

Form 2136 R2.0: Osteopetrosis Post-HSCT Data

Center: CRID:

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):	
<input type="checkbox"/>	Autologous
<input type="checkbox"/>	Allogeneic, unrelated
<input type="checkbox"/>	Allogeneic, related
<input type="checkbox"/>	Syngeneic (identical twin)
Product type (check all that apply):	
<input type="checkbox"/>	Marrow
<input type="checkbox"/>	PBSC
<input type="checkbox"/>	Cord blood
<input type="checkbox"/>	Other product
Specify: _____	
Visit:	
<input type="checkbox"/>	100 day
<input type="checkbox"/>	6 months
<input type="checkbox"/>	1 year
<input type="checkbox"/>	2 years
<input type="checkbox"/>	> 2 years,
Specify: _____	

Disease Resolution Status		Questions: 1 - 25
1	What was the highest serum calcium value since the date of the last report?	
<input type="checkbox"/>	Known	<input type="checkbox"/> Not known
2	_____	
<input type="checkbox"/>	mg/dL	<input type="checkbox"/> mmol/L <input type="checkbox"/> mEq/L
3	What was the date the serum calcium value was tested since the date of last report?	
<input type="checkbox"/>	Known	<input type="checkbox"/> Not known
4	____-____-____	
5	Was hypercalcemia diagnosed at any time prior to this report?	
<input type="checkbox"/>	yes	<input type="checkbox"/> no <input type="checkbox"/> Unknown
6	Did hypercalcemia create a clinical problem necessitating intervention since the date of the last report?	
<input type="checkbox"/>	yes	<input type="checkbox"/> no <input type="checkbox"/> Unknown
7	Were any changes noted in a skeletal x-ray performed since the date of the last report?	
<input type="checkbox"/>	yes	<input type="checkbox"/> no <input type="checkbox"/> Unknown
8	Does the most recent x-ray indicate any current skeletal abnormalities?	
<input type="checkbox"/>	Yes	<input type="checkbox"/> no, x-ray is normal <input type="checkbox"/> Unknown

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9 Specify the status of current skeletal abnormalities compared to the status from the last report:

☐ abnormalities improved

☐ no change

☐ abnormalities worsened

☐ Unknown

10 Specify the date of the first skeletal x-ray which showed evidence of the current status:

☐ Known ☐ Not known

11 Date: ____ - ____ - ____

12 Specify the date of the first skeletal x-ray of normal status:

☐ Known ☐ Not known

13 Date: ____ - ____ - ____

14 Was a bone marrow biopsy performed since the date of the last report?

☐ yes ☐ no ☐ Unknown

15 Specify the date the bone marrow biopsy was performed:

☐ Known ☐ Not known

16 Date: ____ - ____ - ____

17 Specify the bone marrow biopsy results:

☐ Normal ☐ Abnormal ☐ Unknown

18 Specify the status of current bone marrow biopsy result compared to the results from the last report:

☐ abnormalities improved

☐ no change

☐ abnormalities worsened

☐ Unknown

19 Was splenomegaly diagnosed at any time prior to this report?

☐ yes ☐ no ☐ Unknown

20 Did splenomegaly normalize since the date of the the last report?

☐ yes ☐ no ☐ Unknown

21 Was groth delay diagnosed at any time prior to this report?

☐ yes ☐ no ☐ Unknown

22 Did growth rate improve since the date of the last report?

☐ yes ☐ no ☐ Unknown

23 Is a copy of current growth charts included with this report?

☐ yes ☐ no

24 Was a bone biopsy performed since the date of the last report?

☐ yes ☐ no ☐ Unknown

25 Specify the number of osteoclasts in bone biopsy:

☐ few / none ☐ Normal ☐ Increased ☐ Unknown

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Change in Clinical and Radiologic Findings Since the Last Report

Questions: 26 - 86

Specify the presence of the following clinical indicators of osteopetrosis:

26 Aplastic Anemia

- ☐ yes, previous diagnosis
- ☐ yes, first occurrence at this reporting period
- ☐ not diagnosed
- ☐ Unknown

27 Specify the change in status of aplastic anemia compared to results from last report:

- ☐ Improved ☐ no change ☐ worsened ☐ Unknown

28 Blindness / visual impairment

- ☐ yes, previous diagnosis
- ☐ yes, first occurrence at this reporting period
- ☐ not diagnosed
- ☐ Unknown

29 Specify the change in status of blindness / visual impairment compared to results from last report:

- ☐ Improved ☐ no change ☐ worsened ☐ Unknown

30 Convulsions

- ☐ yes, previous diagnosis
- ☐ yes, first occurrence at this reporting period
- ☐ not diagnosed
- ☐ Unknown

31 Specify the change in status of convulsions compared to results from last report:

- ☐ Improved ☐ no change ☐ worsened ☐ Unknown

32 Dentition problems

- ☐ yes, previous diagnosis
- ☐ yes, first occurrence at this reporting period
- ☐ not diagnosed
- ☐ Unknown

33 Specify the change in status of dentition problems compared to results from last report:

- ☐ Improved ☐ no change ☐ worsened ☐ Unknown

34 Exophthalmos

- ☐ yes, previous diagnosis
- ☐ yes, first occurrence at this reporting period
- ☐ not diagnosed
- ☐ Unknown

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35 Specify the change in status of exophthalmos compared to results from last report:

☐ Improved ☐ no change ☐ worsened ☐ Unknown

36 Fractures

- ☐ yes, previous diagnosis
- ☐ yes, first occurrence at this reporting period
- ☐ not diagnosed
- ☐ Unknown

37 Specify the change in status of fractures compared to results from last report:

☐ Improved ☐ no change ☐ worsened ☐ Unknown

38 Frontal bossing / prominent forehead

- ☐ yes, previous diagnosis
- ☐ yes, first occurrence at this reporting period
- ☐ not diagnosed
- ☐ Unknown

39 Specify the change in status of frontal bossing / prominent forehead compared to results from last report:

☐ Improved ☐ no change ☐ worsened ☐ Unknown

40 Gross motor delay

- ☐ yes, previous diagnosis
- ☐ yes, first occurrence at this reporting period
- ☐ not diagnosed
- ☐ Unknown

41 Specify the change in status of gross motor delay compared to results from last report:

☐ Improved ☐ no change ☐ worsened ☐ Unknown

42 Hearing impairment

- ☐ yes, previous diagnosis
- ☐ yes, first occurrence at this reporting period
- ☐ not diagnosed
- ☐ Unknown

43 Specify the change in status of hearing impairment compared to results from last report:

☐ Improved ☐ no change ☐ worsened ☐ Unknown

44 Height below 5th percentile

- ☐ yes, previous diagnosis
- ☐ yes, first occurrence at this reporting period
- ☐ not diagnosed
- ☐ Unknown

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45 Specify the change in status of height below 5th percentile compared to results from last report:

☐ Improved ☐ no change ☐ worsened ☐ Unknown

46 Hepatomegaly

- ☐ yes, previous diagnosis
- ☐ yes, first occurrence at this reporting period
- ☐ not diagnosed
- ☐ Unknown

47 Specify the change in status of hepatomegaly compared to results from last report:

☐ Improved ☐ no change ☐ worsened ☐ Unknown

48 Hypertelorism:

- ☐ yes, previous diagnosis
- ☐ yes, first occurrence at this reporting period
- ☐ not diagnosed
- ☐ Unknown

49 Specify the change in status of hypertelorism compared to results from last report:

☐ Improved ☐ no change ☐ worsened ☐ Unknown

50 Mental development delay

- ☐ yes, previous diagnosis
- ☐ yes, first occurrence at this reporting period
- ☐ not diagnosed
- ☐ Unknown

51 Specify the change in status of mental development delay compared to results from last report:

☐ Improved ☐ no change ☐ worsened ☐ Unknown

52 Nasal congestion

- ☐ yes, previous diagnosis
- ☐ yes, first occurrence at this reporting period
- ☐ not diagnosed
- ☐ Unknown

53 Specify the change in status of nasal congestion compared to results from last report:

☐ Improved ☐ no change ☐ worsened ☐ Unknown

54 Osteomyelitis

- ☐ yes, previous diagnosis
- ☐ yes, first occurrence at this reporting period
- ☐ not diagnosed
- ☐ Unknown

