

**FOLLOW-UP INSERT XXXV**  
**Leukodystrophies**

**FOR REGISTRY USE ONLY:**  
I.D. **U** - [ ] [ ] [ ] [ ] - [ ] [ ] [ ] [ ] [ ] [ ]  
Date received: [ ] [ ] [ ] [ ] [ ] [ ]

TEAM: [ ] [ ] [ ] [ ] IUBMID: [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]  
*(Institutional Unique Blood or Marrow Transplant Identification Number)*

Registry (circle one): **IBMTR** ABMTR EBMT

Date of transplant for which this form is being completed: [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]  
Month Day Year

Date of report: [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]  
Month Day Year

**Follow-up Information\***

**\* Report data for date of last contact as reported in Q.3 of Follow-up Care Form or immediately prior to death**

1. Type of leukodystrophy for which transplant was performed:

544  Globoid Cell Leukodystrophy

Leukocyte galactocerebrosidase enzyme activity determined at current evaluation:

2. Date tested: [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]  Unknown  
Month Day Year

3. Patient's level: [ ] [ ] [ ] [ ] . [ ] 1  nmol/hr/mg protein 2  pmol/hr/mg protein  Unknown

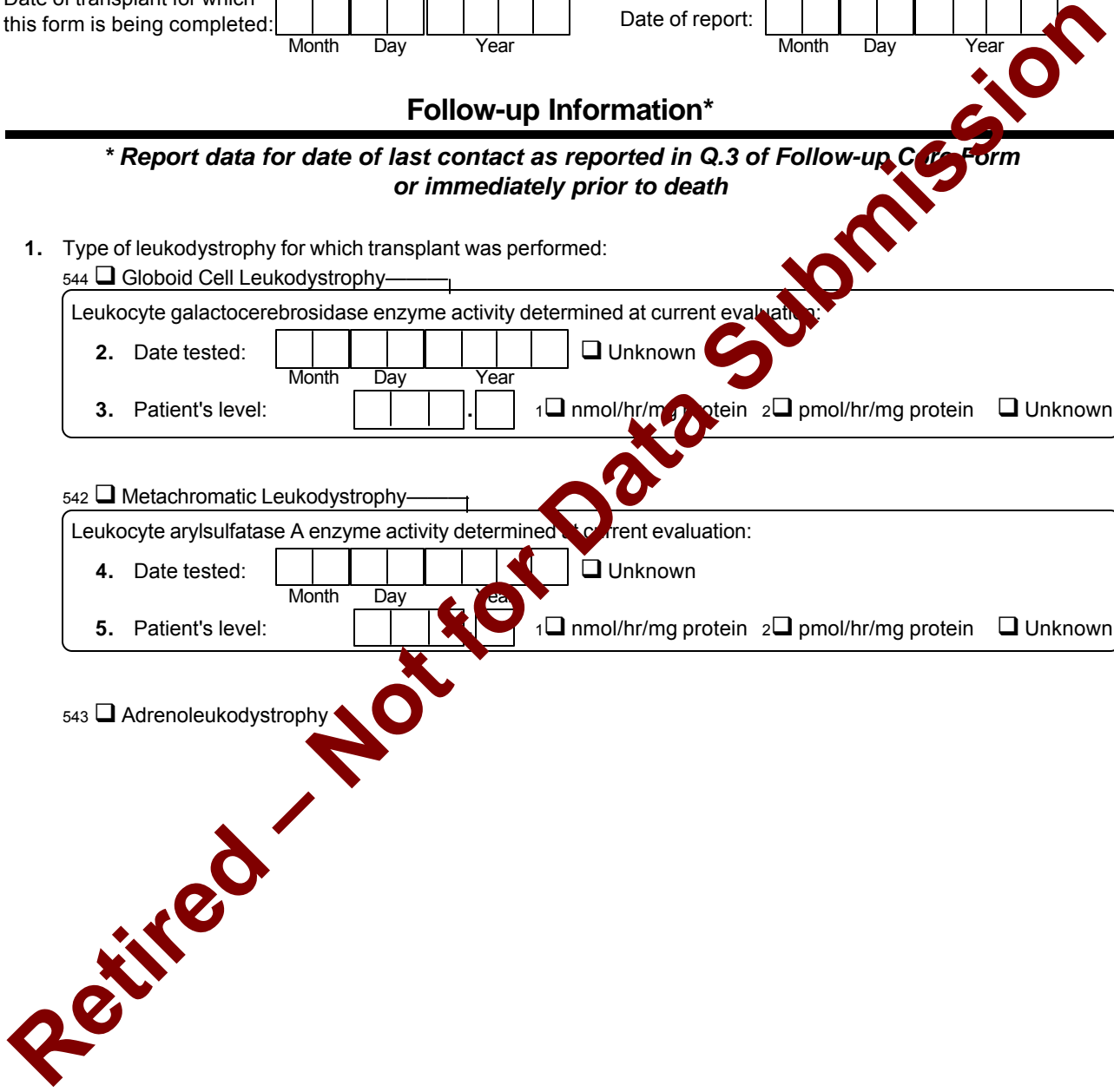
542  Metachromatic Leukodystrophy

Leukocyte arylsulfatase A enzyme activity determined at current evaluation:

4. Date tested: [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]  Unknown  
Month Day Year

5. Patient's level: [ ] [ ] [ ] [ ] . [ ] 1  nmol/hr/mg protein 2  pmol/hr/mg protein  Unknown

543  Adrenoleukodystrophy



TEAM:

IUBMID:

### Clinical Status Posttransplant

6. Did patient develop posttransplant seizures attributed to the underlying disease since the last report?

- 1  Yes
- 0  No
- 8  Unknown

7. Was cerebrospinal fluid (CSF) tested since the last report?

- 1  Yes
- 0  No
- 8  Unknown

8. Date of most recent test:		<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Unknown
		Month	Day	Year				
Results of <u>most recent</u> tests:								
<u>Yes</u> <u>No</u> <u>Unknown</u>								
