



# Neuroblastoma Pre-HSCT Data

## Registry Use Only

Sequence  
Number:

Date  
Received:

CIBMTR Center Number:

CIBMTR Recipient ID:

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  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 239.**

## Clinical and Laboratory Characteristics at Diagnosis

1. What was the date of diagnosis of Neuroblastoma?  /  /   
Month Day Year

Specify the site(s) of primary tumor(s) at diagnosis: Number of tumors present

- |                                                                                            |   |                                               |
|--------------------------------------------------------------------------------------------|---|-----------------------------------------------|
| 2. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Adrenal gland              | → | 3. <input type="text"/> <input type="text"/>  |
| 4. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Bone                       | → | 5. <input type="text"/> <input type="text"/>  |
| 6. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Bone marrow                | → | 7. <input type="text"/> <input type="text"/>  |
| 8. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Cerebellum                 | → | 9. <input type="text"/> <input type="text"/>  |
| 10. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Cerebrospinal fluid (CSF) | → | 11. <input type="text"/> <input type="text"/> |
| 12. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Cerebrum                  | → | 13. <input type="text"/> <input type="text"/> |
| 14. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Cranial nerves            | → | 15. <input type="text"/> <input type="text"/> |
| 16. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Liver                     | → | 17. <input type="text"/> <input type="text"/> |
| 18. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Lymph nodes               | → | 19. <input type="text"/> <input type="text"/> |
| 20. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Mediastinum               | → | 21. <input type="text"/> <input type="text"/> |
| 22. 1 <input type="checkbox"/> yes 2 <input type="checkbox"/> no Paraspinal ganglion       | → | 23. <input type="text"/> <input type="text"/> |

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

CIBMTR Center Number:

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- Site of primary tumor:                      Number of tumors present
24. 1  yes 2  no Retro-orbital area → 25.
26. 1  yes 2  no Skin / subcutaneous tissue → 27.
28. 1  yes 2  no Other site → 29.

30. Specify other site: \_\_\_\_\_

31. 1  yes 2  no Location of primary tumor(s) unknown

32. Were metastases present at diagnosis?

- 1  yes →  
2  no  
3  unknown

Specify the site(s) of metastases:

33. 1  yes 2  no Adrenal gland  
34. 1  yes 2  no Bone  
35. 1  yes 2  no Bone marrow  
36. 1  yes 2  no Cerebellum  
37. 1  yes 2  no Cerebrospinal fluid (CSF)  
38. 1  yes 2  no Cerebrum  
39. 1  yes 2  no Cranial nerves  
40. 1  yes 2  no Liver  
41. 1  yes 2  no Lymph nodes  
42. 1  yes 2  no Mediastinum  
43. 1  yes 2  no Paraspinal ganglion  
44. 1  yes 2  no Retro-orbital area  
45. 1  yes 2  no Skin / subcutaneous tissue  
46. 1  yes 2  no Other site →

47. Specify other site: \_\_\_\_\_

Specify any radiographic tests used to evaluate the disease status at diagnosis:

48. 1  yes 2  no CT scan  
49. 1  yes 2  no Magnetic resonance imaging (MRI)  
50. 1  yes 2  no I-meta-iodobenzylguanidine scan (MIBG)  
51. 1  yes 2  no Skeletal survey  
52. 1  yes 2  no Technetium scan

53. Were any biopsies performed at diagnosis?

- 1  yes →  
2  no

Specify the biopsy site(s) positive for neuroblastoma:

54. 1  yes 2  no Bone marrow  
55. 1  yes 2  no Primary tumor  
56. 1  yes 2  no Skin  
57. 1  yes 2  no Other site →

58. Specify other site: \_\_\_\_\_

59. Specify the histologic findings by Shimada classification:

1  stroma-rich →

60. Specify histology:

- 1  nodular  
2  well differentiated / intermixed

2  stroma-poor →  
3  not classified / unknown

61. Specify histology:

- 1  favorable  
2  unfavorable



CIBMTR Center Number:

CIBMTR Recipient ID:

