**Form 2137 R2.0: Leukodystrophies Post-HSCT Data**

**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 leucocyte 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 leucocyte 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.

**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
- [x] 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 H2O

#### 12 Closing pressure:
- [ ] Known
- [ ] Not known

#### 13 __________________ cm H2O

#### 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 Specify test results:

- Normal
- Abnormal

24 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

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

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:
Form 2137 R2.0: Leukodystrophies Post-HSCT Data

<table>
<thead>
<tr>
<th>Question</th>
<th>Known</th>
<th>Not known</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>40 Verbal score (not percentile):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>41 Score:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>42 Performance score (not percentile):</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>43 Score:</td>
<td></td>
<td></td>
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<tr>
<td>44 Were the Vineland Adaptive Behavior Scales performed since the date of the last report?</td>
<td>yes</td>
<td>no</td>
<td>Unknown</td>
</tr>
<tr>
<td>45 Date of most recent test:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>46 Communication skills score:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>47 Daily Living skills score:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>48 Socialization skills score:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>49 Visual acuity of right eye (OD): (uncorrected vision)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>50 Date of most recent visual acuity test:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>51 Socialization skills score:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>52 Score:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>53 Was the recipient's visual acuity tested since the date of the last report?</td>
<td>yes</td>
<td>no</td>
<td>Unknown</td>
</tr>
<tr>
<td>54 Is the recipient blind?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>55 Date of most recent visual acuity test:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>56 Visual acuity of left eye (OS): (uncorrected vision)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>57 Visual acuity of both eyes (OU): (uncorrected vision)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Mail, fax or email this form to Minneapolis. Fax: 612-627-5895. Email: scanform@ndmp.org. Retain the original form at the transplant center.
62  /  

63 Did the recipient undergo an ophthalmologic 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  

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)
**Form 2137 R2.0: Leukodystrophies Post-HSCT Data**

**Center:**

**CRID:**

<table>
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<tr>
<th>Question</th>
<th>Response Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>78 Was the hearing loss (HL) in decibels (dB) assessed at the speech threshold for 2000 hertz (HZ) since last report?</td>
<td>yes, no, Unknown</td>
</tr>
<tr>
<td>79 Date of most recent evaluation:</td>
<td>Known, Not known</td>
</tr>
<tr>
<td>80 Specify tympanometry results:</td>
<td></td>
</tr>
<tr>
<td>Right ear</td>
<td>normal/mild (0-20 dB HL/25-40 dB HL)</td>
</tr>
<tr>
<td></td>
<td>moderate/moderately severe (45-55 dB HL/60-70 dB HL)</td>
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<td></td>
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<td>82 Left ear</td>
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<tr>
<td></td>
<td>moderate/moderately severe (45-55 dB HL/60-70 dB HL)</td>
</tr>
<tr>
<td></td>
<td>severe/profound (75-90 dB HL/&gt;90 dB HL)</td>
</tr>
<tr>
<td>83 Has there been a change in the recipient's neurologic status since the date of the last report?</td>
<td>Yes, stable/unchanged, Unknown</td>
</tr>
<tr>
<td>84 Specify current neurological status compared to previous report:</td>
<td>Improved, worsened</td>
</tr>
<tr>
<td>85 Is a copy of the physical exam or neurological exam attached?</td>
<td>yes, no</td>
</tr>
</tbody>
</table>