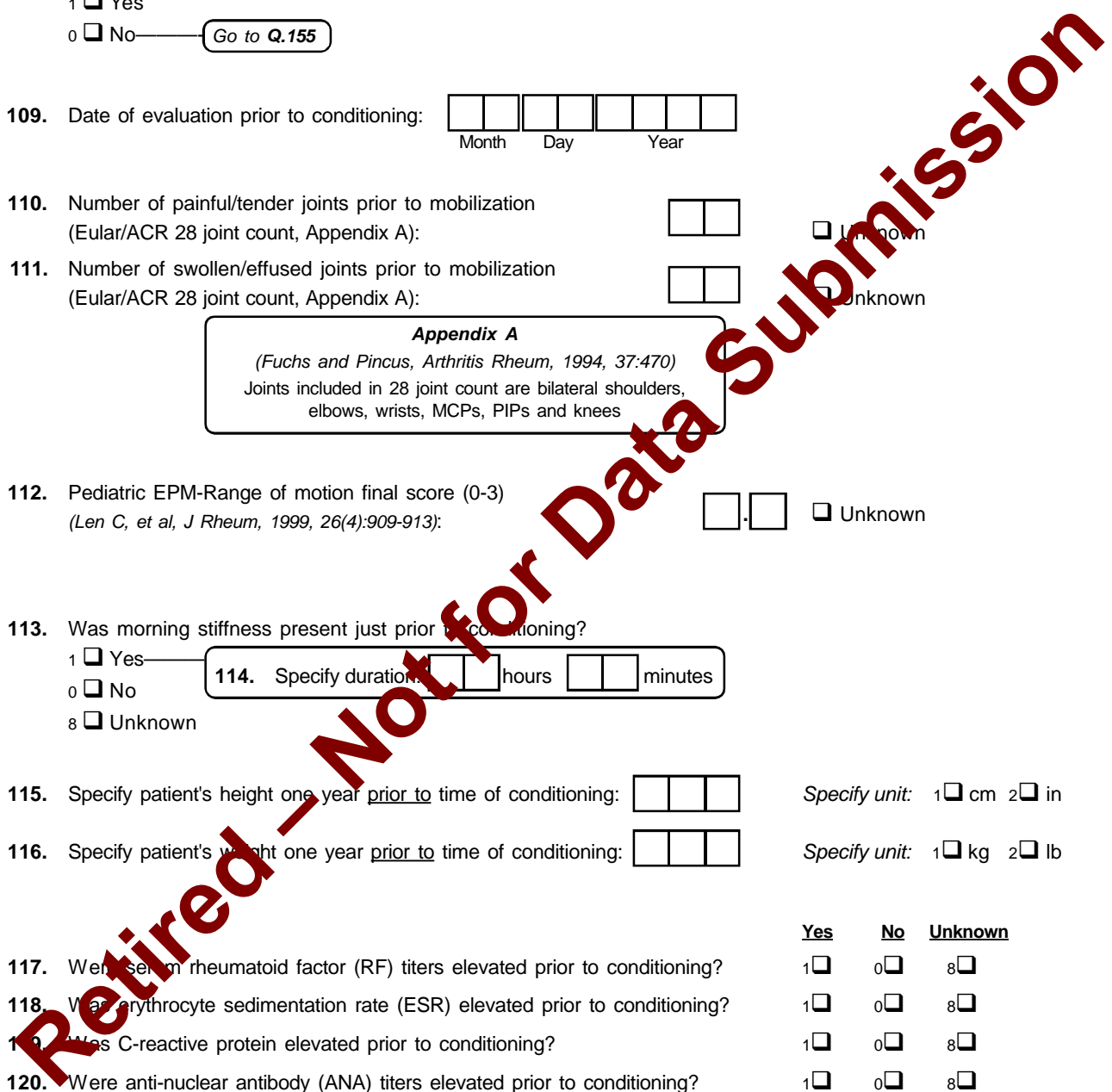
112. Pediatric EPM-Range of motion final score (0-3) (Len C, et al, *J Rheum*, 1999, 26(4):909-913): Unknown

113. Was morning stiffness present just prior to conditioning?
1 Yes — 114. Specify duration: hours minutes
0 No
8 Unknown

