



Osteopetrosis 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 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

CIBMTR Center Number:

CIBMTR Recipient ID:

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

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

- 2 no, x-ray is normal
- 3 unknown

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

CIBMTR Center Number:

CIBMTR Recipient ID:

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

CIBMTR Center Number:

CIBMTR Recipient ID:

35. Gross motor delay

- 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

37. Hearing impairment

- 1 yes, previous diagnosis
- 2 yes, first occurrence at this reporting period
- 3 not diagnosed
- 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

39. Height below 5th percentile

- 1 yes, previous diagnosis
- 2 yes, first occurrence at this reporting period
- 3 not diagnosed
- 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

41. Hepatomegaly

- 1 yes, previous diagnosis
- 2 yes, first occurrence at this reporting period
- 3 not diagnosed
- 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

43. Hypertelorism

- 1 yes, previous diagnosis
- 2 yes, first occurrence at this reporting period
- 3 not diagnosed
- 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

45. Mental development delay

- 1 yes, previous diagnosis
- 2 yes, first occurrence at this reporting period
- 3 not diagnosed
- 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

47. Nasal congestion

- 1 yes, previous diagnosis
- 2 yes, first occurrence at this reporting period
- 3 not diagnosed
- 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

49. Osteomyelitis

- 1 yes, previous diagnosis
- 2 yes, first occurrence at this reporting period
- 3 not diagnosed
- 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

51. Septicemia

- 1 yes, previous diagnosis
- 2 yes, first occurrence at this reporting period
- 3 not diagnosed
- 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

53. Skull circumference above 95th percentile

- 1 yes, previous diagnosis
- 2 yes, first occurrence at this reporting period
- 3 not diagnosed
- 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

CIBMTR Center Number:

CIBMTR Recipient ID:

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: _____
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: _____
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:
1 improved 2 no change 3 worsened 4 unknown

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:
1 improved 2 no change 3 worsened 4 unknown

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:
1 improved 2 no change 3 worsened 4 unknown

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:
1 improved 2 no change 3 worsened 4 unknown

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

CIBMTR Center Number:

CIBMTR Recipient ID:

75. Increased general skeletal sclerosis

- 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

77. Metaphyseal widening

- 1 yes, previous diagnosis
- 2 yes, first occurrence at this reporting period
- 3 not diagnosed
- 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

79. other radiologic finding

- 1 yes, previous diagnosis
- 2 yes, first occurrence at this reporting period
- 3 not diagnosed
- 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: _____