



Osteopetrosis Pre-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, allogeneic, syngeneic
unrelated related (identical twin)

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

This form must be accompanied by Form 2000 – Recipient Baseline Data. All information in the box above, including the date, should be identical with the corresponding Form 2000. Information should come from an actual examination by the Transplant Center physician, or the physician who is following the recipient pre-HSCT, or abstraction of the recipient’s medical records.

If this is a report of a second or subsequent transplant, check here and continue with 100-Day Follow-up insert.

1. What was the date of diagnosis of Osteopetrosis? / /
Month Day Year

2. Specify the inheritance of osteopetrosis:
- 1 autosomal recessive
 - 2 autosomal recessive with carbanhydrase II deficiency
 - 3 autosomal dominant (affected parent)
 - 4 unknown

Clinical and Radiological Findings Prior to the Preparative Regimen

Specify the presence of the following clinical indicators of osteopetrosis:

- 3. 1 yes 2 no 3 unknown aplastic anemia
- 4. 1 yes 2 no 3 unknown blindness / visual impairment
- 5. 1 yes 2 no 3 unknown convulsions
- 6. 1 yes 2 no 3 unknown dentition problems
- 7. 1 yes 2 no 3 unknown exophthalmos
- 8. 1 yes 2 no 3 unknown fractures
- 9. 1 yes 2 no 3 unknown frontal bossing / prominent forehead
- 10. 1 yes 2 no 3 unknown gross motor delay
- 11. 1 yes 2 no 3 unknown hearing impairment
- 12. 1 yes 2 no 3 unknown height below 5th percentile
- 13. 1 yes 2 no 3 unknown hepatomegaly
- 14. 1 yes 2 no 3 unknown hypertelorism
- 15. 1 yes 2 no 3 unknown mental development delay
- 16. 1 yes 2 no 3 unknown nasal congestion
- 17. 1 yes 2 no 3 unknown osteomyelitis
- 18. 1 yes 2 no 3 unknown septicemia
- 19. 1 yes 2 no 3 unknown skull circumference above 95th percentile
- 20. 1 yes 2 no 3 unknown splenomegaly

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

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21. 1 yes 2 no 3 unknown strabismus / nystagmus

22. 1 yes 2 no 3 unknown other hematologic impairment(s) → 23. Specify hematologic impairment:

24. 1 yes 2 no 3 unknown other clinical finding → 25. Specify other finding:

Specify the presence of the following radiologic indicators of osteopetrosis:

26. 1 yes 2 no 3 unknown "Batman sign" / "sign du masque"

27. 1 yes 2 no 3 unknown bone-in-bone

28. 1 yes 2 no 3 unknown cerebral atrophy (by MRI or CT)

29. 1 yes 2 no 3 unknown craniosynostosis

30. 1 yes 2 no 3 unknown hydrocephalus

31. 1 yes 2 no 3 unknown increased general skeletal sclerosis

32. 1 yes 2 no 3 unknown metaphyseal widening

33. 1 yes 2 no 3 unknown other radiologic finding → 34. Specify other finding:

Disease Treatment Given Prior to the Preparative Regimen

35. Was calcitrol given to treat osteopetrosis at any time prior to the preparative regimen?

- 1 yes →
- 2 no
- 3 unknown

36. What was the time duration calcitrol was given?

- 1 known → months
- 2 not known

37. What was the date administration of calcitrol was stopped?

- 1 known → / /
 - 2 not known
- Month Day Year

38. Were corticosteroids given to treat osteopetrosis at any time prior to the preparative regimen?

- 1 yes →
- 2 no
- 3 unknown

39. What was the time duration corticosteroids were given?

- 1 known → months
- 2 not known

40. What was the date administration of corticosteroids was stopped?

- 1 known → / /
 - 2 not known
- Month Day Year

41. Was IFN- γ given to treat osteopetrosis at any time prior to the preparative regimen?

- 1 yes →
- 2 no
- 3 unknown

42. What was the time duration IFN- γ was given?

- 1 known → months
- 2 not known

43. What was the date administration of IFN- γ was stopped?

- 1 known → / /
 - 2 not known
- Month Day Year

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44. Was any other drug given to treat osteopetrosis at any time prior to the preparative regimen?

- 1 yes
- 2 no
- 3 unknown

45. Specify other drug: _____

46. What was the time duration the drug was given?

- 1 known months
- 2 not known

47. What was the date administration of the drug was stopped?

- 1 known
- 2 not known

Month Day Year

48. Did the recipient undergo any red blood transfusions at any time prior to the preparative regimen?

- 1 yes
- 2 no
- 3 unknown

49. Specify the number of donor exposures (best estimate):

- 1 1-5
- 2 6-10
- 3 11-20
- 4 > 20
- 5 unknown

50. Did the recipient undergo any platelet transfusions at any time prior to the preparative regimen?

- 1 yes
- 2 no
- 3 unknown

51. Specify the number of donor exposures (best estimate):

- 1 1-5
- 2 6-10
- 3 11-20
- 4 > 20
- 5 unknown

52. Did the recipient undergo a bone marrow biopsy at any time prior to the preparative regimen?

- 1 yes
- 2 no
- 3 unknown

53. Specify the date the bone marrow biopsy was performed: date unknown

Month Day Year

54. Specify the bone marrow biopsy results:

- 1 normal
- 2 abnormal
- 3 unknown

Hematologic Findings Immediately Prior to the Preparative Regimen

55. Absolute lymphocyte count (untransfused):

- 1 known
- 2 not known

Specify units:

- 1 $\times 10^9/L$ ($\times 10^3/mm^3$)
- 2 $\times 10^6/L$

56. Absolute neutrophil count (ANC) (untransfused):

- 1 known
- 2 not known

- 1 $\times 10^9/L$ ($\times 10^3/mm^3$)
- 2 $\times 10^6/L$

57. Absolute monocyte count (untransfused):

- 1 known .
- 2 not known

- 1 $\times 10^9/L$ ($\times 10^3/mm^3$)
- 2 $\times 10^6/L$

58. Reticulocytes (untransfused):

- 1 known . %
- 2 not known

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59. Was a bone biopsy performed within 2 weeks prior to the preparative regimen?

- 1 yes
- 2 no
- 3 unknown

60. Specify number of osteoclasts in bone biopsy:

- 1 few / none
- 2 normal
- 3 increased
- 4 unknown

61. Signed: _____

Person completing form

Please print name: _____

Phone: (_____) _____

Fax: (_____) _____

E-mail address: _____