Specify any methods used to determine the presence of proto-oncogenes:

82. N-myc amplification:  
1  known →  
2  not known

83. Were proto-oncogenes detected?  
1  yes →  
2  no

84. Specify copy number:

85. trk A expression:  
1  known →  
2  not known

86. Specify expression of proto-oncogenes:  
1  high  
2  low  
3  absent

87. Were any other molecular abnormalities present?  
1  yes →  
2  no  
3  unknown

88. Specify other molecular abnormality: \_\_\_\_\_

89. Is a copy of the DNA report attached?  
1  yes  
2  no

90. Was a cytogenetic analysis performed at diagnosis?

- 1  yes →
- 2  yes, but no evaluable metaphases
- 3  no
- 4  unknown

Specify the tissue(s) analyzed:

91. 1  yes 2  no Bone marrow

92. 1  yes 2  no First degree tumor

93. 1  yes 2  no Other tissue →

94. Specify other tissue: \_\_\_\_\_

95. Number of metaphases:  
1  known →   
2  not known

96. Was the karyotype abnormal?  
1  yes →  
2  no  
3  unknown

Specify the karyotype abnormalities:

97. 1  yes 2  no 3  unknown 1p-

98. 1  yes 2  no 3  unknown 14q-

99. 1  yes 2  no 3  unknown 17q+

100. 1  yes 2  no 3  unknown +17

101. 1  yes 2  no 3  unknown Other abnormality →

102. Specify: \_\_\_\_\_

103. Is a copy of the cytogenetic report attached?  
1  yes  
2  no

CIBMTR Center Number:

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104. Specify the International Neuroblastoma Staging System (INSS) disease stage at diagnosis:

- 1  Stage 1 — localized tumor with complete gross excision, with or without microscopic residual disease; representative ipsilateral lymph nodes negative for tumor microscopically (nodes attached to and removed with the primary tumor may be positive)
- 2  Stage 2A — localized tumor with incomplete gross excision; representative ipsilateral nonadherent lymph nodes negative for tumor microscopically
- 3  Stage 2B — localized tumor with or without complete gross excision, with ipsilateral nonadherent lymph nodes positive for tumor; enlarged contralateral lymph nodes must be negative microscopically
- 4  Stage 3 — unresectable unilateral tumor infiltrating across the midline (defined as the vertebral column; tumors originating on one side and crossing the midline must infiltrate to or beyond the opposite side of the vertebral column), with or without regional lymph node involvement; or localized unilateral tumor with contralateral regional lymph node involvement; or midline tumor with bilateral extension by infiltration (unresectable) or by lymph node involvement
- 5  Stage 4 — any primary tumor with dissemination to distant lymph nodes, bone, bone marrow, liver, skin and/or other organs (except as defined for Stage 4S)
- 6  Stage 4S — localized primary tumor (as defined for Stages 1, 2A, or 2B), with dissemination limited to skin, liver, and/or bone marrow (marrow involvement in Stage 4S should be minimal; i.e., < 10% of total nucleated cells identified as malignant on bone marrow biopsy or on marrow aspirate; more extensive marrow involvement would be considered to be Stage 4; the MIBG scan (if performed) should be negative in the marrow). Stage 4S is limited to infants < 1 year of age.
- 7  unknown →

If the INSS cannot be determined, then the Pediatric Oncology Group (POG) Staging System — or — The Evans Group Staging System may be reported:

105. Specify the POG Stage:

- 1  A — complete gross excision of primary tumor, margins histologically negative or positive. Intracavitary lymph nodes not intimately adhered to and removed with resected tumor must be histologically free of tumor. If primary is in abdomen or pelvis, liver must be histologically free of tumor.
- 2  B — incomplete gross resection of primary. Lymph nodes and liver must be histologically free of tumor.
- 3  C — complete or incomplete gross resection of primary. Intracavitary nodes (cavity of primary) histologically positive for tumor. Liver histologically free of tumor.
- 4  D — disseminated disease beyond intracavitary nodes in bone marrow, bone, liver, skin or lymph nodes beyond cavity containing primary tumor.
- 5  unknown