9.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	Opening pressure	<input type="text"/>	<input type="text"/>	<input type="text"/>	cm H <sub>2</sub> O <input type="checkbox"/> Unknown
10.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	Closing pressure	<input type="text"/>	<input type="text"/>	<input type="text"/>	cm H <sub>2</sub> O <input type="checkbox"/> Unknown
11.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	Total protein	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> mg/L <input type="checkbox"/> g/L <input type="checkbox"/> Unknown

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

- 1  Yes
- 0  No
- 8  Unknown

13. Date of most recent test:		<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Unknown
		Month	Day	Year				
14. Results ( <i>check only one</i> ):								
0 <input type="checkbox"/> Normal								
1 <input type="checkbox"/> Abnormal								
8 <input type="checkbox"/> Unknown								
<i>If the report is available, check here <input type="checkbox"/>, attach copy and reference Q.12</i>								

15. Was Magnetic Resonance Spectroscopy done since the last report?

- 1  Yes
- 0  No
- 8  Unknown

16. Date of most recent test:		<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Unknown
		Month	Day	Year				
17. Results ( <i>check only one</i> ):								
0 <input type="checkbox"/> Normal								
1 <input type="checkbox"/> Abnormal								
8 <input type="checkbox"/> Unknown								
<i>If the report is available, check here <input type="checkbox"/>, attach copy and reference Q.15</i>								

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

- 1  Yes
- 0  No
- 8  Unknown

19. Date of most recent test:		<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/> Unknown
		Month	Day	Year				
20. Results ( <i>check only one</i> ):								
0 <input type="checkbox"/> Normal								
1 <input type="checkbox"/> Abnormal/Impaired								
8 <input type="checkbox"/> Unknown								
<i>If the report is available, check here <input type="checkbox"/>, attach copy and reference Q.18</i>								

Retired / Not for Data Submission

TEAM:

IUBMID:

