



# Neuroblastoma Post-HSCT Data

## Registry Use Only

Sequence Number:

Date Received:

CIBMTR Center Number:

CIBMTR Recipient ID:

Today's Date:  /  /  20

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

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.

## Disease Assessment at the Time of Best Response to HSCT

Best response is based on response to the HSCT, but does NOT include response to any therapy given for disease relapse or progression post-HSCT. When determining the best response to HSCT, compare the post-HSCT disease status to the status immediately prior to the preparative regimen, regardless of time since HSCT. This comparison is meant to capture the BEST disease status in response to HSCT that occurred in the reporting interval, even if a subsequent disease relapse or progression occurred during the same reporting interval. If a recipient already achieved their best response in a previous reporting interval, confirm the best response and check the box to indicate “date previously reported.”

1. Compared to the disease status prior to the preparative regimen, what was the best response to HSCT since the date of the last report? (Include response to any post-HSCT treatment planned as of Day 0.)
  - 1  complete response — no primary tumor, no metastatic sites, catecholamines normal; includes continued complete response
  - 2  very good partial response — primary tumor decreased by 90-99%, no metastatic sites, catecholamines normal; residual <sup>99</sup>Tc bone changes allowed
  - 3  partial response — primary tumor decreased by > 50%, all measurable metastatic sites decreased by > 50%, number of positive bone sites decreased by > 50%, no more than 1 positive bone marrow site allowed, 1 positive marrow aspirate or biopsy allowed if this represents a decrease from the number of positive sites at diagnosis →
  - 4  minimal response — no new lesions; > 50% reduction of any measurable lesion (primary or metastases) with < 50% reduction in any other; < 25% increase in any existing lesion →
  - 5  no response — no new lesions; < 50% reduction but < 25% increase in any existing lesion →
  - 6  progressive disease — any new lesions; increase of any measurable lesion by > 25%; previous negative marrow positive for tumor →
  - 7  not assessed
  - 8  not tested / unknown

Specify the site(s) of persistent tumor:

2. 1  yes 2  no Adrenal gland
3. 1  yes 2  no Bone
4. 1  yes 2  no Bone marrow
5. 1  yes 2  no Cerebellum
6. 1  yes 2  no Cerebrospinal fluid (CSF)
7. 1  yes 2  no Cerebrum
8. 1  yes 2  no Cranial nerves
9. 1  yes 2  no Liver
10. 1  yes 2  no Lymph nodes
11. 1  yes 2  no Mediastinum
12. 1  yes 2  no Paraspinal ganglion
13. 1  yes 2  no Retro-orbital area
14. 1  yes 2  no Skin / subcutaneous tissue
15. 1  yes 2  no Elevated catecholamines
16. 1  yes 2  no Other site ▶

17. Specify: \_\_\_\_\_

Mail this form to your designated campus (Milwaukee or Minneapolis). Retain the original at the transplant center.

CIBMTR Center Number:

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18. Specify the date best response was determined:        date previously reported  
Month Day Year

19. Were tumor markers evaluated for the best response post-HSCT determination?

- 1  yes
- 2  no

	Specify the following tumor marker analyses performed:	Date of best response determination:
20. Homovanillic acid (HVA):		Month Day Year
1 <input type="checkbox"/> known → <input type="text"/> <input type="text"/> <input type="text"/> • <input type="text"/> µg/mg creatinine	21.	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
2 <input type="checkbox"/> not known		
22. Neuron specific enolase:		Month Day Year
1 <input type="checkbox"/> known → <input type="text"/> <input type="text"/> • <input type="text"/> <input type="text"/> ng/mL	23.	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
2 <input type="checkbox"/> not known		
24. Serum ferritin:		Month Day Year
1 <input type="checkbox"/> known → <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> ng/mL	25.	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
2 <input type="checkbox"/> not known		or µg/L
26. Vanilmandelic acid (VMA):		Month Day Year
1 <input type="checkbox"/> known → <input type="text"/> <input type="text"/> <input type="text"/> • <input type="text"/> µg/mg creatinine	27.	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
2 <input type="checkbox"/> not known		
28. Other tumor marker analysis:		
1 <input type="checkbox"/> known →	29. Specify other analysis: _____	
2 <input type="checkbox"/> not known	30. Specify level and units: _____	

31. Was the recipient given planned per protocol post-HSCT treatment for neuroblastoma?

- 1  yes
- 2  no

	32. Was radiotherapy given?
1 <input type="checkbox"/> yes	Specify the site(s) of radiotherapy:
2 <input type="checkbox"/> no	
33. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Bone metastases	
34. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Primary tumor	
	35. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Other site → 36. Specify: _____
	37. Specify the date radiotherapy was started: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Month Day Year
	38. Number of fractions given: <input type="text"/> <input type="text"/>
	39. Dose per fraction: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> cGy (rads)
	40. Was MIBG given?
1 <input type="checkbox"/> yes	Specify the radioisotope given:
2 <input type="checkbox"/> no	
41. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no <sup>131</sup> I-MIBG	
42. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Other → 43. Specify: _____	
	44. Specify the date MIBG treatment was performed: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Month Day Year

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45. Were retinoids given?  
1  yes →  
2  no

Specify the retinoids given:  
46. 1  yes 2  no Isotretinoin  
47. 1  yes 2  no Other → 48. Specify:

49. Specify the date retinoid treatment was started:     
Month Day Year

50. Was immunotherapy given?  
1  yes →  
2  no

Specify the drug(s) given:  
51. 1  yes 2  no  $\alpha$ -interferon  
52. 1  yes 2  no Anti-GD2 antibody CH14.18  
53. 1  yes 2  no Interleukin-2 (IL-2)  
54. 1  yes 2  no Other → 55. Specify:

56. Specify the date immunotherapy was started:     
Month Day Year

57. Was chemotherapy given?  
1  yes →  
2  no

Specify the treatment(s) given:  
58. 1  yes 2  no Adriamycin  
59. 1  yes 2  no Cisplatin  
60. 1  yes 2  no Cyclophosphamide  
61. 1  yes 2  no Dacarbazine (DTIC)  
62. 1  yes 2  no Etoposide (VP16)  
63. 1  yes 2  no Ifosfamide  
64. 1  yes 2  no Melphalan (L-PAM)  
65. 1  yes 2  no Teniposide (VM26)  
66. 1  yes 2  no Vincristine  
67. 1  yes 2  no Other → 68. Specify:

69. Specify the date chemotherapy was started:     
Month Day Year

70. Was other treatment given?  
1  yes →  
2  no

71. Specify other treatment:

72. Specify the date other treatment was started:     
Month Day Year

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73. Did the neuroblastoma recur or progress since the date of the last report?

- 1  yes  
2  no

Specify the known site(s) of disease progression / recurrence:		Date determined:		
		Month	Day	Year
74. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Adrenal gland	→	75. <input type="text"/>	<input type="text"/>	<input type="text"/> 20 <input type="text"/>
76. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Bone	→	77. <input type="text"/>	<input type="text"/>	<input type="text"/> 20 <input type="text"/>
78. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Bone marrow	→	79. <input type="text"/>	<input type="text"/>	<input type="text"/> 20 <input type="text"/>
80. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Cerebellum	→	81. <input type="text"/>	<input type="text"/>	<input type="text"/> 20 <input type="text"/>
82. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Cerebrospinal fluid (CSF)	→	83. <input type="text"/>	<input type="text"/>	<input type="text"/> 20 <input type="text"/>
84. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Cerebrum	→	85. <input type="text"/>	<input type="text"/>	<input type="text"/> 20 <input type="text"/>
86. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Cranial nerves	→	87. <input type="text"/>	<input type="text"/>	<input type="text"/> 20 <input type="text"/>
88. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Liver	→	89. <input type="text"/>	<input type="text"/>	<input type="text"/> 20 <input type="text"/>
90. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Lymph nodes	→	91. <input type="text"/>	<input type="text"/>	<input type="text"/> 20 <input type="text"/>
92. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Mediastinum	→	93. <input type="text"/>	<input type="text"/>	<input type="text"/> 20 <input type="text"/>
94. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Paraspinal ganglion	→	95. <input type="text"/>	<input type="text"/>	<input type="text"/> 20 <input type="text"/>
96. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Retro-orbital area	→	97. <input type="text"/>	<input type="text"/>	<input type="text"/> 20 <input type="text"/>
98. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Skin / subcutaneous tissue	→	99. <input type="text"/>	<input type="text"/>	<input type="text"/> 20 <input type="text"/>
100. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Other site	→	101. <input type="text"/>	<input type="text"/>	<input type="text"/> 20 <input type="text"/>
102. Specify other site: _____				
Specify the methods used to examine sites of disease recurrence / persistence / progression:		Specify disease status:		
103. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Biopsy	→	104. 1 <input type="checkbox"/> positive 2 <input type="checkbox"/> negative		
105. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Bone scan	→	106. 1 <input type="checkbox"/> positive 2 <input type="checkbox"/> negative		
107. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Radiology	→	108. 1 <input type="checkbox"/> positive 2 <input type="checkbox"/> negative		
109. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Other method	→	110. 1 <input type="checkbox"/> positive 2 <input type="checkbox"/> negative		
111. Specify other method: _____				

