Osteopetrosis Post-HSCT Data

Registry Use Only

Sequence Number:

Date Received:

CIBMTR Center Number:

CIBMTR Recipient ID:

Today's Date: Month Day Year

Infusion Date: Month Day Year

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 alloceneic, unrelated alloceneic, 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 Resolution Status

1. What was the highest serum calcium value since the date of the last report?
   1. known
   2. not known

Specify units:
   1. mg/dL
   2. mmol/L
   3. mEq/L

2. What was the date the serum calcium value was tested since the date of the last report?
   1. known
   2. not known

   Month Day Year

3. Was hypercalcemia diagnosed at any time prior to this report?
   1. yes
   2. no
   3. unknown

4. Did hypercalcemia create a clinical problem necessitating intervention since the date of the last report?
   1. yes
   2. no
   3. unknown
5. Were any changes noted in a skeletal x-ray performed since the date of the last report?
   1 【yes】
   2 【no】
   3 【unknown】

6. Does the most recent x-ray indicate any current skeletal abnormalities?
   1 【yes】
   2 【no, x-ray is normal】
   3 【unknown】

7. Specify the status of current skeletal abnormalities compared to the status from the last report:
   1 【abnormalities improved】
   2 【no change】
   3 【abnormalities worsened】
   4 【unknown】

8. Specify the date of the first skeletal x-ray which showed evidence of the current status:
   1 【known】
   2 【not known】
   Month Day Year

9. Specify the date of the first skeletal x-ray of normal status:
   1 【known】
   2 【not known】
   Month Day Year

10. Was a bone marrow biopsy performed since the date of the last report?
    1 【yes】
    2 【no】
    3 【unknown】

11. Specify the date the bone marrow biopsy was performed:
    1 【known】
    2 【not known】
    Month Day Year

12. Specify the bone marrow biopsy results:
    1 【normal】
    2 【abnormal】
    3 【unknown】

13. Specify the status of current bone marrow biopsy results compared to the results from the last report:
    1 【abnormalities improved】
    2 【no change】
    3 【abnormalities worsened】
    4 【unknown】

14. Was splenomegaly diagnosed at any time prior to this report?
    1 【yes】
    2 【no】
    3 【unknown】

15. Did splenomegaly normalize since the date of the last report?
    1 【yes】
    2 【no】
    3 【unknown】

16. Was growth delay diagnosed at any time prior to this report?
    1 【yes】
    2 【no】
    3 【unknown】

17. Did growth rate improve since the date of the last report?
    1 【yes】
    2 【no】
    3 【unknown】
18. Is a copy of current growth charts included with this report?
   1  yes
   2  no

19. Was a bone biopsy performed since the date of the last report?
   1  yes
   2  no
   3  unknown

20. Specify the number of osteoclasts in bone biopsy:
   1  few / none
   2  normal
   3  increased
   4  unknown

Change in Clinical and Radiologic Findings Since the Last Report

Specify the presence of the following clinical indicators of osteopetrosis:

21. Aplastic anemia
   1  yes, previous diagnosis
   2  yes, first occurrence at this reporting period
   3  not diagnosed
   4  unknown

22. Specify the change in status of aplastic anemia compared to results from the last report:
   1  improved
   2  no change
   3  worsened
   4  unknown

23. Blindness / visual impairment
   1  yes, previous diagnosis
   2  yes, first occurrence at this reporting period
   3  not diagnosed
   4  unknown

24. Specify the change in status of blindness / visual impairment compared to results from the last report:
   1  improved
   2  no change
   3  worsened
   4  unknown

25. Convulsions
   1  yes, previous diagnosis
   2  yes, first occurrence at this reporting period
   3  not diagnosed
   4  unknown

26. Specify the change in status of convulsions compared to results from the last report:
   1  improved
   2  no change
   3  worsened
   4  unknown

27. Dentition problems
   1  yes, previous diagnosis
   2  yes, first occurrence at this reporting period
   3  not diagnosed
   4  unknown

28. Specify the change in status of dentition problems compared to results from the last report:
   1  improved
   2  no change
   3  worsened
   4  unknown

29. Exophthalmos
   1  yes, previous diagnosis
   2  yes, first occurrence at this reporting period
   3  not diagnosed
   4  unknown

30. Specify the change in status of exophthalmos compared to results from the last report:
   1  improved
   2  no change
   3  worsened
   4  unknown

31. Fractures
   1  yes, previous diagnosis
   2  yes, first occurrence at this reporting period
   3  not diagnosed
   4  unknown