### Clinical Status Posttransplant (continued)

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

- 1  Yes
- 0  No
- 8  Unknown

<b>22.</b> Date of test:	<table border="1" style="display: inline-table;"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr><tr><td style="text-align: center;">Month</td><td style="text-align: center;">Day</td><td colspan="4" style="text-align: center;">Year</td></tr></table>							Month	Day	Year				<input type="checkbox"/> Unknown
Month	Day	Year												
<b>23.</b> Indicate test instrument and standard scores ( <i>check only one</i> ):														
1 <input type="checkbox"/> Bayley Scales of Infant Development														
2 <input type="checkbox"/> Stanford Binet Intelligence Scale 4th Edition														
3 <input type="checkbox"/> Wechsler Preschool and Primary Scale of Intelligence (WPPSI – Revised)														
4 <input type="checkbox"/> Wechsler Intelligence Scale for Children – III (WISC – III)														
7 <input type="checkbox"/> Other, specify: _____														
<b>24.</b> Full scale score ( <i>not percentile</i> ):	<table border="1" style="display: inline-table;"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr></table>					<input type="checkbox"/> Unknown								
<b>25.</b> Verbal score ( <i>not percentile</i> ):	<table border="1" style="display: inline-table;"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr></table>					<input type="checkbox"/> Unknown								
<b>26.</b> Performance score ( <i>not percentile</i> ):	<table border="1" style="display: inline-table;"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr></table>					<input type="checkbox"/> Unknown								

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

- 1  Yes
- 0  No
- 8  Unknown

<b>28.</b> Date of most recent test:	<table border="1" style="display: inline-table;"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr><tr><td style="text-align: center;">Month</td><td style="text-align: center;">Day</td><td colspan="4" style="text-align: center;">Year</td></tr></table>							Month	Day	Year				<input type="checkbox"/> Unknown
Month	Day	Year												
<b>29.</b> Communication skills:	<table border="1" style="display: inline-table;"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr></table>					<input type="checkbox"/> Unknown								
<b>30.</b> Daily living skills:	<table border="1" style="display: inline-table;"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr></table>					<input type="checkbox"/> Unknown								
<b>31.</b> Socialization skills:	<table border="1" style="display: inline-table;"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr></table>					<input type="checkbox"/> Unknown								

