Form 2042 R2.0: Juvenile Idiopathic Arthritis Pre-HSCT Data

Key Fields

| Sequence Number: | ____________________________ |
| Date Received: | __ __ __ __ - __ __ - __ __ |
| CIBMTR Center Number: | ____________________________ |
| CIBMTR Recipient ID: | ____________________________ |
| Today's Date: | __ __ __ __ - __ __ - __ __ |
| Date of HSCT for which this form is being completed: | __ __ __ __ - __ __ - __ __ |

**HSCT Type (check all that apply):**
- Autologous
- Allogeneic unrelated
- Allogeneic related
  - Syngeneic (identical twin)

**Product Type (check all that apply):**
- Marrow
- PBSC
- Cord blood
- Other product
  - Specify: ____________________________

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

## Disease Assessment at Diagnosis

### Questions: 1 - 31

1. **What was the date of diagnosis of Juvenile Idiopathic Arthritis?** __ __ __ __ - __ __ - __ __

2. **Specify the JIA subclass:**
   - Systemic JIA
   - Polyarticular rheumatoid arthritis with oligoarticular onset
   - Polyarticular rheumatoid arthritis with polyarticular onset
   - Other subtype

3. **Were the Schneider criteria (persistent thrombocytosis and corticosteroids to control fever) for systemic JIA fulfilled?**
   - Yes
   - No
   - Unknown

4. **Specify JIA subtype: ____________________________

Specify the following laboratory studies performed at diagnosis of JIA:

5. **Anti-nuclear antibody**
   - Yes
   - No
   - Unknown

6. **Specify lab study results:**
   - Normal
   - Abnormal
   - Unknown
7 C-reactive protein
   yes  no  Unknown

8 Specify lab study results:
   Normal  Abnormal  Unknown

9 Erythrocyte sedimentation rate
   yes  no  Unknown

10 Specify lab study results:
    Normal  Abnormal  Unknown

11 Rheumatoid factor
    yes  no  Unknown

12 Specify lab study results:
    Normal  Abnormal  Unknown

13 Other lab study
    yes  no  Unknown

14 Specify lab study results:
    Normal  Abnormal  Unknown

15 Specify lab study: ____________________________

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
    yes  no  Unknown

17 Disease progression while on therapy
    yes  no  Unknown

18 Systemic JIA with polyarticular course
    yes  no  Unknown

19 Were the Schneider criteria (persistent thrombocytosis and corticosteroids to control fever) for systemic JIA fulfilled?
    yes  no  Unknown

20 Toxicity from conventional treatment(s)
    yes  no  Unknown

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

21 Avascular necrosis of femoral head
    yes  no

22 Cataracts
    yes  no
<p>| | | | | | |</p>
<table>
<thead>
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</thead>
<tbody>
<tr>
<td>23</td>
<td>Growth delay</td>
<td>yes</td>
<td>no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>Hepatic dysfunction (≥ 3 fold increase in liver function tests)</td>
<td>yes</td>
<td>no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>Renal insufficiency (&gt; 30% increase in creatinine)</td>
<td>yes</td>
<td>no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26</td>
<td>Severe gastrointestinal (GI) toxicity</td>
<td>yes</td>
<td>no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>27</td>
<td>Specify GI toxicity:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>28</td>
<td>Severe hypertension</td>
<td>yes</td>
<td>no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>29</td>
<td>Severe myelosuppression</td>
<td>yes</td>
<td>no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30</td>
<td>Other toxicity</td>
<td>yes</td>
<td>no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>31</td>
<td>Specify other toxicity:</td>
<td></td>
<td></td>
<td></td>
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</table>

### Pre-HSCT Treatment for Juvenile Idiopathic Arthritis

**Questions: 32 - 71**

<p>| | | | | | |</p>
<table>
<thead>
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</thead>
<tbody>
<tr>
<td>32</td>
<td>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?)</td>
<td>yes</td>
<td>no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>33</td>
<td>Were corticosteroids given?</td>
<td>yes</td>
<td>no</td>
<td>Unknown</td>
<td></td>
</tr>
<tr>
<td>34</td>
<td>Was treatment stopped?</td>
<td>yes</td>
<td>no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>35</td>
<td>Specify reason treatment stopped:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>failure</td>
<td>Toxicity</td>
<td>other reason</td>
<td>Reason unknown</td>
<td></td>
</tr>
<tr>
<td>36</td>
<td>Specify other reason:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>37</td>
<td>Was prednisone or other corticosteroid dosing changed between diagnosis and just prior to mobilization for stem cell collection?</td>
<td>dose unchanged</td>
<td>dose increased</td>
<td>dose decreased</td>
<td>Unknown</td>
</tr>
<tr>
<td>38</td>
<td>Was cyclophosphamide (CTX, Cytoxan, Neosar) given?</td>
<td>yes</td>
<td>no</td>
<td>Unknown</td>
<td></td>
</tr>
<tr>
<td>39</td>
<td>Was treatment stopped?</td>
<td>yes</td>
<td>no</td>
<td></td>
<td></td>
</tr>
<tr>
<td>40</td>
<td>Specify reason treatment stopped:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>failure</td>
<td>Toxicity</td>
<td>other reason</td>
<td>Reason unknown</td>
<td></td>
</tr>
</tbody>
</table>
### Form 2042 R2.0: Juvenile Idiopathic Arthritis Pre-HSCT Data

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>41 Specify other reason:</td>
<td>____________________________________________________________________</td>
</tr>
<tr>
<td>42 Was cyclosporine (CsA, Neoral, Sandimmune) given?</td>
<td>yes</td>
</tr>
<tr>
<td>43 Was treatment stopped?</td>
<td>yes</td>
</tr>
<tr>
<td>44 Specify reason treatment stopped:</td>
<td>failure</td>
</tr>
<tr>
<td>45 Specify other reason:</td>
<td>____________________________________________________________________</td>
</tr>
<tr>
<td>46 Etanercept (Enbrel)</td>
<td>yes</td>
</tr>
<tr>
<td>47 Was treatment stopped?</td>
<td>yes</td>
</tr>
<tr>
<td>48 Specify reason treatment stopped:</td>
<td>failure</td>
</tr>
<tr>
<td>49 Specify other reason:</td>
<td>____________________________________________________________________</td>
</tr>
<tr>
<td>50 Was methotrexate (MTX, Folex) given?</td>
<td>yes</td>
</tr>
<tr>
<td>51 Was treatment stopped?</td>
<td>yes</td>
</tr>
<tr>
<td>52 Specify reason treatment stopped:</td>
<td>failure</td>
</tr>
<tr>
<td>53 Specify other reason:</td>
<td>____________________________________________________________________</td>
</tr>
<tr>
<td>54 Specify the maximum weekly dose:</td>
<td>____________________________________________________________________</td>
</tr>
<tr>
<td>55 Specify the duration of therapy:</td>
<td>____________________________________________________________________</td>
</tr>
<tr>
<td>56 Were non-steroidal anti-inflammatory drugs (NSAIDS) given?</td>
<td>yes</td>
</tr>
<tr>
<td>57 Was treatment stopped?</td>
<td>yes</td>
</tr>
<tr>
<td>58 Specify reason treatment stopped:</td>
<td>failure</td>
</tr>
<tr>
<td>59 Specify other reason:</td>
<td>____________________________________________________________________</td>
</tr>
<tr>
<td>60 Was other treatment given?</td>
<td>yes</td>
</tr>
</tbody>
</table>

**Mail, fax or email this form to Minneapolis. Fax: 612-527-5895. Email: scanform@nmdp.org. Retain the original form at the transplant center.**

CIBMTR Form 2042 revision 2 last updated July 2007. Copyright(c) 2012 National Marrow Donor Program and The Medical College of Wisconsin, Inc. All rights reserved.
61 Treatment Stopped?
   yes   no

62 Specify reason treatment stopped:
   failure  Toxicity  other reason  Reason unknown

63 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)?
   yes   no   Unknown

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

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)?
   yes   no   Unknown

68 Were the NSAIDS discontinued prior to mobilization?
   yes   no   Unknown

69 Specify the date NSAIDS were stopped: __ __ __ __ __ __ __ __ __

70 Specify the reason for stopping:
   failure  Toxicity  other reason  Reason unknown

71 Specify other reason:__________________________

---

**Disease Assessment Prior to Mobilization Therapy for Stem Cell Collection Questions: 72 - 85**

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---
78 Specify the recipient's height at the time of mobilization:
    Known  |  Unknown

79 [ ] [ ] [ ] [ ] [ ] in  |  cm

80 Specify the recipient's weight at the time of mobilization:
    Known  |  Unknown

81 [ ] [ ] [ ] [ ] [ ] lbs  |  kg

82 Specify the recipient's height one year prior to the time of mobilization:
    Known  |  Unknown

83 [ ] [ ] [ ] [ ] [ ] in  |  cm

84 Specify the recipient's weight one year prior to the time of mobilization:
    Known  |  Unknown

85 [ ] [ ] [ ] [ ] [ ] lbs  |  kg

Laboratory Studies Prior to Mobilization Therapy for Stem Cell Collection

Questions: 86 - 131

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

86 Antinuclear antibody (ANA) titers
    [ ] yes  [ ] no  [ ] Unknown

87 C-reactive protein
    [ ] yes  [ ] no  [ ] Unknown

88 Erythrocyte sedimentation rate (ESR)
    [ ] yes  [ ] no  [ ] Unknown

89 Serum rheumatoid factor (RF) titers
    [ ] yes  [ ] no  [ ] Unknown

90 Date CBC tested: __ __ __ __ - __ __

91 WBC:
    Known  |  Not known

92 [ ] [ ] [ ] [ ] [ ] x 10^3/L (x 10^9/mm^3)
    [ ] [ ] [ ] [ ] [ ] x 10^9/L

93 Segs:
    Known  |  Not known
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94 %

95 Bands:

96 %

97 Lymphocytes:

98 %

99 Monocytes:

100 %

101 Eosinophils:

102 %

103 Basophils:

104 %

105 Hemoglobin:

106 _________ g/dL g/L mmol/L

107 Hematocrit:

108 %

109 Platelets:

110 _________ x 10^9/L (x 10^9/mm^3) 

111 Creatinine:

112 _________ mg/dL mmol/L µmol/L

113 Alkaline phosphatase:

Mail, fax or email this form to Minneapolis. Fax: 612-627-5895. Email: scanform@nmdp.org. Retain the original form at the transplant center.
Specify the results of the following immune function studies performed just prior to mobilization:

Quantitative Immunoglobulins:

123 IgG
- Normal
- Decreased
- Increased
- Unknown

124 IgA
- Normal
- Decreased
- Increased
- Unknown

125 IgM
- Normal
- Decreased
- Increased
- Unknown

126 IgE
- Normal
- Decreased
- Increased
- Unknown

Lymphocyte subsets:

127 CD3
- Normal
- Decreased
- Increased
- Unknown

128 CD4
- Normal
- Decreased
- Increased
- Unknown
### Radiographic Assessment Prior to Mobilization for Stem Cell Collection

<table>
<thead>
<tr>
<th>Question</th>
<th>Normal</th>
<th>Decreased</th>
<th>Increased</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>132</td>
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</table>

### Functional Assessment Prior to Mobilization Therapy for Stem Cell Collection

<table>
<thead>
<tr>
<th>Question</th>
<th>Normal</th>
<th>Decreased</th>
<th>Increased</th>
<th>Unknown</th>
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</thead>
<tbody>
<tr>
<td>135</td>
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</table>

### Did the recipient complete a Childhood Health Assessment Questionnaire (CHAQ) prior to mobilization?  

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

<table>
<thead>
<tr>
<th>Question</th>
<th>Normal</th>
<th>Decreased</th>
<th>Increased</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>136</td>
<td></td>
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<td>137</td>
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<td>138</td>
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</table>

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

<table>
<thead>
<tr>
<th>Question</th>
<th>Normal</th>
<th>Decreased</th>
<th>Increased</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>139</td>
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<td>140</td>
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<tr>
<td>141</td>
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</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Question</th>
<th>Normal</th>
<th>Decreased</th>
<th>Increased</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>142</td>
<td></td>
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<td>143</td>
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<tr>
<td>144</td>
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</table>