106. Specify the Evans Stage:

- 1  I — tumor confined to the organ structure of origin
- 2  II — tumors extending in continuity beyond the organ or structure of origin but not crossing the midline. Regional lymph nodes on the homolateral side may be involved.
- 3  III — tumors extending in continuity beyond the organ or structure of origin but not crossing the midline. Regional lymph nodes on the homolateral side may be involved.
- 4  IV — remote disease involving skeleton, soft tissues, distant lymph node groups, etc.
- 5  IV-S — patients with local stage I or II disease but who have remote disease confined to one or more of the following: liver, skin, bone marrow (with no evidence of bone metastases on complete skeletal survey)
- 6  unknown

CIBMTR Center Number:

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107. Are other family members known to have neuroblastoma or ganglioneuroma?

- 1  yes
- 2  no
- 3  unknown

Specify the family member(s) diagnosed with neuroblastoma or ganglioneuroma:

108. 1  yes 2  no 3  unknown Father

109. 1  yes 2  no 3  unknown Mother

110. 1  yes 2  no 3  unknown Sister

112. 1  yes 2  no 3  unknown Brother

114. 1  yes 2  no 3  unknown Other relative

111. Specify the number of sisters affected:   number unknown

113. Specify the number of brothers affected:   number unknown

115. Specify relationship: \_\_\_\_\_

116. Does the recipient have a family history of other genetic diseases in first-degree blood relatives?

- 1  yes
- 2  no
- 3  unknown

Specify the diagnoses present in the immediate family:

117. 1  yes 2  no 3  unknown Beckwith-Wiedemann syndrome (EMG syndrome)

118. 1  yes 2  no 3  unknown Nesidioblastosis

119. 1  yes 2  no 3  unknown Neurofibromatosis

120. 1  yes 2  no 3  unknown Trisomy 18

121. 1  yes 2  no 3  unknown Other disease

122. Specify genetic disease: \_\_\_\_\_

123. Did spontaneous regression of the recipient's tumor occur?

- 1  yes
- 2  no
- 3  unknown

124. Did the recipient undergo surgery as part of the initial disease treatment plan?

- 1  yes
- 2  no

125. Specify surgery timepoint:

1  at diagnosis

2  after induction chemotherapy

3  unknown

126. Specify the histological diagnosis of resected tissue:

1  ganglioneuroblastoma

2  ganglioneuroma

3  neuroblastoma

Specify the site(s) of surgery: Extent of surgery: (see definitions below)

127. Abdomen Gross Near Subtotal Partial Biopsy

1  yes 128. 1  2  3  4  5

2  no

3  unknown

Date of surgery: Month Day Year

129.

130. Head or neck

1  yes 131. 1  2  3  4  5

2  no

3  unknown

132.

133. Mediastinum

1  yes 134. 1  2  3  4  5

2  no

3  unknown

135.

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Specify the site(s) of surgery:      Extent of surgery:      Date of surgery:

(see definitions below)

136. Pelvis      Gross    Near    Subtotal    Partial    Biopsy

1  yes      →    137. 1  2  3  4  5  138.             

2  no

3  unknown

139. Other site

1  yes      →    140. 1  2  3  4  5  141.             

2  no

3  unknown      142. Specify other surgery site: \_\_\_\_\_

**Extent of Surgery Codes**

1 Gross total resection — > 95% resection, no radiographic residual tumor

2 Near total resection — 90-95% resection, minimal radiographic residual tumor

3 Subtotal resection — 51-89% resection, moderate radiographic residual tumor

4 Partial resection — 10-50% resection, significant radiographic residual tumor

5 Biopsy only — < 10% resection, no radiographic change post-op from pre-op

143. Did the recipient undergo radiotherapy as part of the initial disease treatment plan?

- 1  yes      →
- 2  no
- 3  unknown

Specify the site(s) of radiotherapy:

144. Primary tumor bed after resection

1  yes      →

2  no

145. Specify total number of fractions given:   

146. Specify the dose per fraction:           cGy (rads)

147. Other site

1  yes      →

2  no

148. Specify other radiotherapy site: \_\_\_\_\_

149. Specify total number of fractions given:   

150. Specify the dose per fraction:           cGy (rads)

CIBMTR Center Number:

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151. Did the recipient undergo chemotherapy as part of the initial disease treatment plan?