115. Specify patient's height one year prior to time of conditioning: Specify unit: 1 cm 2 in

116. Specify patient's weight one year prior to time of conditioning: Specify unit: 1 kg 2 lb

	<u>Yes</u>	<u>No</u>	<u>Unknown</u>
117. Were serum rheumatoid factor (RF) titers elevated prior to conditioning?	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>
118. Was erythrocyte sedimentation rate (ESR) elevated prior to conditioning?	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>
119. Was C-reactive protein elevated prior to conditioning?	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>
120. Were anti-nuclear antibody (ANA) titers elevated prior to conditioning?	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>



TEAM:

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Laboratory Evaluation Just Prior to Conditioning

		<u>Specify Units</u>	<u>Unknown</u>
CBC Differential			
121. Segs:	<input type="text"/> <input type="text"/> <input type="text"/>	%	<input type="checkbox"/>
122. Bands:	<input type="text"/> <input type="text"/> <input type="text"/>	%	<input type="checkbox"/>
123. Monocytes:	<input type="text"/> <input type="text"/> <input type="text"/>	%	<input type="checkbox"/>
124. Eosinophils:	<input type="text"/> <input type="text"/> <input type="text"/>	%	<input type="checkbox"/>
125. Basophils:	<input type="text"/> <input type="text"/> <input type="text"/>	%	<input type="checkbox"/>
126. Alkaline phosphatase:	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	1 <input type="checkbox"/> U/L 2 <input type="checkbox"/> μ kat/L	<input type="checkbox"/>
127. Albumin:	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	1 <input type="checkbox"/> g/dL 2 <input type="checkbox"/> g/L	<input type="checkbox"/>

Indicate results of the following immune function studies just prior to conditioning:

Normal Decreased Increased Unknown

Quantitative Immunoglobulins:

128. IgG:	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	8 <input type="checkbox"/>
129. IgA:	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	8 <input type="checkbox"/>
130. IgM:	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	8 <input type="checkbox"/>
131. IgE:	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	8 <input type="checkbox"/>
Lymphocyte subsets:				
132. CD3:	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	8 <input type="checkbox"/>
133. CD4:	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	8 <input type="checkbox"/>
134. CD8:	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	8 <input type="checkbox"/>
135. CD19:	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	8 <input type="checkbox"/>
136. CD16:	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	8 <input type="checkbox"/>

Radiographic Evaluation Just Prior to Conditioning

137. Were radiographic bone erosions present prior to conditioning?

- 1 Yes
 0 No
 8 Unknown

138. Was advanced skeletal age of affected joints noted radiographically prior to conditioning?

- 1 Yes
 0 No
 8 Unknown

139. Did patient have osteoporosis just prior to conditioning?

- 1 Yes
 0 No
 8 Unknown

140. Were osteoporotic fractures present?

- 1 Yes 0 No 8 Unknown

TEAM:

IUBMID:

Patient Assessment Prior to Conditioning

141. Did the patient complete a Childhood Health Assessment Questionnaire (CHAQ) prior to conditioning (see Appendix B on pg 5)?

- 1 Yes
- 0 No
- 8 Unknown

Specify range of possible scores for the CHAQ pain sub-scale:

142. Patient's score: .

143. Worst possible score: .

144. Best possible score: .

Specify range of possible scores for the CHAQ disability sub-scale:

145. Patient's score: .

146. Worst possible score: .

147. Best possible score: .

Specify range of possible scores for the CHAQ severity sub-scale:

148. Patient's score: .

149. Worst possible score: .

150. Best possible score: .

151. Did the physician complete a Global Assessment of the patient's disease state just prior to conditioning?

- 1 Yes
- 0 No
- 8 Unknown

Specify range of possible scores for Physician Rated Global Assessment:

152. Patient's score: .

153. Worst possible score: .

154. Best possible score: .

Retired - Not for Data Submission

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.*

155. Did patient receive treatment for JIA posttransplant?

- 1 Yes
- 0 No
- 8 Unknown

Cite all disease-modifying drug regimens patient received posttransplant:

	Reason for Therapy (use codes below)			Start Date			Still Receiving
	Yes	No	Unk	Month	Day	Year	
156. <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk Corticosteroids	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>
157. <input type="checkbox"/> — If Other, specify: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>
158. <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk Cyclophosphamide	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>
159. <input type="checkbox"/> — If Other, specify: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>
160. <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk Cyclosporin-A	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>
161. <input type="checkbox"/> — If Other, specify: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>
162. <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk Etanercept	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>
163. <input type="checkbox"/> — If Other, specify: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>
164. <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk Methotrexate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>
165. <input type="checkbox"/> — If Other, specify: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>
166. <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk NSAIDS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>
167. <input type="checkbox"/> — If Other, specify: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>
168. <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk Other(s) specify: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>
169. <input type="checkbox"/> — If Other, specify: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>
170. <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>
171. <input type="checkbox"/> — If Other, specify: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>
172. <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>
173. <input type="checkbox"/> — If Other, specify: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>
174. <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>
175. <input type="checkbox"/> — If Other, specify: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>

Retired - Not for Data Submission

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

TEAM:

IUBMID:

Disease Status at Current Evaluation

176. Number of painful/tender joints at current evaluation (Eular/ACR 28 joint count, Appendix A): Unknown

177. Number of swollen/effused joints at current evaluation (Eular/ACR 28 joint count, Appendix A): Unknown

Appendix A
(Fuchs and Pincus, Arthritis Rheum, 1994, 37:470)
Joints included in 28 joint count are bilateral shoulders, elbows, wrists, MCPs, PIPs and knees

178. Pediatric EPM-Range of motion final score (0-3) (Len C, et al, J Rheum, 1999, 26(4):909-913): Unknown

179. Was the erythrocyte sedimentation rate elevated?
1 Yes 0 No 8 Unknown

180. Was C-reactive protein elevated?
1 Yes 0 No 8 Unknown

181. Was morning stiffness present?
1 Yes 0 No 8 Unknown
182. Specify duration: hours minutes

183. Specify patient's height at current evaluation: Specify unit: 1 cm 2 in

184. Specify patient's weight at current evaluation: Specify unit: 1 kg 2 lb

Indicate results of the following immune function studies at current evaluation:

Normal Decreased Increased Unknown

Quantitative Immunoglobulins:

185. IgG: 0 1 2 8

186. IgA: 0 1 2 8

187. IgM: 0 1 2 8

188. IgE: 0 1 2 8

Lymphocyte subsets:

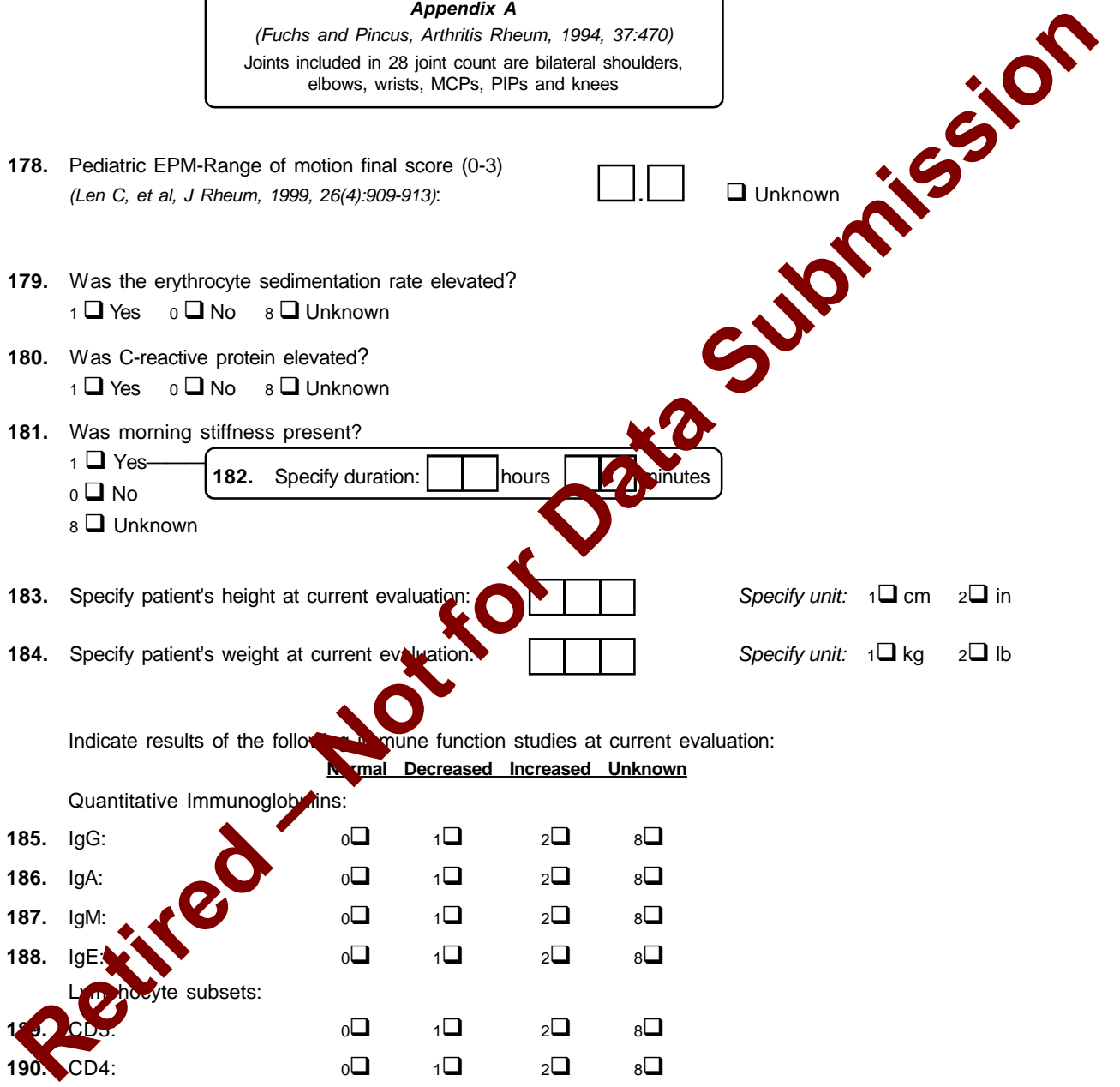
189. CD3: 0 1 2 8

190. CD4: 0 1 2 8

191. CD8: 0 1 2 8

192. CD19: 0 1 2 8

193. CD16: 0 1 2 8



TEAM:

IUBMID:

Radiographic Evaluation at Current Evaluation

194. Were radiographic bone erosions present at current evaluation?

- 1 Yes
- 0 No
- 8 Unknown

195. Was advanced skeletal age of affected joints noted radiographically at current evaluation?

- 1 Yes
- 0 No
- 8 Unknown

196. Did patient have osteoporosis at current evaluation?

- 1 Yes
- 0 No
- 8 Unknown

197. Were osteoporotic fractures present?
1 Yes 0 No 8 Unknown

Patient Assessment at Current Evaluation

198. Did the patient complete a Childhood Health Assessment Questionnaire (CHAQ) at current evaluation (see Appendix B on pg 5)?

- 1 Yes
- 0 No
- 8 Unknown

Specify range of possible scores for the CHAQ main sub-scale:

199. Patient's score: .

200. Worst possible score: .

201. Best possible score: .

Specify range of possible scores for the CHAQ disability sub-scale:

202. Patient's score: .

203. Worst possible score: .

204. Best possible score: .

Specify range of possible scores for the CHAQ severity sub-scale:

205. Patient's score: .

206. Worst possible score: .

207. Best possible score: .

208. Did the physician complete a Global Assessment of the patient's disease state at current evaluation?

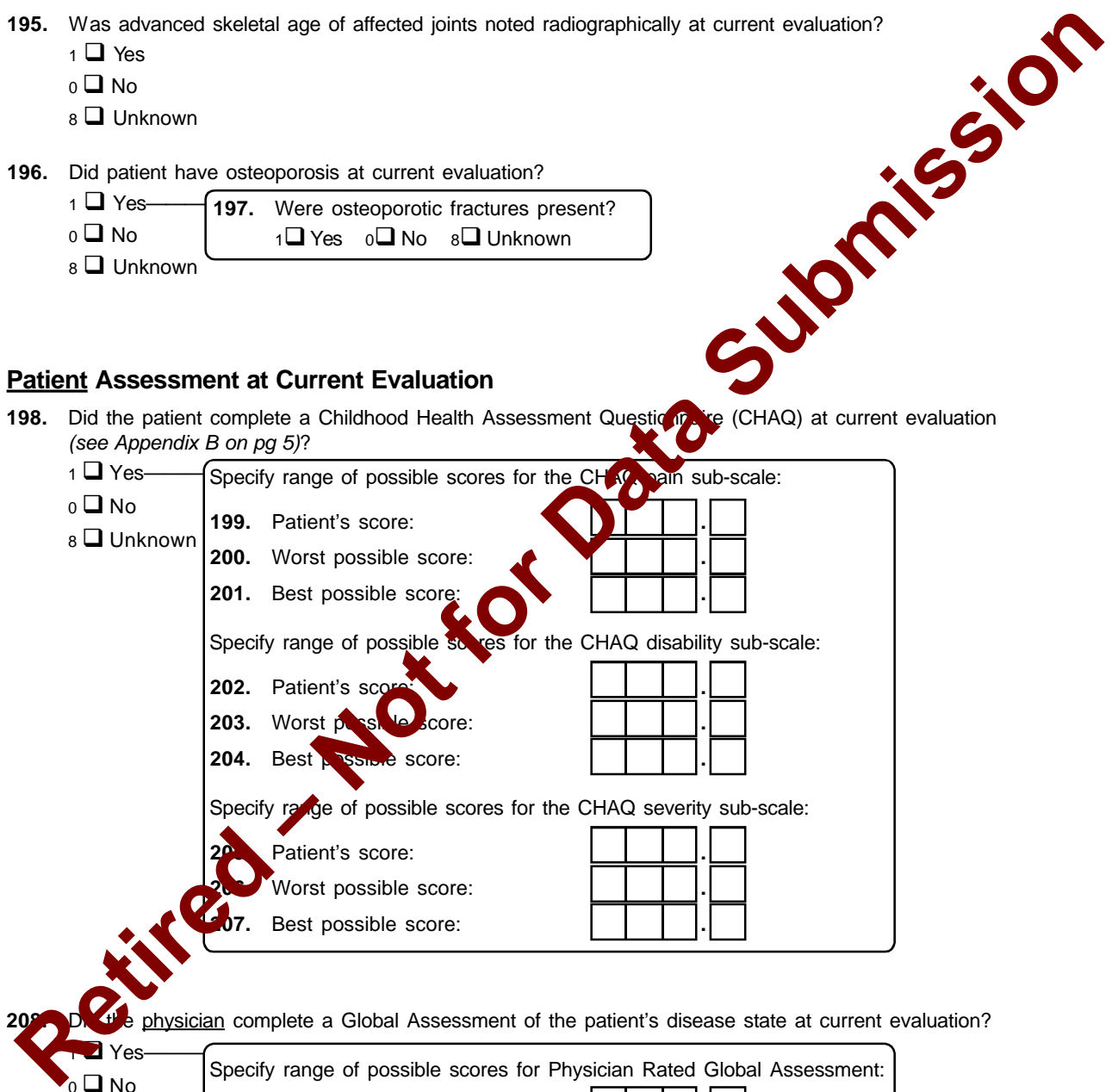
- 1 Yes
- 0 No
- 8 Unknown

Specify range of possible scores for Physician Rated Global Assessment:

209. Patient's score: .

210. Worst possible score: .

211. Best possible score: .



TEAM:

IUBMID:

212. Specify percent clinical improvement at time of best response compared with evaluation just prior to conditioning according to criteria of the American College of Rheumatology (ACR) (see Appendix C):

1 Disease is worse—Date of progression:

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Month	Day	Year			

2 No improvement

3 20% improvement (ACR20)—Date of maximal improvement:

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Month	Day	Year			

4 50% improvement (ACR50)—Date of maximal improvement:

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Month	Day	Year			

5 70% improvement (ACR70)—Date of maximal improvement:

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Month	Day	Year			

6 Remission—Date of remission:

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Month	Day	Year			

Appendix C
(Giannini, EH, et al., "Arthritis Rheum" 1997, Jul;40(7):1202-9)
Requires 20%* or more improvement in 3 of the following with no more than 1 of the remaining variables worsened by more than 30%*:

- Physician global assessment of disease activity
- Patient global assessment of overall well-being
- Functional ability
- Number of joints with active arthritis
- Number of joints with limited range of motion
- Erythrocyte sedimentation rate (ESR)

Substitute 50% or 70%, for 50% and 70% improvement levels, respectively.

213. Specify percent clinical improvement at current evaluation compared with evaluation just prior to conditioning according to criteria of the American College of Rheumatology (ACR) (see Appendix C):

1 Disease is worse—Date of progression, if different from Q.2012:

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Month	Day	Year			

2 No improvement

3 20% improvement (ACR20)

4 50% improvement (ACR50)

5 70% improvement (ACR70)

6 Remission

Retired - Not for Data Submission