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55 Specify the change in status of osteomyelitis compared to results from last report:

☐ Improved ☐ no change ☐ worsened ☐ Unknown

56 Septicemia

- ☐ yes, previous diagnosis
- ☐ yes, first occurrence at this reporting period
- ☐ not diagnosed
- ☐ Unknown

57 Specify the change in status of septicemia compared to results from last report:

☐ Improved ☐ no change ☐ worsened ☐ Unknown

58 Skull circumference above 95th percentile

- ☐ yes, previous diagnosis
- ☐ yes, first occurrence at this reporting period
- ☐ not diagnosed
- ☐ Unknown

59 Specify the change in status of skull circumference compared to results from last report:

☐ Improved ☐ no change ☐ worsened ☐ Unknown

60 Splenomegaly

- ☐ yes, previous diagnosis
- ☐ yes, first occurrence at this reporting period
- ☐ not diagnosed
- ☐ Unknown

61 Specify the change in status of splenomegaly compared to results from last report:

☐ Improved ☐ no change ☐ worsened ☐ Unknown

62 Strabismus / nystagmus

- ☐ yes, previous diagnosis
- ☐ yes, first occurrence at this reporting period
- ☐ not diagnosed
- ☐ Unknown

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

☐ Improved ☐ no change ☐ worsened ☐ Unknown

64 Other hematologic impairment(s)

- ☐ yes, previous diagnosis
- ☐ yes, first occurrence at this reporting period
- ☐ not diagnosed
- ☐ Unknown

65 Specify the hematologic impairment _____

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66 Specify the change in status of the hematologic impairment compared to results from last report:

Improved no change worsened Unknown

67 Other clinical finding

yes, previous diagnosis
yes, first occurrence at this reporting period
not diagnosed
Unknown

68 Specify other clinical finding

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

Improved no change worsened Unknown

Specify the presence of the following radiologic indicators of osteopetrosis:

70 "Batman sign" / "sign du masque"

yes, previous diagnosis
yes, first occurrence at this reporting period
not diagnosed
Unknown

71 Specify the change in status of Batman sign compared to results from last report:

Improved no change worsened Unknown

72 Bone-in-bone sign

yes, previous diagnosis
yes, first occurrence at this reporting period
not diagnosed
Unknown

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

Improved no change worsened Unknown

74 Cerebral atrophy (by MRI or CT)

yes, previous diagnosis
yes, first occurrence at this reporting period
not diagnosed
Unknown

75 Specify the change in status of cerebral atrophy compared to results from last report:

Improved no change worsened Unknown

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76 Craniosynostosis

- ☐ yes, previous diagnosis
- ☐ yes, first occurrence at this reporting period
- ☐ not diagnosed
- ☐ Unknown

77 Specify the change in status of carniosynostosis compared to results from last report:

- ☐ Improved ☐ no change ☐ worsened ☐ Unknown

78 Hydrocephalus

- ☐ yes, previous diagnosis
- ☐ yes, first occurrence at this reporting period
- ☐ not diagnosed
- ☐ Unknown

79 Specify the change in status of hydrocephalus compared to results from last report:

- ☐ Improved ☐ no change ☐ worsened ☐ Unknown

80 Increased general skeletal sclerosis

- ☐ yes, previous diagnosis
- ☐ yes, first occurrence at this reporting period
- ☐ not diagnosed
- ☐ Unknown

81 Specify the change in status of sclerosis compared to results from last report:

- ☐ Improved ☐ no change ☐ worsened ☐ Unknown

82 Metaphyseal widening

- ☐ yes, previous diagnosis
- ☐ yes, first occurrence at this reporting period
- ☐ not diagnosed
- ☐ Unknown

83 Specify the change in status of metaphyseal widening compared to results from last report:

- ☐ Improved ☐ no change ☐ worsened ☐ Unknown

84 Other radiologic finding

- ☐ yes, previous diagnosis
- ☐ yes, first occurrence at this reporting period
- ☐ not diagnosed
- ☐ Unknown

85 Specify other radiologic findings _____

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

- ☐ Improved ☐ no change ☐ worsened ☐ Unknown

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Center:

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First Name: Last Name:

Phone: Fax:

E-mail address: