FOLLOW-UP INSERT XV
Osteopetrosis

FOR REGISTRY USE ONLY:
I.D. O – –
Date received:

TEAM:

IUBMID:
(Institutional Unique Blood or Marrow Transplant Identification Number)

Registry (circle one): IBMTR ABMTR EBMT

Date of transplant for which this form is being completed: Month Day Year

Date of report: Month Day Year

Follow-up Information*

**** Report data for date of last contact or immediately prior to death***

Status of Disease Resolution

1. Highest serum calcium value since last report: . 1 ❑ mg/dL 2 ❑ mmol/L 3 ❑ mEq/L 8 ❑ Unk

2. Date serum calcium tested: Month Day Year ❑ Unknown

3. Did hypercalcemia create a clinical problem which made intervention necessary since last report?
1 ❑ Yes
0 ❑ No
7 ❑ Not applicable
8 ❑ Unknown

4. Has skeletal X-ray changed since last report?
1 ❑ Yes
0 ❑ No
8 ❑ Unknown

5. Is skeletal X-ray normal?
1 ❑ Yes
6. Date of first normal X-ray: Month Day Year ❑ Unk
0 ❑ No
7. Compared to last report:
1 ❑ Improved 2 ❑ No change 3 ❑ Worse 8 ❑ Unknown
8 ❑ Unknown
8. Date of first X-ray showing evidence of current status: Month Day Year ❑ Unk

9. Was a bone marrow biopsy done since last report?
1 ❑ Yes
0 ❑ No
8 ❑ Unknown

10. Date of biopsy: Month Day Year ❑ Unknown

11. Is bone marrow biopsy normal?
1 ❑ Yes 0 ❑ No 8 ❑ Unknown

12. Indicate change in bone marrow biopsy compared to last biopsy:
1 ❑ Improved 2 ❑ No change 3 ❑ Worse 8 ❑ Unknown

13. Did spleen size normalize since last report?
1 ❑ Yes
0 ❑ No
7 ❑ N/A, no splenomegaly at last report
8 ❑ Unknown

TEAM: | | | | | IUBMID: | | | | | | |

Status of Disease Resolution *(continued)*

14. Did growth rate improve since last report?

1 ❑ Yes
0 ❑ No
7 ❑ N/A, no growth delay at last report
8 ❑ Unknown

If more recent Growth Curves are available, check here ❑, attach copy and reference Q.14

15. Was a bone biopsy performed since last report?

1 ❑ Yes
0 ❑ No
8 ❑ Unknown

16. Specify osteoclast numbers:
1 ❑ Few/None 2 ❑ Normal 3 ❑ Increased 8 ❑ Unknown

Indicate Change in Clinical Findings Since Last Report

	Improved	No Change	Worse	1st Occurred This Report	Not Evident Pre- & Post-Tx	Unknown	
17.	1❑	2❑	3❑	4❑	7❑	8❑	Aplastic Anemia
18.	1❑	2❑	3❑	4❑	7❑	8❑	Blindness/Visual Impairment
19.	1❑	2❑	3❑	4❑	7❑	8❑	Convulsions
20.	1❑	2❑	3❑	4❑	7❑	8❑	Dentition problems
21.	1❑	2❑	3❑	4❑	7❑	8❑	Exophthalmos
22.	1❑	2❑	3❑	4❑	7❑	8❑	Fractures
23.	1❑	2❑	3❑	4❑	7❑	8❑	Frontal bossing/Prominent forehead
24.	1❑	2❑	3❑	4❑	7❑	8❑	Gross motor delay
25.	1❑	2❑	3❑	4❑	7❑	8❑	Hearing impairment
26.	1❑	2❑	3❑	4❑	7❑	8❑	Height below 5th percentile
27.	1❑	2❑	3❑	4❑	7❑	8❑	Hepatomegaly
28.	1❑	2❑	3❑	4❑	7❑	8❑	Hypertelorism
29.	1❑	2❑	3❑	4❑	7❑	8❑	Mental development delay
30.	1❑	2❑	3❑	4❑	7❑	8❑	Nasal congestion
31.	1❑	2❑	3❑	4❑	7❑	8❑	Osteomyelitis
32.	1❑	2❑	3❑	4❑	7❑	8❑	Septicemia
33.	1❑	2❑	3❑	4❑	7❑	8❑	Skull circumference above 95th percentile
34.	1❑	2❑	3❑	4❑	7❑	8❑	Splenomegaly
35.	1❑	2❑	3❑	4❑	7❑	8❑	Strabismus/Nystagmus
36.	1❑	2❑	3❑	4❑	7❑	8❑	Other hematologic impairment(s), if *yes* specify: _____
37.	1❑	2❑	3❑	4❑	7❑	8❑	Other, if *yes* specify: _____

Indicate Change in Radiologic Findings Since Last Report

	Improved	No Change	Worse	1st Occurred This Report	Not Evident Pre- & Post-Tx	Unknown	
38.	1❑	2❑	3❑	4❑	7❑	8❑	"Batman sign"/"Sign du masque"
39.	1❑	2❑	3❑	4❑	7❑	8❑	Bone-in-bone
40.	1❑	2❑	3❑	4❑	7❑	8❑	Cerebral atrophy (by MRI or CT)
41.	1❑	2❑	3❑	4❑	7❑	8❑	Craniosynostosis
42.	1❑	2❑	3❑	4❑	7❑	8❑	Hydrocephalus
43.	1❑	2❑	3❑	4❑	7❑	8❑	Increased general skeletal sclerosis
44.	1❑	2❑	3❑	4❑	7❑	8❑	Metaphyseal widening
45.	1❑	2❑	3❑	4❑	7❑	8❑	Other, if *yes* specify: _____