ERROR CORRECTION FORM

Sequence Number: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐

CIBMTR Recipient ID: ☐☐☐☐☐☐☐☐☐

Visit:
☐ 100 day
☐ 6 month
☐ ☐☐ year

Today's Date: ☐☐ Month ☐☐ Day 2 0 ☐☐ Year

Infusion Date: ☐☐ Month ☐☐ Day 2 0 ☐☐ Year

CIBMTR Center Number: ☐☐☐☐☐

Initials: ☐☐☐

CIBMTR®
CENTER FOR INTERNATIONAL BLOOD & MARROW TRANSPLANT RESEARCH

Leukodystrophies Post-HSCT Data

Registry Use Only

Sequence Number: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Date Received: ☐☐ Month ☐☐ Day ☐☐☐☐ Year

CIBMTR Center Number: ☐☐☐☐☐

CIBMTR Recipient ID: ☐☐☐☐☐☐☐☐☐☐

Today's Date: ☐☐ Month ☐☐ Day 2 0 ☐☐ 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.

1. For which type of leukodystrophy was the transplant performed?

1 ☐ globoid cell leukodystrophy →

2. Specify the leukocyte galactocerebrosidase enzyme activity since the date of the last report: ☐☐☐.☐
1 ☐ nmol/hr/mg protein
2 ☐ pmol/hr/mg protein

3. Date tested: ☐☐ Month ☐☐ Day 2 0 ☐☐ Year ☐ date unknown

2 ☐ metachromatic leukodystrophy →

4. Specify the leukocyte arylsulfatase A enzyme activity since the date of the last report: ☐☐☐.☐
1 ☐ nmol/hr/mg protein
2 ☐ pmol/hr/mg protein

5. Date tested: ☐☐ Month ☐☐ Day 2 0 ☐☐ Year ☐ date unknown

3 ☐ adrenoleukodystrophy

For 100-day follow-up reports, only questions 1–6 are required. Please sign below and submit only page 1 of this form. For all visits beyond 100 days post-HSCT, continue with question 7.

6. Signed: _____
Person completing form

Please print name: _____

Phone number: (_____) _____

Fax number: (_____) _____

E-mail address: _____

CIBMTR Form 2137 (LDS) v1.0 (1–5) July 2007

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

Fax this form to your designated campus (Milwaukee 414-805-0714 or Minneapolis 612-627-5895).

ERROR CORRECTION FORM

Sequence Number:

CIBMTR Recipient ID:

Visit:
☐ 100 day
☐ 6 month
☐ ____ year

Today's Date: Month ____ Day ____ Year 20____

Infusion Date: Month ____ Day ____ Year 20____

CIBMTR Center Number:

Initials:

CIBMTR Center Number:

CIBMTR Recipient ID:

Clinical Status Post-HSCT

7. Is there a history of post-HSCT seizures attributed to the underlying disease since the date of the last report?
   1 ☐ yes
   2 ☐ no
   3 ☐ unknown

8. Was cerebrospinal fluid (CSF) testing performed since the date of the last report?
   1 ☐ yes →
   2 ☐ no
   3 ☐ unknown

   Specify the results of most recent tests:

   9. Date of most recent test:
      1 ☐ known → Month ____ Day ____ Year 20____
      2 ☐ not known

   10. Opening pressure:
      1 ☐ known → ____ cm H_2O
      2 ☐ not known

   11. Closing pressure:
      1 ☐ known → ____ cm H_2O
      2 ☐ not known

   12. Total protein:
      1 ☐ known → ____.____
      2 ☐ not known
      1 ☐ mg/dL
      2 ☐ g/L

13. Was Magnetic Resonance Imaging (MRI) performed since the date of the last report?
   1 ☐ yes →
   2 ☐ no
   3 ☐ unknown

   14. Date of most recent MRI:
      1 ☐ known → Month ____ Day ____ Year 20____
      2 ☐ not known

   15. Specify MRI results:
      1 ☐ normal
      2 ☐ abnormal

   16. Is a copy of the MRI report attached?
      1 ☐ yes
      2 ☐ no

17. Was Magnetic Resonance Spectroscopy performed since the date of the last report?
   1 ☐ yes →
   2 ☐ no
   3 ☐ unknown

   18. Date of most recent test:
      1 ☐ known → Month ____ Day ____ Year 20____
      2 ☐ not known

   19. Specify test results:
      1 ☐ normal
      2 ☐ abnormal

   20. Is a copy of the report attached?
      1 ☐ yes
      2 ☐ no

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ERROR CORRECTION FORM

Sequence Number:

CIBMTR Recipient ID:

Visit:
☐ 100 day
☐ 6 month
☐ ____ year

Today's Date: Month ____ Day ____ Year 20____

Infusion Date: Month ____ Day ____ Year 20____

CIBMTR Center Number:

Initials:

CIBMTR Center Number:

CIBMTR Recipient ID:

21. Were nerve conduction velocities tested since the date of the last report?
1 ☐ yes →
2 ☐ no
3 ☐ unknown

22. Date of most recent test:
1 ☐ known → Month ____ Day ____ Year 20____
2 ☐ not known

23. Specify median nerve conduction velocity: ____ m/sec

24. Specify peroneal nerve conduction velocity: ____ m/sec

25. Specify results:
1 ☐ normal
2 ☐ abnormal / impaired

26. Is a copy of the report attached?
1 ☐ yes
2 ☐ no

27. Was a Mental Development test performed since the date of the last report?
1 ☐ yes →
2 ☐ no
3 ☐ unknown

28. Date of most recent test:
1 ☐ known → Month ____ Day ____ Year 20____
2 ☐ not known

29. Specify the test instrument used:
1 ☐ Bayley Scales of Infant Development
2 ☐ Stanford Binet Intelligence Scale
3 ☐ Wechsler Preschool and Primary Scale of Intelligence (WPPSI – Revised)
4 ☐ Wechsler Intelligence Scale for Children – III (WISC – III)
5 ☐ other test → 30. Specify: _____