- 1  yes
- 2  no
- 3  unknown

152. Specify the date the first chemotherapy cycle began:        date unknown  
Month Day Year

153. Specify the date the last chemotherapy cycle began:        date unknown  
Month Day Year

154. Specify the total number of chemotherapy cycles given:    number unknown

Specify the treatment(s) given:

- 155. 1  yes 2  no Adriamycin
- 156. 1  yes 2  no Cisplatin
- 157. 1  yes 2  no Cyclophosphamide
- 158. 1  yes 2  no Dacarbazine (DTIC)
- 159. 1  yes 2  no Etoposide (VP16)
- 160. 1  yes 2  no Ifosfamide
- 161. 1  yes 2  no Melphalan (L-PAM)
- 162. 1  yes 2  no Retinoids
- 163. 1  yes 2  no Teniposide (VM26)
- 164. 1  yes 2  no Vincristine
- 165. 1  yes 2  no Other treatment

166. Specify treatment:

167. Specify the best response to chemotherapy: (*International Neuroblastoma Response Criteria*)

- 1  complete response (CR) — no primary tumor, no metastatic sites, catecholamines normal

168. Did neuroblastoma recur?

- 1  yes
- 2  no

169. Specify the date of recurrence:

Month Day Year

- 2  very good partial response (VGPR) — primary tumor decreased by 90-99%, no metastatic sites, catecholamines normal; residual <sup>99</sup>Tc bone changes allowed
- 3  partial response (PR) — 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 (MR) — 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 (NR) — no new lesions; < 50% reduction but < 25% increase in any existing lesion
- 6  progressive disease (PD) — any new lesions; increase of any measurable lesion by > 25%; previous negative marrow positive for tumor
- 7  not evaluable (NE)
- 8  not tested / unknown

170. Specify reason:

171. Specify the date the best response to chemotherapy was determined:        date unknown  
Month Day Year





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266. Specify the disease status immediately prior to the preparative regimen: (See question 167 for complete definitions.)

- 1  complete response →
- 2  very good partial response
- 3  partial response ➤
- 4  minimal response →
- 5  no response →
- 6  progressive disease →
- 7  not evaluable →
- 8  not tested / unknown

267. Specify the total number of complete remissions:

Specify any known sites of disease immediately prior to the preparative regimen:

- 268. 1  yes 2  no Adrenal gland
- 269. 1  yes 2  no Bone
- 270. 1  yes 2  no Bone marrow →
- 274. 1  yes 2  no Cerebellum
- 275. 1  yes 2  no Cerebrospinal fluid (CSF)
- 276. 1  yes 2  no Cerebrum
- 277. 1  yes 2  no Cranial nerves
- 278. 1  yes 2  no Liver
- 279. 1  yes 2  no Lymph nodes
- 280. 1  yes 2  no Mediastinum
- 281. 1  yes 2  no Paraspinal ganglion
- 282. 1  yes 2  no Retro-orbital area
- 283. 1  yes 2  no Skin / subcutaneous tissue
- 284. 1  yes 2  no Other site →

Specify the method(s) used to evaluate the disease status immediately prior to the preparative regimen:  
271. 1  yes 2  no Bone marrow morphology  
272. 1  yes 2  no Flow cytometric analysis  
273. 1  yes 2  no Immunofluorescence

285. Specify other site: \_\_\_\_\_

286. Specify the percent of cells positive for neuroblastoma:  .  %

287. Specify reason: \_\_\_\_\_

288. Specify the date the disease status was determined:  /  /

289. Signed: \_\_\_\_\_

*Person completing form*

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

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

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

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