

Form 2036 R2.0: Osteopetrosis Pre-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: _____	

Osteopetrosis Pre-HSCT Data		Questions: 1 - 2
<input type="checkbox"/>	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? ____-____-____		
2 Specify the inheritance of osteopetrosis:		
<input type="checkbox"/>	autosomal recessive	
<input type="checkbox"/>	autosomal recessive with carbanhydrase II deficiency	
<input type="checkbox"/>	autosomal dominant	
<input type="checkbox"/>	Unknown	

Clinical and Radiological Findings Prior to the Preparative Regimen		Questions: 3 - 34
Specify the presence of the following clinical indicators of osteopetrosis:		
3 aplastic anemia		
<input type="checkbox"/>	yes	<input type="checkbox"/> no <input type="checkbox"/> Unknown
4 blindness / visual impairment		
<input type="checkbox"/>	yes	<input type="checkbox"/> no <input type="checkbox"/> Unknown
5 convulsions		
<input type="checkbox"/>	yes	<input type="checkbox"/> no <input type="checkbox"/> Unknown
6 dentition problems		
<input type="checkbox"/>	yes	<input type="checkbox"/> no <input type="checkbox"/> Unknown
7 exophthalmos		
<input type="checkbox"/>	yes	<input type="checkbox"/> no <input type="checkbox"/> Unknown
8 fractures		
<input type="checkbox"/>	yes	<input type="checkbox"/> no <input type="checkbox"/> Unknown

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9 frontal bossing / prominent forehead

☐ yes ☐ no ☐ Unknown

10 gross motor delay

☐ yes ☐ no ☐ Unknown

11 hearing impairment

☐ yes ☐ no ☐ Unknown

12 height below 5th percentile

☐ yes ☐ no ☐ Unknown

13 hepatomegaly

☐ yes ☐ no ☐ Unknown

14 hypertelorism

☐ yes ☐ no ☐ Unknown

15 mental development delay

☐ yes ☐ no ☐ Unknown

16 nasal congestion

☐ yes ☐ no ☐ Unknown

17 osteomyelitis

☐ yes ☐ no ☐ Unknown

18 septicemia

☐ yes ☐ no ☐ Unknown

19 skull circumference above 95th percentile

☐ yes ☐ no ☐ Unknown

20 splenomegaly

☐ yes ☐ no ☐ Unknown

21 strabismus / nystagmus

☐ yes ☐ no ☐ Unknown

22 other hematologic impairment(s)

☐ yes ☐ no ☐ Unknown

23 Specify hematologic impairment: \_\_\_\_\_

24 other clinical finding

☐ yes ☐ no ☐ Unknown

25 specify other finding \_\_\_\_\_

Specify the presense of the following radiologic indicators of osteopetrosis:

26 "Batman sign" / "sign du masque"

☐ yes ☐ no ☐ Unknown

27 bone-in-bone

☐ yes ☐ no ☐ Unknown

28 cerebral atrophy (by MRI or CT)

☐ yes ☐ no ☐ Unknown

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29 craniosynostosis

☐ yes ☐ no ☐ Unknown

30 hydrocephalus

☐ yes ☐ no ☐ Unknown

31 increased general skeletal sclerosis

☐ yes ☐ no ☐ Unknown

32 metaphyseal widening

☐ yes ☐ no ☐ Unknown

33 other radiologic finding

☐ yes ☐ no ☐ Unknown

34 specify other finding: \_\_\_\_\_

Disease Treatment Given Prior to the Preparative Regimen

Questions: 35 - 62

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

☐ yes ☐ no ☐ Unknown

36 What was the time duration calcitrol was given?

☐ Known ☐ Not known

37 \_\_\_\_\_ months

38 What was the date administration of calcitrol was stopped?

☐ Known ☐ Not known

39 \_\_\_\_-\_\_\_\_-\_\_\_\_

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

☐ yes ☐ no ☐ Unknown

41 What was the time duration corticosteroids were given?

☐ Known ☐ Not known

42 \_\_\_\_\_ months

43 What was the date administration of corticosteroids was stopped?

☐ Known ☐ Not known

44 \_\_\_\_-\_\_\_\_-\_\_\_\_

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

☐ yes ☐ no ☐ Unknown

46 What was the time duration IFN-γ was given?

☐ Known ☐ Not known

47 \_\_\_\_\_ months

48 What was the date administration of IFN-γ was stopped?

☐ Known ☐ Not known

49 \_\_\_\_-\_\_\_\_-\_\_\_\_

50 Was any other drug given to treat osteopetrosis at any time prior to preparative regimen?

☐ yes ☐ no ☐ Unknown

51 Specify other drug: \_\_\_\_\_

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52 What was the time duration the drug was given?

Known Not known

53 \_\_\_\_\_ months

54 What was the date administration of the drug was stopped?

Known Not known

55 \_\_\_\_ - \_\_\_\_ - \_\_\_\_

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

yes no Unknown

57 Specify the number of donor exposures (best estimate):

1-5 6-10 11-20 >20 Unknown

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

yes no Unknown

59 Specify the number of donor exposures (best estimate):

1-5 6-10 11-20 >20 Unknown

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

yes no Unknown

61 Specify the date the bone marrow biopsy was performed: \_\_\_\_ - \_\_\_\_ - \_\_\_\_ Date unknown

62 Specify the bone marrow biopsy results

Normal Abnormal Unknown

Hematologic Findings Immediately Prior to the Preparative Regimen

Questions: 63 - 72

63 Absolute lymphocyte count (untransfused):

Known Not known

64 \_\_\_\_\_ Unit: x 10<sup>9</sup>/L (x 10<sup>3</sup>/mm<sup>3</sup>) x 10<sup>6</sup>/L

65 Absolute neutrophil count (ANC) (untransfused)

Known Not known

66 \_\_\_\_\_ Unit: x 10<sup>9</sup>/L (x 10<sup>3</sup>/mm<sup>3</sup>) x 10<sup>6</sup>/L

67 Absolute monocyte count (untransfused):

Known Not known

68 \_\_\_\_\_ Unit: x 10<sup>9</sup>/L (x 10<sup>3</sup>/mm<sup>3</sup>) x 10<sup>6</sup>/L

69 Reticulocytes (untransfused):

Known Not known

70 \_\_\_\_\_ %

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

☐ yes ☐ no ☐ Unknown

72 Specify number of osteoclasts in bone biopsy:

☐ few / none ☐ Normal ☐ Increased ☐ Unknown

First Name: Last Name:

Phone: Fax:

E-mail address: