



Juvenile Idiopathic Arthritis Post-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, unrelated allogeneic, related syngeneic (identical twin)

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

Visit: 100 day 6 month 1 year 2 years > 2 years, specify:

To be completed in conjunction with a Form 2100 – 100 Days Post-HSCT Data, Form 2200 – Six Months to Two Years Post-HSCT Data, or Form 2300 – Yearly Follow-Up for Greater Than Two Years Post-HSCT Data. Information reported here should reflect the date of last contact as reported in the post-HSCT data collection form, or immediately prior to death.

Disease Assessment at the Time of Best Response to HSCT

- Specify the percent of clinical improvement at the time of best response since HSCT compared to the evaluation just prior to mobilization, according to American College of Rheumatology (ACR) criteria:
Giannini EH, Ruperto N, Ravelli A, Lovell DJ, Felson DT, Martini A. Preliminary definition of improvement in juvenile arthritis. Arthritis Rheum 1997; 40 (7): 1202–1209. Requires 20% or more improvement in 3 of following 6 criteria, with no more than 1 of the remaining variables worsened by more than 30%*: • physician global assessment of disease activity • parent / recipient 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.*

1 disease is worse → 3. Specify the date of disease progression: / /
Month Day Year

2 no improvement

3 20% improvement (ACR20) → 4. Specify the date of maximal improvement: / /
Month Day Year

4 50% improvement (ACR50) →

5 70% improvement (ACR70) →

6 disease in remission → 5. Specify the date of disease remission: / /
Month Day Year

2. Date of assessment for best response: / /
Month Day Year

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

CIBMTR Center Number:

CIBMTR Recipient ID:

Radiographic Assessment for This Reporting Period

62. Were radiographic bone erosions present since the date of the last report?

- 1 yes
- 2 no
- 3 unknown

63. Was advanced skeletal age of affected joints noted radiographically since the date of the last report?

- 1 yes
- 2 no
- 3 unknown

64. Was osteoporosis present since the date of the last report?

- 1 yes
- 2 no
- 3 unknown

65. Were osteoporotic fractures present?

- 1 yes
- 2 no
- 3 unknown

Functional Assessment for This Reporting Period

66. Did the recipient complete a Childhood Health Assessment Questionnaire (CHAQ) since the date of the last report?

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:

67. Recipient's pain assessment: .

68. Worst possible pain score: .

69. Best possible pain score: .

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

70. Recipient's disability assessment: .

71. Worst possible disability score: .

72. Best possible disability score: .

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

73. Recipient's severity assessment: .

74. Worst possible severity score: .

75. Best possible severity score: .

76. Did the physician complete a Global Assessment of Functioning of the recipient's health since the date of the last report?

- 1 yes
- 2 no
- 3 unknown

77. Physician-rated Global Assessment score: .

78. Worst possible score: .

79. Best possible score: .

CIBMTR Center Number:

CIBMTR Recipient ID:

80. Specify the percent of clinical improvement since the date of the last report, according to American College of Rheumatology (ACR) criteria:

Giannini EH, Ruperto N, Ravelli A, Lovell DJ, Felson DT, Martini A. Preliminary definition of improvement in juvenile arthritis. Arthritis Rheum 1997; 40 (7): 1202–1209. Requires 20% or more improvement in 3 of following 6 criteria, with no more than 1 of the remaining variables worsened by more than 30%*: • physician global assessment of disease activity • parent / recipient 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.*

1 disease is worse \longrightarrow 81. Specify the date of disease progression:
Month Day Year

2 no improvement

3 20% improvement (ACR20) \longrightarrow 82. Specify the date of maximal improvement:
Month Day Year

4 50% improvement (ACR50) \longrightarrow

5 70% improvement (ACR70) \longrightarrow

6 disease in remission \longrightarrow 83. Specify the date of disease remission:
Month Day Year

84. Signed: _____

Person completing form

Please print name: _____

Phone number: (_____) _____

Fax number: (_____) _____

E-mail address: _____