

National Marrow Donor Program®
Insert V – Leukodystrophies
Annual Follow-up Visit of
Recipient

Registry Use Only

Sequence
Number:

Date
Received:

Unrelated

Recipient NMDP ID: - -

Recipient Last Name:

Recipient Local ID (optional):

Today's Date: / / TC Code:

Month Day Year

Date of Transplant for which this form is being completed: / /

Month Day Year

Visit: Form 140 — 1 year 2 year
 Form 150 — year

Product type: Marrow (Form 140/150) PBSC (Form 540/550) Cord blood (Form 640/650)

This form must be accompanied by Form 140, 540, 640 – 6-Month to 2-Year Follow-Up Visit or Form 150, 550, 650 – Yearly Follow-Up Greater Than Two Years Post-Transplant. All information in the form above, including the date, should be identical with the corresponding Form 140/150, 540/550, 640/650. Information should come from an actual examination by the Transplant Center physician, or the physician who is following the recipient post transplant, or abstraction of the recipient's medical records.

1. For which type of leukodystrophy was the transplant performed

Globoid Cell
Leukodystrophy →

2. Report the leukocyte arylsulphatase enzyme activity as determined at the most recent follow-up evaluation.

Result: • 1 nmol/hr/mg protein 2 pmol/hr/mg protein

Date tested: / /

Month Day Year

Metachromatic
Leukodystrophy →

3. Report the leukocyte arylsulfatase A enzyme activity as determined at the most recent follow-up evaluation:

Result: • 1 nmol/hr/mg protein 2 pmol/hr/mg protein

Date tested: / /

Month Day Year

Adrenoleuko-
dystrophy →

4. Report the mean fasting plasma very-long-chain fatty acid (VLCFA) C26:0 as determined at the most recent follow-up evaluation:

Plasma level: • μg/mL

Date tested: / /

Month Day Year

Recipient NMDP ID: - -

Recipient Last Name:

Clinical Status Post-Transplant

5. Is there a history of post-transplant seizures attributed to the underlying disease since the last report?

- 1 yes
- 2 no
- 3 unknown

6. Was cerebrospinal fluid (CSF) testing done since the last report?

- 1 yes
- 2 no
- 3 unknown

7. Report results of most recent tests:

a. Opening pressure

- 1 yes cm H₂O
- 2 no
- 3 unknown

b. Total protein

- 1 yes . 1 mg/dL 2 g/L
- 2 no
- 3 unknown

c. Serum albumin

- 1 yes . 1 mg/dL 2 g/L
- 2 no
- 3 unknown

d. Serum IgG

- 1 yes . 1 mg/dL 2 g/L
- 2 no
- 3 unknown

8. Date of most recent test:

Month Day Year

9. Was Magnetic Resonance Imaging (MRI) done since the last report?

- 1 normal
- 2 abnormal
- 3 unknown/not done

10. Date of most recent report:

(If possible, attach a copy of the report.)

Month Day Year

11. Magnetic Resonance Spectroscopy results since the last report:

- 1 normal
- 2 abnormal
- 3 unknown/not done

12. Date of most recent test:

(If possible, attach a copy of the report.)

Month Day Year

13. Were nerve conduction velocities tested since the last report?

- 1 yes
- 2 no
- 3 unknown

14. Specify nerve conduction velocities:

a. Median nerve: m/sec

b. Peroneal nerve: m/sec

15. Date of most recent test:

Month Day Year

Recipient NMDP ID: - -

Recipient Last Name:

16. Was a Mental Development test done since the last report?

- 1 yes
2 no
3 unknown

17. Indicate test instrument; report results of most recent test; report score, not percentile:

- 1 Bayley Scales of Infant Development
2 Stanford Binet Intelligence Scale 4th ed
3 Wechsler Preschool and Primary Scale of Intelligence (WPPSI – Revised)
4 Wechsler Intelligence Scale for Children – III (WISC – III)
5 Other, specify: _____

18. Date of most recent test: / /
Month Day Year

19. Full scale score:

20. Verbal score:

21. Performance score:

22. Were the Vineland Adaptive Behavior Scales done since the last report?

- 1 yes
2 no
3 unknown

23. Score results:

a. Communication skills:

b. Daily living skills:

c. Socialization skills:

24. Date of most recent test: / /
Month Day Year

25. Was visual acuity tested since the last report?

- 1 yes
2 no
3 unknown

26. Is patient blind?

- 1 yes
2 no

27. Visual acuity:

a. Right eye: /

b. Left eye: /

28. Date of most recent test: / /
Month Day Year

29. Was an audiologic evaluation (auditory brain stem or conditioned response) done since the last report?

- 1 yes
2 no
3 unknown

30. Tympanometry results:

	Normal	Retracted	Flat
a. Right ear:	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
b. Left ear:	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

Recipient NMDP ID: - -

Recipient Last Name:

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

- 1 yes
2 no
3 unknown

32. Speech Threshold results at 500 HZ:

	Normal - Mild	Moderate - Moderately Severe	Severe - Profound
a. Right ear:	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
b. Left ear:	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

See Degree of Hearing Loss chart below for scale ranges.

33. 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

34. Speech Threshold results at 2000 HZ:

	Normal - Mild	Moderate - Moderately Severe	Severe - Profound
a. Right ear:	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
b. Left ear:	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

See Degree of Hearing Loss chart below for scale ranges.

Degree of Hearing Loss: Pure tones and speech testing

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

35. Has there been a change in the neurologic status since the last report? (Clinical status, not neuro-psych status.)

- 1 yes
2 no
3 unknown

36. Status is:

- 1 improved
2 worse

If possible, please provide documentation of this change (e.g., physical examination, neurologic examination report).