32. Specify the change in status of fractures compared to results from the last report:
   1  improved
   2  no change
   3  worsened
   4  unknown

33. Frontal bossing / prominent forehead
   1  yes, previous diagnosis
   2  yes, first occurrence at this reporting period
   3  not diagnosed
   4  unknown

34. Specify the change in status of frontal bossing / prominent forehead compared to results from the last report:
   1  improved
   2  no change
   3  worsened
   4  unknown
35. Gross motor delay  
   1 ☐ yes, previous diagnosis  
   2 ☐ yes, first occurrence at this reporting period  
   3 ☐ not diagnosed  
   4 ☐ unknown  
37. Hearing impairment  
   1 ☐ yes, previous diagnosis  
   2 ☐ yes, first occurrence at this reporting period  
   3 ☐ not diagnosed  
   4 ☐ unknown  
39. Height below 5th percentile  
   1 ☐ yes, previous diagnosis  
   2 ☐ yes, first occurrence at this reporting period  
   3 ☐ not diagnosed  
   4 ☐ unknown  
41. Hepatomegaly  
   1 ☐ yes, previous diagnosis  
   2 ☐ yes, first occurrence at this reporting period  
   3 ☐ not diagnosed  
   4 ☐ unknown  
43. Hypertelorism  
   1 ☐ yes, previous diagnosis  
   2 ☐ yes, first occurrence at this reporting period  
   3 ☐ not diagnosed  
   4 ☐ unknown  
45. Mental development delay  
   1 ☐ yes, previous diagnosis  
   2 ☐ yes, first occurrence at this reporting period  
   3 ☐ not diagnosed  
   4 ☐ unknown  
47. Nasal congestion  
   1 ☐ yes, previous diagnosis  
   2 ☐ yes, first occurrence at this reporting period  
   3 ☐ not diagnosed  
   4 ☐ unknown  
49. Osteomyelitis  
   1 ☐ yes, previous diagnosis  
   2 ☐ yes, first occurrence at this reporting period  
   3 ☐ not diagnosed  
   4 ☐ unknown  
51. Septicemia  
   1 ☐ yes, previous diagnosis  
   2 ☐ yes, first occurrence at this reporting period  
   3 ☐ not diagnosed  
   4 ☐ unknown  
53. Skull circumference above 95th percentile  
   1 ☐ yes, previous diagnosis  
   2 ☐ yes, first occurrence at this reporting period  
   3 ☐ not diagnosed  
   4 ☐ unknown  

36. Specify the change in status of gross motor delay compared to results from the last report:  
   1 ☐ improved  
   2 ☐ no change  
   3 ☐ worsened  
   4 ☐ unknown  
38. Specify the change in status of hearing impairment compared to results from the last report:  
   1 ☐ improved  
   2 ☐ no change  
   3 ☐ worsened  
   4 ☐ unknown  
40. Specify the change in status of height below 5th percentile compared to results from the last report:  
   1 ☐ improved  
   2 ☐ no change  
   3 ☐ worsened  
   4 ☐ unknown  
42. Specify the change in status of hepatomegaly compared to results from the last report:  
   1 ☐ improved  
   2 ☐ no change  
   3 ☐ worsened  
   4 ☐ unknown  
44. Specify the change in status of hypertelorism compared to results from the last report:  
   1 ☐ improved  
   2 ☐ no change  
   3 ☐ worsened  
   4 ☐ unknown  
46. Specify the change in status of mental development delay compared to results from the last report:  
   1 ☐ improved  
   2 ☐ no change  
   3 ☐ worsened  
   4 ☐ unknown  
48. Specify the change in status of nasal congestion compared to results from the last report:  
   1 ☐ improved  
   2 ☐ no change  
   3 ☐ worsened  
   4 ☐ unknown  
50. Specify the change in status of osteomyelitis compared to results from the last report:  
   1 ☐ improved  
   2 ☐ no change  
   3 ☐ worsened  
   4 ☐ unknown  
52. Specify the change in status of septicemia compared to results from the last report:  
   1 ☐ improved  
   2 ☐ no change  
   3 ☐ worsened  
   4 ☐ unknown  
54. Specify the change in status of skull circumference compared to results from the last report:  
   1 ☐ improved  
   2 ☐ no change  
   3 ☐ worsened  
   4 ☐ unknown  

Fax this form to your designated campus (Milwaukee 414-805-0714 or Minneapolis 612-627-5895).
### CIBMTR Recipient ID:

