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

- [ ] globoid cell leukodystrophy
- [ ] metachromatic leukodystrophy
- [ ] adrenoleukodystrophy

2. Specify the leukocyte galactocerebrosidase enzyme activity since the date of the last report:

   - [ ] nmol/hr/mg protein
   - [ ] pmol/hr/mg protein

   Date tested: __________ Month Day Year

   Date unknown

3. Date tested: __________ Month Day Year

4. Specify the leukocyte arylsulfatase A enzyme activity since the date of the last report:

   - [ ] nmol/hr/mg protein
   - [ ] pmol/hr/mg protein

   Date tested: __________ Month Day Year

   Date unknown

5. Date tested: __________ Month Day Year

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.
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
   2) not known

10. Opening pressure:
    1) known
    2) not known

11. Closing pressure:
    1) known
    2) not known

12. Total protein:
    1) known
    2) not known

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
    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
    2) not known

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

20. Is a copy of the report attached?
    1) yes
    2) no
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
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
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
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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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
   2. [ ] not known

   [ ] Month
   [ ] Day
   [ ] 20
   [ ] Year

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 ophthalmologic exam under anesthesia since the date of the last report?
   1. [ ] yes
   2. [ ] no
   3. [ ] unknown

46. Date of most recent exam:
   1. [ ] known
   2. [ ] not known

   [ ] Month
   [ ] Day
   [ ] 20
   [ ] Year

47. Specify results:
   1. [ ] normal
   2. [ ] abnormal / impaired

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

50. Date of most recent evaluation:
    1. [ ] known
    2. [ ] not known

    [ ] Month
    [ ] Day
    [ ] 20
    [ ] Year

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