

ERROR CORRECTION FORM

Sequence Number:

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CIBMTR Recipient ID:

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Today's Date:

Month	Day	Year																	

Infusion Date:

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Hemophagocytic Lymphohistiocytosis Pre-HSCT Data

Registry Use Only

Sequence Number:

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Date Received:

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Today's Date:

Month	Day	Year																	

Date of HSCT for which this form is being completed:

Month	Day	Year																	

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

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

This form must be accompanied by Form 2000 – Recipient Baseline Data. All information in the box above, including the date, should be identical with the corresponding Form 2000. Information should come from an actual examination by the Transplant Center physician, or the physician who is following the recipient pre-HSCT, or abstraction of the recipient's medical records.

If this is a report of a second or subsequent transplant, check here and continue with question 90.

1. What was the date of diagnosis of Hemophagocytic Lymphohistiocytosis?

2. Is there a family history of hemophagocytic disorders?

- 1 yes
2 no
3 unknown

Specify affected member(s):

3. 1 yes 2 no Aunt(s) / uncle(s)
4. 1 yes 2 no Cousin(s)
5. 1 yes 2 no Sibling(s)
6. 1 yes 2 no Other

7. Specify relationship: _____

8. Is there a family history of consanguinity (descent from common ancestors / inter-familial marriage)?

- 1 yes
2 no
3 unknown

9. Describe:

Specify the following clinical and laboratory features at diagnosis:

- | | Present | Absent | Unknown | |
|-----|--------------------------|--------------------------|--------------------------|---|
| 10. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | Anemia (hemoglobin < 10 g/dL) |
| 11. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | Fever (> 38.5° C for > 7 days within 1 week of diagnosis) |
| 12. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | Hepatomegaly (> 3 cm below right costal margin) |
| 13. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | Hypertriglyceridemia (> 200 mg/dL) |
| 14. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | Hypofibrinogenemia (< 150 mg/dL) |
| 15. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | Neutropenia (ANC < 1.0 x 10 ⁹ /L) |
| 16. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | Splenomegaly (> 3 cm below left costal margin) |
| 17. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | Thrombocytopenia (< 100 x 10 ⁹ /L) |

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Month	Day	Year	Year	Year	Year	Year	Year

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Specify the cerebrospinal fluid findings at diagnosis:

18. Neopterin level 1 normal 2 elevated 3 not tested

19. Protein 1 normal 2 elevated 3 not tested

20. WBC count 1 ≤ 5 cells/μl 2 > 5 cells/μl 3 not tested

21. Was there evidence of hemophagocytosis in the cerebrospinal fluid at diagnosis?

- 1 yes
2 no
3 not tested

22. Were central nervous system (CNS) abnormalities found on computed tomography (CT or CAT) or magnetic resonance imaging (MRI) scans at any time prior to the preparative regimen?

- 1 yes
2 no
3 unknown / not tested

	Specify type of scan performed:
23. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no CT	→ 24. Specify abnormality detected on CT: _____
25. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no MRI	→ 26. Specify abnormality detected on MRI: _____
27. Is a copy of the report(s) attached?	
1 <input type="checkbox"/> yes	
2 <input type="checkbox"/> no	

28. Were there any clinical neurologic abnormalities at any time prior to the preparative regimen?

- 1 yes
2 no
3 unknown

	Specify abnormalities:
29. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no	Abnormal gait
30. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no	Developmental delay
31. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no	Mental retardation
32. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no	Motor weakness
33. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no	Seizures
34. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no	Sensory deficits
35. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no	Other → 36. Specify abnormality: _____

Infection History at Time of Presentation with Disease

37. Was an infection documented at diagnosis?

- 1 yes
2 no

	Specify infection(s):								
38. Cytomegalovirus (CMV):									
1 <input type="checkbox"/> yes	→ 39. Specify the test method used for diagnosis of CMV:								
2 <input type="checkbox"/> no	1 <input type="checkbox"/> culture								
	2 <input type="checkbox"/> polymerase chain reaction (PCR)								
40. Epstein-Barr virus (EBV):									
1 <input type="checkbox"/> yes	→ 41. Specify the test method used for diagnosis of EBV:								
2 <input type="checkbox"/> no	1 <input type="checkbox"/> in situ hybridization								
	2 <input type="checkbox"/> PCR								
	3 <input type="checkbox"/> serology → Specify titers:								
	42. EBNA: <table border="1" style="width: 100%; height: 26px;"><tr><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td></tr></table>								
	43. Early antigen: <table border="1" style="width: 100%; height: 26px;"><tr><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td></tr></table>								
	44. Viral capsid IgG: <table border="1" style="width: 100%; height: 26px;"><tr><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td></tr></table>								
	45. Viral capsid IgM: <table border="1" style="width: 100%; height: 26px;"><tr><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td></tr></table>								

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Today's Date:

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46. Other infection:

- 1 yes →
2 no

47. Specify other infection:
(see codes below)

48. If other organism (code 198, 209, 219, 259, 329, or 409), specify:

Specify infection site(s):

49. 1 yes 2 no Blood
50. 1 yes 2 no Cerebrospinal fluid (CSF)
51. 1 yes 2 no Urine
52. 1 yes 2 no Tissue biopsy →
54. 1 yes 2 no Other body fluid →

53. Specify tissue / site: _____

55. Specify fluid / site: _____

Codes for Commonly Reported Organisms

Bacterial Infections

- 121 Acinetobacter
- 122 Actinomyces
- 123 Bacillus
- 124 Bacteroides (gracillis, uniformis, vulgaris, other species)
- 125 Bordetella pertussis (whooping cough)
- 126 Borrelia (Lyme disease)
- 127 Branhamella or Moraxella catarrhalis (other species)
- 128 Campylobacter (all species)
- 129 Capnocytophaga
- 171 Chlamydia pneumoniae
- 172 Other chlamydia, specify
- 113 Chlamydia, NOS
- 130 Citrobacter (freundii, other species)
- 131 Clostridium (all species except difficile)
- 132 Clostridium difficile
- 173 Corynebacterium jeikeium
- 133 Corynebacterium (all non-diphtheria species)
- 101 Coxiella
- 134 Enterobacter
- 177 Enterococcus, vancomycin resistant (VRE)
- 135 Enterococcus (all species)
- 136 Escherichia (also E. coli)
- 137 Flavimonas oryzihabitans
- 138 Flavobacterium
- 139 Fusobacterium
- 144 Haemophilus (all species, including influenzae)
- 145 Helicobacter pylori
- 146 Klebsiella
- 147 Lactobacillus (bulgaricus, acidophilus, other species)
- 102 Legionella
- 103 Leptospira

- 148 Leptotrichia buccalis
- 149 Leuconostoc (all species)
- 104 Listeria
- 150 Methylobacterium
- 151 Micrococcus, NOS
- 112 Mycobacterium avium-intracellulare (MAC, MAI)
- 174 Mycobacterium species (cheloneae, fortuitum, haemophilum, kansasii, mucogenicum)
- 110 Mycobacterium tuberculosis (tuberculosis, Koch bacillus)
- 175 Other mycobacterium, specify
- 176 Mycobacterium, NOS
- 105 Mycoplasma
- 152 Neisseria (gonorrhoea, meningitidis, other species)
- 106 Nocardia
- 153 Pasteurella multocida
- 154 Propionibacterium (acnes, avidum, granulosum, other species)
- 155 Proteus
- 156 Pseudomonas (all species except cepacia & maltophilia)
- 157 Pseudomonas or Burkholderia cepacia
- 158 Pseudomonas or Stenotrophomonas or Xanthomonas maltophilia
- 159 Rhodococcus
- 107 Rickettsia
- 160 Salmonella (all species)
- 161 Serratia marcescens
- 162 Shigella
- 163 Staphylococcus, coagulase negative (not aureus)
- 164 Staphylococcus aureus
- 165 Staphylococcus, NOS
- 166 Stomatococcus mucilaginosus
- 167 Streptococcus (all species except Enterococcus)

- 178 Streptococcus pneumoniae
- 168 Treponema (syphilis)
- 169 Vibrio (all species)
- 197 Multiple bacteria at a single site, specify bacterial codes
- 198 Other bacteria, specify ‡
- 501 Suspected atypical bacterial infection
- 502 Suspected bacterial infection

Fungal Infections

- 200 Candida, NOS
- 201 Candida albicans
- 206 Candida guilliermondii
- 202 Candida krusei
- 207 Candida lusitanae
- 203 Candida parapsilosis
- 204 Candida tropicalis
- 205 Candida (Torulopsis) glabrata
- 209 Other Candida, specify ‡
- 210 Aspergillus, NOS §
- 211 Aspergillus flavus §
- 212 Aspergillus fumigatus §
- 213 Aspergillus niger §
- 219 Other Aspergillus, specify ‡ §
- 220 Cryptococcus species
- 230 Fusarium species §
- 261 Histoplasmosis
- 240 Zygomycetes, NOS §
- 241 Mucormycosis §
- 242 Rhizopus §
- 250 Yeast, NOS
- 259 Other fungus, specify ‡
- 260 Pneumocystis (PCP / PJP)
- 503 Suspected fungal infection §

§ For fungal species marked with a section symbol (§), also complete a Fungal Infection insert (SUP-FNG).

Viral Infections

- 301 Herpes simplex (HSV1, HSV2)
- 302 Varicella (herpes zoster, chicken pox)
- 303 Cytomegalovirus (CMV)
- 304 Adenovirus
- 305 Enterovirus (coxsackie, echo, polio)
- 306 Hepatitis A (HAV)
- 307 Hepatitis B (HBV, Australian antigen)
- 308 Hepatitis C (HCV)
- 309 HIV-1 (HTLV-III)
- 310 Influenza, NOS
- 323 Influenza A
- 324 Influenza B
- 311 Measles (rubeola)
- 312 Mumps
- 313 Progressive multifocal leukoencephalopathy (PML)
- 314 Respiratory syncytial virus (RSV)
- 315 Rubella (German measles)
- 316 Parainfluenza
- 317 Human herpesvirus-6 (HHV-6)
- 318 Epstein-Barr virus (EBV)
- 319 Polyoma virus (BK virus, JC virus)
- 320 Rotavirus
- 321 Rhinovirus
- 322 Human papilloma virus (HPV)
- 329 Other virus, specify ‡
- 504 Suspected viral infection

Parasitic Infections

- 402 Toxoplasma
- 403 Giardia
- 404 Cryptosporidium
- 409 Other parasite, specify ‡
- 505 Suspected parasite infection

Other Infections

- 509 No organism identified

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Specify the site(s) where hemophagocytosis was documented at diagnosis:

- | Present | Absent | Not tested | |
|--------------------------------|----------------------------|----------------------------|--------------|
| 56. 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | Bone marrow |
| 57. 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | CSF |
| 58. 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | Liver |
| 59. 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | Lymph nodes |
| 60. 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | Spleen |
| 61. 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | Other site → |

62. Specify site of hemophagocytosis:

63. What is the current natural killer cell function? (*Refers to specific cytolysis of NK-sensitive target cells, e.g. K562.*)

- 1 absent (≤ 10% normal response)
- 2 decreased (11–60% normal response)
- 3 normal
- 4 increased
- 5 not tested

64. Was treatment given at any time prior to the preparative regimen?

- 1 yes →
- 2 no
- 3 unknown

Specify therapy and reason for therapy:

65. Cyclosporine:	Given for induction / maintenance?	66. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no	Given for disease relapse?	67. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no				
1 <input type="checkbox"/> yes →								
2 <input type="checkbox"/> no								
68. Intrathecal methotrexate:		69. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no		70. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no				
1 <input type="checkbox"/> yes →								
2 <input type="checkbox"/> no								
71. IVIG:		72. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no		73. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no				
1 <input type="checkbox"/> yes →								
2 <input type="checkbox"/> no								
74. Steroids:		75. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no		76. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no				
1 <input type="checkbox"/> yes →								
2 <input type="checkbox"/> no								
77. VP-16 / VM-26:		78. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no		79. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no				
1 <input type="checkbox"/> yes →								
2 <input type="checkbox"/> no								
80. Other drug:		81. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no		82. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no				
1 <input type="checkbox"/> yes →								
2 <input type="checkbox"/> no		83. Specify other drug: _____						
84. Radiation therapy:		85. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no		86. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no				
1 <input type="checkbox"/> yes →								
2 <input type="checkbox"/> no		87. Specify radiation field: _____						
		88. Specify total dose: <table border="1" style="display: inline-table; width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td><td></td></tr></table> cGy						
89. Was this therapy given following the HLH-94 protocol of the Histiocyte Society?								
1 <input type="checkbox"/> yes								
2 <input type="checkbox"/> no								
3 <input type="checkbox"/> unknown								

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90. Was CNS disease quiescent (inactive) at any time prior to the preparative regimen?

- 1 yes
 2 no
 3 unknown

Specify:

91. 1 yes 2 no 3 unknown Normal or stable CT or MRI of CNS

92. 1 yes 2 no 3 unknown Normal CSF neopterin level

93. 1 yes 2 no 3 unknown Normal CSF protein

94. 1 yes 2 no 3 unknown Normal CSF WBC (< 5 cells/mm³)

95. Is a copy of the report attached?

1 yes
 2 no

96. Was systemic disease quiescent at any time prior to the preparative regimen?

- 1 yes
 2 no
 3 unknown

Specify:

97. 1 yes 2 no 3 unknown ANC > 1.0 x 10⁹/L (without growth factor support)

98. 1 yes 2 no 3 unknown Hemoglobin > 9 g/dL without transfusion

99. 1 yes 2 no 3 unknown Hepatomegaly resolved (≤ 3 cm below costal margin)

100. 1 yes 2 no 3 unknown Normal fibrinogen

101. 1 yes 2 no 3 unknown Normal triglycerides

102. 1 yes 2 no 3 unknown Platelets > 100 x 10⁹/L without transfusion

103. 1 yes 2 no 3 unknown Splenomegaly resolved (≤ 3 cm below costal margin)

104. Were there any signs of disease relapse / reactivation prior to HSCT?

- 1 yes
 2 no

105. Specify the date of the first relapse / reactivation:

Month	Day	Year					

106. Specify the site of the first relapse / reactivation:

1 CNS
 2 systemic
 3 both

107. Specify the date of the second relapse / reactivation: not applicable

Month	Day	Year					

108. Specify the site of the second relapse / reactivation:

1 CNS
 2 systemic
 3 both

109. Specify the date of the third relapse / reactivation: not applicable

Month	Day	Year					

110. Specify the site of the third relapse / reactivation:

1 CNS
 2 systemic
 3 both

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Specify the clinical and laboratory features just prior to the preparative regimen:

111. 1 yes 2 no 3 unknown Anemia (hemoglobin < 10 g/dL)
112. 1 yes 2 no 3 unknown Fever (> 38.5° C for > 7 days within 1 week of conditioning)
113. 1 yes 2 no 3 unknown Hepatomegaly (> 3 cm below right costal margin)
114. 1 yes 2 no 3 unknown Hypertriglyceridemia (> 200 mg/dL)
115. 1 yes 2 no 3 unknown Hypofibrinogenemia (< 150 mg/dL)
116. 1 yes 2 no 3 unknown Neutropenia (ANC < 1.0 x 10⁹/L)
117. 1 yes 2 no 3 unknown Splenomegaly (> 3 cm below left costal margin)
118. 1 yes 2 no 3 unknown Thrombocytopenia (< 100 x 10⁹/L)
119. What was the status of CNS disease just prior to the preparative regimen?
1 active
2 non-active, quiescent
3 CNS disease absent at diagnosis

120. Signed: _____
Person completing form

Please print name: _____

Phone: (_____) _____

Fax: (_____) _____

E-mail address: _____