32. Was patient blind?

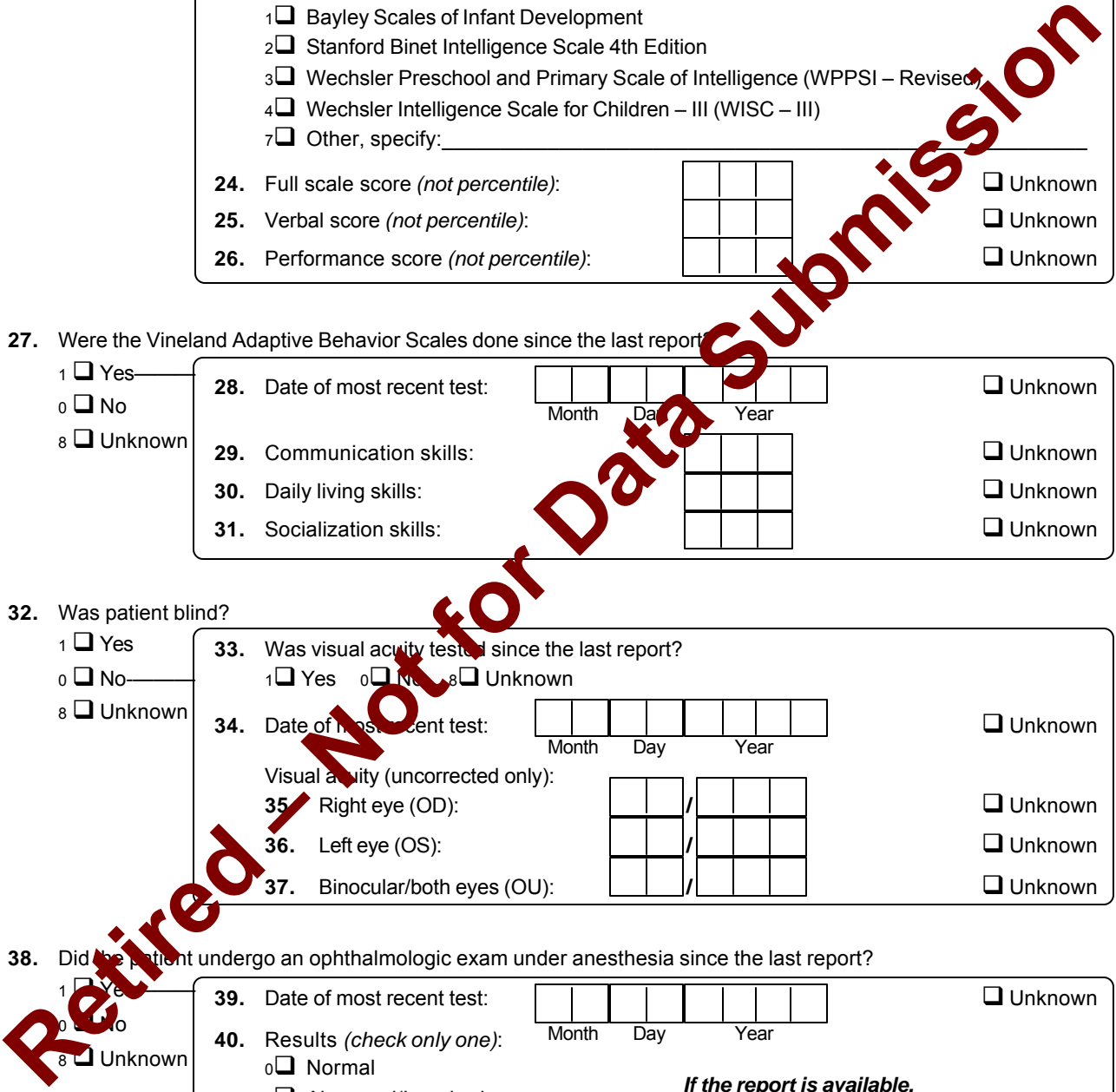
- 1  Yes
- 0  No
- 8  Unknown

<b>33.</b> Was visual acuity tested since the last report?														
1 <input type="checkbox"/> Yes    0 <input type="checkbox"/> No    8 <input type="checkbox"/> Unknown														
<b>34.</b> Date of most recent test:	<table border="1" style="display: inline-table;"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr><tr><td style="text-align: center;">Month</td><td style="text-align: center;">Day</td><td colspan="4" style="text-align: center;">Year</td></tr></table>							Month	Day	Year				<input type="checkbox"/> Unknown
Month	Day	Year												
Visual acuity (uncorrected only):														
<b>35.</b> Right eye (OD):	<table border="1" style="display: inline-table;"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr></table> /					<input type="checkbox"/> Unknown								
<b>36.</b> Left eye (OS):	<table border="1" style="display: inline-table;"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr></table> /					<input type="checkbox"/> Unknown								
<b>37.</b> Binocular/both eyes (OU):	<table border="1" style="display: inline-table;"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr></table> /					<input type="checkbox"/> Unknown								

38. Did the patient undergo an ophthalmologic exam under anesthesia since the last report?

- 1  Yes
- 0  No
- 8  Unknown

<b>39.</b> Date of most recent test:	<table border="1" style="display: inline-table;"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr><tr><td style="text-align: center;">Month</td><td style="text-align: center;">Day</td><td colspan="4" style="text-align: center;">Year</td></tr></table>							Month	Day	Year				<input type="checkbox"/> Unknown
Month	Day	Year												
<b>40.</b> Results ( <i>check only one</i> ):														
0 <input type="checkbox"/> Normal														
1 <input type="checkbox"/> Abnormal/Impaired														
8 <input type="checkbox"/> Unknown														
<b>If the report is available, check here <input type="checkbox"/>, attach copy and reference Q.38</b>														



TEAM:

IUBMID:

41. Was the hearing tested since the last report?

- 1  Yes
- 0  No
- 8  Unknown

42. Date of most recent test:

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Month	Day	Year					

Unknown

43. Results (check only one):

- 0  Normal
- 1  Abnormal/Impaired
- 8  Unknown

*If the report is available,  
check here , attach copy and reference Q.41*

44. Did neurologic status change since the last report  
(Report clinical status, not neuropsychological status)?

- 1  Yes
- 2  Stable/unchanged
- 8  Unknown

Status:

- 45. 1  Improved
- 46. 1  Worsened

*If Physical Examination or Neurologic  
Examination Reports are available,  
check here , attach copy and reference Q.44*

**Retired – Not for Data Submission**