



CIBMTR Center Number:

CIBMTR Recipient ID:

9. Donor result:

- 1  known →    .  1  nmol/hr/mg protein  
2  not known 2  pmol/hr/mg protein

3  adrenoleuko-  
dystrophy →

10. Mean fasting plasma very-long-chain fatty acid (VLCFA) C26:0 level at diagnosis:

- 1  known →  .    μg/mL  
2  not known

11. Was the acid level measured within two weeks prior to the preparative regimen?

- 1  yes →  
2  no  
3  unknown

12. Date recipient tested:        
Month Day Year

13. Plasma level:  .    μg/mL

14. Was treatment given for adrenal insufficiency between diagnosis and HSCT?

- 1  yes →  
2  no  
3  unknown

Specify adrenal insufficiency:

15. 1  yes 2  no 3  unknown Glucocorticoid

16. 1  yes 2  no 3  unknown Mineralocorticoid

17. Was treatment given to lower plasma very-long-chain fatty acids at any time prior to HSCT?

- 1  yes →  
2  no  
3  unknown

Specify treatment(s):

18. 1  yes 2  no 3  unknown 4-phenylbutyrate

19. 1  yes 2  no 3  unknown GTE:GTO oil (Lorenzo's oil)

20. 1  yes 2  no 3  unknown Lovastatin or related compound

21. 1  yes 2  no 3  unknown Other →

22. Specify:  
\_\_\_\_\_

23. Donor's mean fasting VLCFA C26:0 level:

- 1  known →  .    μg/mL  
2  not known

### Clinical Status Prior to the Preparative Regimen

24. Is there a history of seizures at any time prior to the preparative regimen?

- 1  yes  
2  no  
3  unknown

25. Was cerebrospinal fluid (CSF) testing done prior to the preparative regimen?

- 1  yes →  
2  no  
3  unknown

Specify results of most recent tests:

26. Date of most recent testing:        
Month Day Year

27. Opening pressure:    .  cm H<sub>2</sub>O  
1  known →  
2  not known

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28. Closing pressure:  
1  known →  .  cm H<sub>2</sub>O  
2  not known

29. Total protein:  
1  known →  .  1  mg/dL  
2  not known 2  g/L

30. Was Magnetic Resonance Imaging (MRI) performed at any time prior to the preparative regimen?

- 1  yes →
- 2  no
- 3  unknown

31. Date of most recent test prior to the preparative regimen:  /  /   
Month Day Year

32. Specify MRI results:  
1  normal  
2  abnormal  
3  not known

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

34. Was Magnetic Resonance Spectroscopy performed at any time prior to the preparative regimen?

- 1  yes →
- 2  no
- 3  unknown

35. Date of most recent test prior to the preparative regimen:  /  /   
Month Day Year

36. Specify MRS results:  
1  normal  
2  abnormal  
3  not known

37. Is a copy of the MRS report attached?  
1  yes  
2  no

38. Were nerve conduction velocities tested at any time prior to the preparative regimen?

- 1  yes →
- 2  no
- 3  unknown

39. Date of most recent test prior to the preparative regimen:  /  /   
Month Day Year

40. Specify results:  
1  normal  
2  abnormal / impaired  
3  not known

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

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42. Was a Mental Development test administered at any time prior to the preparative regimen?

- 1  yes
- 2  no
- 3  unknown

43. Date of most recent test prior to the preparative regimen:     
Month Day Year

44. Specify test instrument administered:

- 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

45. Specify other test:

46. Full scale score: *(not percentile)*

- 1  known
- 2  not known

47. Performance score: *(not percentile)*

- 1  known
- 2  not known

48. Verbal score: *(not percentile)*

- 1  known
- 2  not known

49. Were the Vineland Adaptive Behavior Scales administered at any time prior to the preparative regimen?

- 1  yes
- 2  no
- 3  unknown

50. Date of most recent test prior to the preparative regimen:     
Month Day Year

51. Communication skills:

- 1  known
- 2  not known

52. Daily living skills

- 1  known
- 2  not known

53. Socialization skills

- 1  known
- 2  not known

54. Was visual acuity tested at any time prior to the preparative regimen?

- 1  yes
- 2  no
- 3  unknown

55. Is the recipient blind?

- 1  yes
- 2  no

56. Date of most recent test prior to the preparative regimen:

Month Day Year

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

- 1  known  /
- 2  not known

58. Visual acuity of left eye (OS): *(uncorrected vision)*

- 1  known  /
- 2  not known

59. Visual acuity of both eyes (OU): *(uncorrected vision)*

- 1  known  /
- 2  not known

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60. Did the recipient undergo an ophthalmologic exam under anesthesia at any time prior to the preparative regimen?

- 1  yes
- 2  no
- 3  unknown

61. Date of most recent test prior to the preparative regimen:

Month                      Day                      Year

62. Specify results:

- 1  normal
- 2  abnormal / impaired
- 3  not known

63. Is a copy of the report attached?

- 1  yes
- 2  no

64. Was the hearing loss (HL) in decibels (dB) assessed at the speech threshold for 500 hertz (HZ) at any time prior to the preparative regimen?

- 1  yes
- 2  no
- 3  unknown

65. Date of most recent evaluation:

- 1  known
- 2  not known

       

Month                      Day                      Year

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

66. 1  normal / mild    2  moderate / moderately severe    3  severe / profound    Right ear

67. 1  normal / mild    2  moderate / moderately severe    3  severe / profound    Left ear

68. Was the hearing loss (HL) in decibels (dB) assessed at the speech threshold for 2000 hertz (HZ) at any time prior to the preparative regimen?

- 1  yes
- 2  no
- 3  unknown

69. Date of most recent evaluation:

- 1  known
- 2  not known

       

Month                      Day                      Year

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

70. 1  normal / mild    2  moderate / moderately severe    3  severe / profound    Right ear

71. 1  normal / mild    2  moderate / moderately severe    3  severe / profound    Left ear

72. Signed: \_\_\_\_\_

*Person completing form*

Please print name: \_\_\_\_\_

Phone: (\_\_\_\_\_) \_\_\_\_\_

Fax: (\_\_\_\_\_) \_\_\_\_\_

E-mail address: \_\_\_\_\_