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112. Was the recipient given treatment for post-HSCT persistent, progressive or recurrent disease since the date of the last report?

- 1  yes
- 2  no
- 3  unknown

113. Was radiotherapy given?

- 1  yes
- 2  no

Specify the site(s) of radiotherapy:

- 114. 1  yes 2  no Bone metastases
- 115. 1  yes 2  no Primary tumor
- 116. 1  yes 2  no Other

117. Specify:

118. Specify the date radiotherapy was started:

Month Day Year

119. Number of fractions given:

120. Dose per fraction:

cGy (rads)

121. Was MIBG given?

- 1  yes
- 2  no

Specify the radioisotope given:

- 122. 1  yes 2  no <sup>131</sup>I-MIBG
- 123. 1  yes 2  no Other

124. Specify:

125. Specify the date MBIG treatment was performed:

Month Day Year

126. Were retinoids given?

- 1  yes
- 2  no

Specify the retinoids given:

- 127. 1  yes 2  no Isotretinoin
- 128. 1  yes 2  no Other

129. Specify:

130. Specify the date retinoid treatment was started:

Month Day Year

131. Was immunotherapy given?

- 1  yes
- 2  no

Specify the drug(s) given:

- 132. 1  yes 2  no  $\alpha$ -interferon
- 133. 1  yes 2  no Anti-GD2 antibody CH14.18
- 134. 1  yes 2  no Interleukin-2 (IL-2)
- 135. 1  yes 2  no Other

136. Specify:

137. Specify the date immunotherapy was started:

Month Day Year

138. Was chemotherapy given?

- 1  yes
- 2  no

Specify the treatment(s) given:

- 139. 1  yes 2  no Adriamycin
- 140. 1  yes 2  no Cisplatin
- 141. 1  yes 2  no Cyclophosphamide
- 142. 1  yes 2  no Dacarbazine (DTIC)
- 143. 1  yes 2  no Etoposide (VP16)
- 144. 1  yes 2  no Ifosfamide
- 145. 1  yes 2  no Melphalan (L-PAM)
- 146. 1  yes 2  no Teniposide (VM26)
- 147. 1  yes 2  no Vincristine
- 148. 1  yes 2  no Other

149. Specify:

150. Specify the date chemotherapy was started:

Month Day Year

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<p>151. Was other treatment given?</p> <p>1 <input type="checkbox"/> yes</p> <p>2 <input type="checkbox"/> no</p>	<p>152. Specify other treatment: _____</p> <p>153. Specify the date other treatment was started:</p> <table border="1"><tr><td><input type="text"/><input type="text"/></td><td><input type="text"/><input type="text"/></td><td><input type="text"/><input type="text"/><input type="text"/><input type="text"/></td></tr><tr><td>Month</td><td>Day</td><td>Year</td></tr></table>	<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
<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					

154. What is the current disease status?

- 1  complete remission
- 2  not in complete remission

155. Date the current disease status was established in this reporting period: 

<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

156. Signed: \_\_\_\_\_  
*Person completing form*

Please print name: \_\_\_\_\_

Phone: (\_\_\_\_\_) \_\_\_\_\_

Fax: (\_\_\_\_\_) \_\_\_\_\_

E-mail address: \_\_\_\_\_