

ERROR CORRECTION FORM

Sequence Number:

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CIBMTR Recipient ID:

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Visit:

100 day
 6 month

 year

Today's Date:

		2	0		
Month	Day	Year	Year		

Infusion Date:

		2	0		
Month	Day	Year	Year		

CIBMTR Center Number:

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Initials:

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X-Linked Lymphoproliferative Syndrome Post-HSCT Data

Registry Use Only

Sequence Number:

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Date Received:

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CIBMTR Center Number:

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CIBMTR Recipient ID:

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Today's Date:

		2	0		
Month	Day	Year	Year		

Date of HSCT for which this form is being completed:

Month	Day	Year	Year		

HSCT type: autologous allogeneic, unrelated allogeneic, related syngeneic (identical twin)

Product type: marrow PBSC cord blood other product, specify: _____

Visit: 100 day 6 month 1 year 2 years > 2 years, specify:

To be completed in conjunction with a Form 2100 – 100 Days Post-HSCT Data, Form 2200 – Six Months to Two Years Post-HSCT Data, or Form 2300 – Yearly Follow-Up for Greater Than Two Years Post-HSCT Data. Information reported here should reflect the date of last contact as reported in the post-HSCT data collection form, or immediately prior to death.

Post-HSCT Clinical Status

Specify the recipient's clinical status post-HSCT:

- | | | | |
|-------------------------------------|------------------------------------|-------------------------------------|---|
| 1. <input type="checkbox"/> present | 2. <input type="checkbox"/> absent | 3. <input type="checkbox"/> unknown | Hepatomegaly (> 3 cm below right costal margin) |
| 2. <input type="checkbox"/> present | 2. <input type="checkbox"/> absent | 3. <input type="checkbox"/> unknown | Hypertriglyceridemia (> 200 mg/dL) |
| 3. <input type="checkbox"/> present | 2. <input type="checkbox"/> absent | 3. <input type="checkbox"/> unknown | Hypofibrinogenemia (< 150 mg/dL) |
| 4. <input type="checkbox"/> present | 2. <input type="checkbox"/> absent | 3. <input type="checkbox"/> unknown | Splenomegaly (> 3 cm below left costal margin) |

Specify the recipient's cerebrospinal fluid findings post-HSCT:

- | | | | |
|--|--|--|-----------------|
| 5. <input type="checkbox"/> normal | 2. <input type="checkbox"/> elevated | 3. <input type="checkbox"/> not tested | Neopterin level |
| 6. <input type="checkbox"/> normal | 2. <input type="checkbox"/> elevated | 3. <input type="checkbox"/> not tested | Protein |
| 7. <input type="checkbox"/> ≤ 5 cells/μl | 2. <input type="checkbox"/> > 5 cells/μl | 3. <input type="checkbox"/> not tested | WBC count |

8. What was the recipient's clinical neurologic status post-HSCT?

- 1 normal
2 abnormal →

	Improvement in Pre-Transplant Abnormalities?		Stable Pre-Transplant Abnormalities?		Deterioration of Pre-Transplant Abnormalities?		Abnormalities Developed Post-transplant?	
	1	2	1	2	1	2	1	2
Seizures	9.1 <input type="checkbox"/> yes	2 <input type="checkbox"/> no	10.1 <input type="checkbox"/> yes	2 <input type="checkbox"/> no	11.1 <input type="checkbox"/> yes	2 <input type="checkbox"/> no	12.1 <input type="checkbox"/> yes	2 <input type="checkbox"/> no
Mental retardation	13.1 <input type="checkbox"/> yes	2 <input type="checkbox"/> no	14.1 <input type="checkbox"/> yes	2 <input type="checkbox"/> no	15.1 <input type="checkbox"/> yes	2 <input type="checkbox"/> no	16.1 <input type="checkbox"/> yes	2 <input type="checkbox"/> no
Developmental delay	17.1 <input type="checkbox"/> yes	2 <input type="checkbox"/> no	18.1 <input type="checkbox"/> yes	2 <input type="checkbox"/> no	19.1 <input type="checkbox"/> yes	2 <input type="checkbox"/> no	20.1 <input type="checkbox"/> yes	2 <input type="checkbox"/> no
Abnormal gait	21.1 <input type="checkbox"/> yes	2 <input type="checkbox"/> no	22.1 <input type="checkbox"/> yes	2 <input type="checkbox"/> no	23.1 <input type="checkbox"/> yes	2 <input type="checkbox"/> no	24.1 <input type="checkbox"/> yes	2 <input type="checkbox"/> no
Motor weakness	25.1 <input type="checkbox"/> yes	2 <input type="checkbox"/> no	26.1 <input type="checkbox"/> yes	2 <input type="checkbox"/> no	27.1 <input type="checkbox"/> yes	2 <input type="checkbox"/> no	28.1 <input type="checkbox"/> yes	2 <input type="checkbox"/> no
Sensory deficits	29.1 <input type="checkbox"/> yes	2 <input type="checkbox"/> no	30.1 <input type="checkbox"/> yes	2 <input type="checkbox"/> no	31.1 <input type="checkbox"/> yes	2 <input type="checkbox"/> no	32.1 <input type="checkbox"/> yes	2 <input type="checkbox"/> no
Other dysfunction	33. Specify other dysfunction: _____							
	34.1 <input type="checkbox"/> yes	2 <input type="checkbox"/> no	35.1 <input type="checkbox"/> yes	2 <input type="checkbox"/> no	36.1 <input type="checkbox"/> yes	2 <input type="checkbox"/> no	37.1 <input type="checkbox"/> yes	2 <input type="checkbox"/> no

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Visit:

- 100 day
 6 month

--	--

 year

Today's Date:

Month	Day	Year	Year	Year	Year	Year	Year	Year	Year	Year	Year	Year	Year	Year	Year	Year	Year	Year	Year	Year	Year

Infusion Date:

Month	Day	Year	Year	Year	Year	Year	Year	Year	Year	Year	Year	Year	Year	Year	Year	Year	Year	Year	Year	Year	Year

CIBMTR Center Number:

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Initials:

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38. Was an MRI or CT performed on the central nervous system post-HSCT?

- 1 yes
2 no

39. Specify results:

- 1 improvement in pre-HSCT abnormalities
2 stable pre-HSCT abnormalities
3 worsening of pre-HSCT abnormalities

Current Assessment of Immunologic Function Post-Transplant

Specify the clinical status post-HSCT: (*Absent is defined as < 10% normal; decreased is defined as 11–50% normal.*)

40. IgG 1 absent 2 decreased 3 normal 4 increased 5 unknown
41. IgA 1 absent 2 decreased 3 normal 4 increased 5 unknown
42. IgM 1 absent 2 decreased 3 normal 4 increased 5 unknown
43. Natural killer cell activity 1 absent 2 decreased 3 normal 4 increased 5 unknown
44. Other immunologic evaluation 1 absent 2 decreased 3 normal 4 increased 5 unknown
45. Specify other evaluation: _____

46. Did the recipient receive IVIG within two months prior to the time the immunoglobulin levels were measured?

- 1 yes
2 no
3 unknown

47. Was the recipient transplanted for lymphoma and XLP?

- 1 yes
2 no

48. Specify post-HSCT status of lymphoma:

- 1 CR
2 PR
3 relapse
4 unknown

49. Signed: _____

Person completing form

Please print name: _____

Phone: (_____) _____

Fax: (_____) _____

E-mail address: _____