Form 2137 R2.0: Leukodystrophies 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)

- Autologous
- Allogeneic, unrelated
- Allogeneic, related
- Syngeneic (identical twin)

Product type: (check all that apply)

- Marrow
- PBSC
- Cord blood
- Other product

  Specify: _____

Visit:

- 100 day
- 6 months
- 1 year
- 2 years
- > 2 years,

  Specify: _____

Leukodystrophies Post-HSCT Data	Questions: 1 - 5

1 For which type of leukodystrophy was the transplant performed?

- globoid cell leukodystrophy (Krabbe Disease)
- metachromatic leukodystrophy (MLD)
- adrenoleukodystrophy (ALD)

2 Specify the leudocyte galactocerebrosidase enzyme activity since the date of the last report: _____ Unit:
- nmol/hr/mg protein
- pmol/hr/mg protein

3 Date tested: __ __ __ __ - __ __- __ __   Date unknown

4 Specify the leukocyte arylsulfatase A enzyme activity since the date of the last report: _____ Unit:
- nmol/hr/mg protein
- pmol/hr/mg protein

5 Date tested: __ __ __ __ - __ __- __ __   Date unknown

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

First Name: _____ Last Name: _____

Phone number: _____ Fax number: _____

E-mail address: _____

Clinical Status Post-HSCT	Questions: 6 - 85

6 Is there a history of post-HSCT seizures attributed to the underlying disease since the date of the last report?

- yes
- no
- Unknown

7 Was cerebrospinal fluid(CSF) testing performed since the date of the last report?

☐ yes ☐ no ☐ Unknown

Specify the results of most recent tests:

8 Date of most recent test:

☐ Known ☐ Not known

9 CSF test date __ __ __ __ - __ __- __ __

10 Opening pressure:

☐ Known ☐ Not known

11 _____ cm H$_2$O

12 Closing pressure

☐ Known ☐ Not known

13 _____ cm H$_2$O

14 Total protein:

☐ Known ☐ Not known

15 total protein result _____ Total protein: ☐ mg/dL ☐ g/L

16 Was Magnetic Resonance Imaging (MRI) performed since the date of the last report?

☐ yes ☐ no ☐ Unknown

17 Date of most recent MRI:

☐ Known ☐ Not known

18 __ __ __ __ - __ __- __ __

19 Specify MRI results:

☐ Normal ☐ Abnormal

20 Is a copy of the MRI report attached?

☐ yes ☐ no

21 Was Magnetic Resonance Spectroscopy performed since the date of the last report?

☐ yes ☐ no ☐ Unknown

22 Date of most recent test:

☐ Known ☐ Not known

23 __ __ __ __ - __ __- __ __

24 Specify test results:

☐ Normal ☐ Abnormal

25 Is a copy of the report attached?

☐ yes ☐ no

26 Were nerve conduction velocities tested since the date of the last report?

☐ yes ☐ no ☐ Unknown

27 Date of most recent test:

☐ Known ☐ Not known

28 __ __ __ __ - __ __- __ __

29 Specify median nerve conduction velocity: _____ m/sec

30 Specify peroneal nerve conduction velocity: _____ m/sec

31 Specify results:

☐ Normal ☐ Abnormal

32 Is a copy of the report attached?

☐ yes ☐ no

33 Was a Mental Development test performed since the date of the last report?

☐ yes ☐ no ☐ Unknown

34 Date of most recent test:

☐ Known ☐ Not known

35 __ __ __ __ - __ __ - __ __

36 Specify the test instrument used:

☐ Bayley Scales of Infant Development

☐ Stanford Binet Intelligence Scale

☐ Wechsler Preschool and Primary Scale of Intelligence (WPPSI - Revised)

☐ Wechsler Intelligence Scale for Children - III (WISC - III)