31. Full scale score (not percentile):
1 ☐ known → ____
2 ☐ not known

32. Verbal score (not percentile):
1 ☐ known → ____
2 ☐ not known

33. Performance score (not percentile):
1 ☐ known → ____
2 ☐ not known

34. Were the Vineland Adaptive Behavior Scales performed since the date of the last report?
1 ☐ yes →
2 ☐ no
3 ☐ unknown

35. Date of most recent test:
1 ☐ known → Month ____ Day ____ Year 20____
2 ☐ not known

36. Communication skills score:
1 ☐ known → ____
2 ☐ not known

37. Daily Living skills score:
1 ☐ known → ____
2 ☐ not known

38. Socialization skills score:
1 ☐ known → ____
2 ☐ not known

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Sequence Number:

CIBMTR Recipient ID:

Visit:
☐ 100 day
☐ 6 month
☐ ____ year

Today's Date: Month ____ Day ____ Year 20____

Infusion Date: Month ____ Day ____ Year 20____

CIBMTR Center Number:

Initials:

CIBMTR Center Number:

CIBMTR Recipient ID:

39. Was the recipient's visual acuity tested since the date of the last report?
1 ☐ yes →
2 ☐ no
3 ☐ unknown

40. Is the recipient blind?
1 ☐ yes
2 ☐ no →

41. Date of most recent visual acuity test:
1 ☐ known → Month ____ Day ____ Year 20____
2 ☐ not known

42. Visual acuity of right eye (OD): *(uncorrected vision)*
1 ☐ known → ____ / ____
2 ☐ not known

43. Visual acuity of left eye (OS): *(uncorrected vision)*
1 ☐ known → ____ / ____
2 ☐ not known

44. Visual acuity of both eyes (OU): *(uncorrected vision)*
1 ☐ known → ____ / ____
2 ☐ not known

45. Did the recipient undergo an opthalmologic exam under anesthesia since the date of the last report?
1 ☐ yes →
2 ☐ no
3 ☐ unknown

46. Date of most recent exam:
1 ☐ known → Month ____ Day ____ Year 20____
2 ☐ not known

47. Specify results:
1 ☐ normal
2 ☐ abnormal / impaired

48. Is a copy of the report attached?
1 ☐ yes
2 ☐ no

49. Was an audiologic evaluation (auditory brain stem or conditioned response) performed since the date of the last report?
1 ☐ yes →
2 ☐ no
3 ☐ unknown

50. Date of most recent evaluation:
1 ☐ known → Month ____ Day ____ Year 20____
2 ☐ not known

Specify tympanometry results:
51. 1 ☐ normal 2 ☐ retracted 3 ☐ flat Right ear
52. 1 ☐ normal 2 ☐ retracted 3 ☐ flat Left ear

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Visit:
☐ 100 day
☐ 6 month
☐ ____ year

Today's Date: Month / Day / 20__ Year

Infusion Date: Month / Day / 20__ Year

CIBMTR Center Number:

Initials:

CIBMTR Center Number:

CIBMTR Recipient ID:

53. Was the hearing loss (HL) in decibels (dB) assessed at the speech threshold for 500 hertz (HZ) since the date of the last report?

1 ☐ yes →
2 ☐ no
3 ☐ unknown

54. Date of most recent evaluation:
1 ☐ known → Month / Day / 20__ Year
2 ☐ not known

Specify tympanometry results: *(See Degree of Hearing Loss chart below for scale ranges.)*

55. 1 ☐ normal / mild 2 ☐ moderate / moderately severe 3 ☐ severe / profound Right ear

56. 1 ☐ normal / mild 2 ☐ moderate / moderately severe 3 ☐ severe / profound Left ear

57. Was the hearing loss (HL) in decibels (dB) assessed at the speech threshold for 2000 hertz (HZ) since the last report?

1 ☐ yes →
2 ☐ no
3 ☐ unknown

58. Date of most recent evaluation:
1 ☐ known → Month / Day / 20__ Year
2 ☐ not known

Specify tympanometry results: *(See Degree of Hearing Loss chart below for scale ranges.)*

59. 1 ☐ normal / mild 2 ☐ moderate / moderately severe 3 ☐ severe / profound Right ear

60. 1 ☐ normal / mild 2 ☐ moderate / moderately severe 3 ☐ severe / profound Left ear

Degree of Hearing Loss: Pure Tones and Speech Testing

Normal:	0–20 dB HL	Moderate:	45–55 dB HL	Severe:	75–90 dB HL
Mild:	25–40 dB HL	Moderately Severe:	60–70 dB HL	Profound:	> 90 dB HL

61. Has there been a change in the recipient's neurologic status since the date of the last report?
(Report clinical status, not neuropsychological status.)

1 ☐ yes →
2 ☐ stable / unchanged
3 ☐ unknown

62. Specify current neurologic status compared to previous report:
1 ☐ improved
2 ☐ worsened

63. Is a copy of the physical exam or neurologic exam attached?
1 ☐ yes
2 ☐ no

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