### Did the physician complete a Global Assessment of Functioning of the recipient’s health prior to mobilization?

<table>
<thead>
<tr>
<th>Question</th>
<th>Normal</th>
<th>Decreased</th>
<th>Increased</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>145</td>
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<td>146</td>
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<td>147</td>
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<tr>
<td>148</td>
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</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Question</th>
<th>Normal</th>
<th>Decreased</th>
<th>Increased</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>149</td>
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</tbody>
</table>

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 205.
150 Specify the number of painful / tender joints prior to the preparative regimen: 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.

151 Specify the number of swollen / effused joints prior to the preparative regimen: 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.

152 Specify the pediatric EPM Range of Motion final score (0.0 - 3.0): 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.

153 Was morning stiffness present prior to the preparative regimen?

154 Specify the duration of morning stiffness: ___________ ___________ Hours Minutes

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

156 ________________ ________________ in cm

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

158 ________________ ________________ lbs kg

Laboratory Studies Prior to the Start of the Preparative Regimen

159 Antinuclear antibody (ANA) titers

160 C-reactive protein

161 Erythrocyte sedimentation rate (ESR)

162 Serum rheumatoid factor (RF) titers

163 Date tested: __ __ __ __ __ __

164 Segs: Known Not known

165 %

166 Bands: Known Not known
Specify the results of the following immune function studies performed just prior to the start of the preparative regimen:

**Quantitative immunoglobulins:**

- **IgG**
  - Normal
  - Decreased
  - Increased
  - Unknown

- **IgA**
  - Normal
  - Decreased
  - Increased
  - Unknown

- **IgM**
  - Normal
  - Decreased
  - Increased
  - Unknown

- **IgE**
  - Normal
  - Decreased
  - Increased
  - Unknown

**Lymphocyte subsets:**

- **CD3**
  - Normal
  - Decreased
  - Increased
  - Unknown

- **CD4**
  - Normal
  - Decreased
  - Increased
  - Unknown
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Radiographic Assessment Prior to the Start of the Preparative Regimen

187 Were radiographic bone erosions present prior to the start of the preparative regimen?
- yes
- no
- Unknown

188 Was advanced skeletal age of affected joints noted radiographically prior to the start of the preparative regimen?
- yes
- no
- Unknown

189 Was osteoporosis present prior to the start of the preparative regimen?
- yes
- no
- Unknown

190 Were osteoporotic fractures present?
- yes
- no
- Unknown

Functional Assessment Prior to the Start of the Preparative Regimen

- yes
- no
- Unknown

Specify the following scores for the CHAQ pain sub-scale:
192 Recipient's pain assessment:
193 Worst possible pain score:
194 Best possible pain score:

Specify the following scores for the CHAQ disability sub-scale:
195 Recipient's disability assessment:
196 Worst possible disability score:
197 Best possible disability score:

Specify the following scores for the CHAQ severity sub-scale:
198 Recipient's severity assessment:
199 Worst possible severity score:
200 Best possible severity score:

201 Did the physician complete a Global Assessment of Functioning of the recipient's health prior to the preparative regimen?
- yes
- no
- Unknown

202 Physician-rated Global Assessment score:
203 Worst possible score:
204 Best possible score:

First Name: __________________________ Last Name: __________________________
### Form 2042 R2.0: Juvenile Idiopathic Arthritis Pre-HSCT Data

**Center:**

**CRID:**

<table>
<thead>
<tr>
<th>Sequence Number:</th>
<th>CIBMTR Recipient ID:</th>
<th>Initials:</th>
</tr>
</thead>
<tbody>
<tr>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Today's Date:</th>
<th>Infusion Date:</th>
<th>CIBMTR Center Number:</th>
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</thead>
<tbody>
<tr>
<td>Month Day Year</td>
<td>Month Day Year</td>
<td></td>
</tr>
</tbody>
</table>

Phone number: ___________________________  Fax number: ___________________________

E-mail address: ___________________________