<table>
<thead>
<tr>
<th>CIBMTR Center Number:</th>
<th>CIBMTR Recipient ID:</th>
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### 55. Splenomegaly

| 1 | yes, previous diagnosis |
| 2 | yes, first occurrence at this reporting period |
| 3 | not diagnosed |
| 4 | unknown |

### 56. Specify the change in status of splenomegaly compared to results from the last report:

| 1 | improved |
| 2 | no change |
| 3 | worsened |
| 4 | unknown |

### 57. Strabismus / nystagmus

| 1 | yes, previous diagnosis |
| 2 | yes, first occurrence at this reporting period |
| 3 | not diagnosed |
| 4 | unknown |

### 58. Specify the change in status of strabismus / nystagmus compared to results from the last report:

| 1 | improved |
| 2 | no change |
| 3 | worsened |
| 4 | unknown |

### 59. Other hematologic impairment(s)

| 1 | yes, previous diagnosis |
| 2 | yes, first occurrence at this reporting period |
| 3 | not diagnosed |
| 4 | unknown |

### 60. Specify the hematologic impairment:

### Specify the hematologic impairment:

### 61. Specify the change in status of the hematologic impairment compared to results from the last report:

| 1 | improved |
| 2 | no change |
| 3 | worsened |
| 4 | unknown |

### 62. Other clinical finding

| 1 | yes, previous diagnosis |
| 2 | yes, first occurrence at this reporting period |
| 3 | not diagnosed |
| 4 | unknown |

### 63. Specify the other clinical finding:

### Specify the change in status compared to results from the last report:

| 1 | improved |
| 2 | no change |
| 3 | worsened |
| 4 | unknown |

### 64. Specify the change in status compared to results from the last report:

| 1 | improved |
| 2 | no change |
| 3 | worsened |
| 4 | unknown |

### Specify the presence of the following radiologic indicators of osteopetrosis:

### 65. “Batman sign” / “sign du masque”

| 1 | yes, previous diagnosis |
| 2 | yes, first occurrence at this reporting period |
| 3 | not diagnosed |
| 4 | unknown |

### 66. Specify the change in status of Batman sign compared to results from the last report:

### 67. Bone-in-bone sign

| 1 | yes, previous diagnosis |
| 2 | yes, first occurrence at this reporting period |
| 3 | not diagnosed |
| 4 | unknown |

### 68. Specify the change in status of bone-in-bone appearance compared to results from the last report:

### 69. Cerebral atrophy (by MRI or CT)

| 1 | yes, previous diagnosis |
| 2 | yes, first occurrence at this reporting period |
| 3 | not diagnosed |
| 4 | unknown |

### 70. Specify the change in status of cerebral atrophy compared to results from the last report:

### 71. Craniosynostosis

| 1 | yes, previous diagnosis |
| 2 | yes, first occurrence at this reporting period |
| 3 | not diagnosed |
| 4 | unknown |

### 72. Specify the change in status of craniosynostosis compared to results from the last report:

### 73. Hydrocephalus

| 1 | yes, previous diagnosis |
| 2 | yes, first occurrence at this reporting period |
| 3 | not diagnosed |
| 4 | unknown |

### 74. Specify the change in status of hydrocephalus compared to results from the last report:

| 1 | improved |
| 2 | no change |
| 3 | worsened |
| 4 | unknown |

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Fax this form to your designated campus (Milwaukee 414-805-0714 or Minneapolis 612-627-5895).
75. Increased general skeletal sclerosis
   1 yes, previous diagnosis
   2 yes, first occurrence at this reporting period
   3 not diagnosed
   4 unknown

77. Metaphyseal widening
   1 yes, previous diagnosis
   2 yes, first occurrence at this reporting period
   3 not diagnosed
   4 unknown

79. other radiologic finding
   1 yes, previous diagnosis
   2 yes, first occurrence at this reporting period
   3 not diagnosed
   4 unknown

76. Specify the change in status of sclerosis compared to results from the last report:
   1 improved
   2 no change
   3 worsened
   4 unknown

78. Specify the change in status of metaphyseal widening compared to results from the last report:
   1 improved
   2 no change
   3 worsened
   4 unknown

80. Specify the other radiologic finding: ____________________________

81. Specify the change in status compared to results from the last report:
   1 improved
   2 no change
   3 worsened
   4 unknown

82. Signed: ____________________________________________________

   Person completing form

Please print name: ________________________________________________

Phone number: (_________ ) _______________________________________

Fax number: (_________ ) _______________________________________

E-mail address: _________________________________________________