☐ other test

37 Specify : _____

38 Full scale score (not percentile):

☐ Known ☐ Not known

39 Score: _____

40 Verbal score(not percentile):

☐ Known ☐ Not known

41 Score: _____

42 Performance score(not percentile):

☐ Known ☐ Not known

43 Score: _____

44 Were the Vineland Adaptive Behavior Scales performed since the date of the last report?

☐ yes ☐ no ☐ Unknown

45 Date of most recent test:

☐ Known ☐ Not known

46 __ __ __ __ - __ __ - __ __

47 Communication skills score:

☐ Known ☐ Not known

48 Score: _____

49 Daily Living skills score:

☐ Known ☐ Not known

50 Score: _____

51 Socialization skills score:

☐ Known ☐ Not known

52 Score: _____

53 Was the recipient's visual acuity tested since the date of the last report?

☐ yes   ☐ no   ☐ Unknown

54 Is the recipient blind?

☐ yes   ☐ no

55 Date of most recent visual acuity test:

☐ Known   ☐ Not known

56 __ __ __ __ - __ __ - __ __

57 Visual acuity of right eye (OD): (uncorrected vision)

☐ Known   ☐ Not known

58 _____ / _____

59 Visual acuity of left eye (OS): (uncorrected vision)

☐ Known   ☐ Not known

60 _____ / _____

61 Visual acuity of both eyes (OU): (uncorrected vision)

☐ Known   ☐ Not known

62 _____ / _____

63 Did the recipient undergo an opthalmologic exam under anesthesia since the date of the last report?

☐ yes   ☐ no   ☐ Unknown

64 Date of most recent exam:

☐ Known   ☐ Not known

65 __ __ __ __ - __ __ - __ __

66 Specify results:

☐ Normal   ☐ abnormal/impaired

67 Is a copy of the report attached?

☐ yes   ☐ no

68 Was an audiologic evaluation (auditory brain stem or conditioned response) performed since the date of the last report?

☐ yes   ☐ no   ☐ Unknown

69 Date of most recent evaluation:

☐ Known   ☐ Not known

70 __ __ __ __ - __ __ - __ __

Specify tympanometry results:

71 Right ear

☐ Normal   ☐ retracted   ☐ flat

72 Left ear

☐ Normal   ☐ retracted   ☐ flat

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

☐ yes   ☐ no   ☐ Unknown

74 Date of most recent evaluation:

☐ Known   ☐ Not known

75 __ __ __ __ - __ __ - __ __

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Center: CRID:

Specify tympanometry results:

76 Right ear

☐ normal/mild (0-20dB HL / 25-40 dB HL)

☐ moderate/moderately severe (45-55 dB HL / 60-70 dB HL)

☐ severe/profound (75-90 dB HL / >90 dB HL)

77 Left ear

☐ normal/mild (0-20dB HL / 25-40 dB HL)

☐ moderate/moderately severe (45-55 dB HL / 60-70 dB HL)

☐ severe/profound (75-90 dB HL / >90 dB HL)

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

☐ yes   ☐ no   ☐ Unknown

79 Date of most recent evaluation:

☐ Known   ☐ Not known

80   __ __ __ __ - __ __ - __ __

Specify tympanometry results:

81 Right ear

☐ normal/mild (0-20 dB HL/25-40 db HL)

☐ moderate/moderately severe (45-55 dB HL/60-70 db HL)

☐ severe/profound (75-90 dB HL/>90 db HL)

82 Left ear

☐ normal/mild (0-20 dB HL/25-40 db HL)

☐ moderate/moderately severe (45-55 dB HL/60-70 db HL)

☐ severe/profound (75-90 dB HL/>90 db HL)

83 Has there been a change in the recipient's neurologic status since the date of the last report?

☐ Yes

☐ stable/ unchanged

☐ Unknown

84 Specify current neurological status compared to previous report:

☐ Improved   ☐ worsened

85 Is a copy of the physical exam or neurological exam attached?

☐ yes   ☐ no