Clinical and Laboratory Characteristics at Diagnosis

1. What was the date of diagnosis of Neuroblastoma?
   
<table>
<thead>
<tr>
<th>Number of</th>
<th>Tumors Present</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tumors</td>
<td>Yes</td>
</tr>
<tr>
<td>Primary</td>
<td></td>
</tr>
<tr>
<td>Tumor</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Specified Site(s) of Primary Tumor(s) at Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Adrenal gland</td>
</tr>
<tr>
<td>Bone</td>
</tr>
<tr>
<td>Bone marrow</td>
</tr>
<tr>
<td>Cerebellum</td>
</tr>
<tr>
<td>Cerebrospinal fluid (CSF)</td>
</tr>
<tr>
<td>Cerebrum</td>
</tr>
<tr>
<td>Cranial nerves</td>
</tr>
<tr>
<td>Liver</td>
</tr>
<tr>
<td>Lymph nodes</td>
</tr>
<tr>
<td>Mediastinum</td>
</tr>
<tr>
<td>Paraspinal ganglion</td>
</tr>
</tbody>
</table>

If this is a report of a second (or subsequent) transplant, check here and continue with question 239.
Number of Site of primary tumor: tumors present

24. 1 □ yes 2 □ no Retro-orbital area
26. 1 □ yes 2 □ no Skin / subcutaneous tissue
28. 1 □ yes 2 □ no Other site

30. Specify other site:

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

32. Were metastases present at diagnosis?

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:

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

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
2 □ stroma-poor
3 □ not classified / unknown

60. Specify histology:
1 □ nodular
2 □ well differentiated / intermixed

61. Specify histology:
1 □ favorable
2 □ unfavorable
Laboratory Values at Diagnosis of Neuroblastoma

62. WBC:
   1. known
   2. not known
   Specify units:
   1. \( \times 10^9/L \times 10^{3/mm^3} \)
   2. \( \times 10^9/L \)

63. Hemoglobin (untransfused):
   1. known
   2. not known
   Specify units:
   1. \( g/dL \)
   2. \( g/L \)
   3. \( mmol/L \)

64. Platelets (untransfused):
   1. known
   2. not known
   Specify units:
   1. \( \times 10^9/L \times 10^{3/mm^3} \)
   2. \( \times 10^6/L \)

65. Hematocrit:
   1. known
   2. not known

Specify the following tumor marker analyses performed at diagnosis:

66. Homovanillic acid (HVA):
   1. known
   2. not known
   Specify units:
   \( \mu g/mg \) creatinine

67. Neuron specific enolase:
   1. known
   2. not known
   Specify units:
   \( ng/mL \)

68. Serum ferritin:
   1. known
   2. not known
   Specify units:
   \( ng/mg \) or \( \mu g/L \)

69. Vanilmandelic acid (VMA):
   1. known
   2. not known
   Specify units:
   \( \mu g/mg \) creatinine

70. LDH:
   1. known
   2. not known
   Specify units:
   1. \( U/L \)
   2. \( \mu kat/L \)
   71. Upper limit of normal for LDH:

72. Other tumor marker analysis:
   1. known
   2. not known
   Specify other analysis: _______________________
   Specify level and units: _______________________

73. Specify other analysis: _______________________

74. Specify level and units: _______________________

75. Was a DNA analysis performed at diagnosis?
   1. yes
   2. no
   3. unknown
   Specify the tissue(s) analyzed:
   76. 1. yes 2. no Bone marrow
   77. 1. yes 2. no First degree tumor
   78. 1. yes 2. no Other tissue
   Specify ploidy:
   80. Modal number:
      1. known
      2. not known
   81. DNA index:
      1. known
      2. not known
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: __________________________

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

102. Specify: __________________________

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

Specify the number of metaphases:
1. known
2. not known

95. Number of metaphases:

103. Is a copy of the cytogenetic report attached?
1. yes
2. no
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
107. Are other family members known to have neuroblastoma or ganglioneuroma?

- **Yes**: Specify the family member(s) diagnosed with neuroblastoma or ganglioneuroma:
  - **Father**
  - **Mother**
  - **Sister**
  - **Brother**
  - **Other relative**

- **No**: Specify relationship: __________

- **Unknown**: Specify relationship: __________

110. Specify the number of sisters affected: __________

112. Specify the number of brothers affected: __________

115. Specify relationship: __________

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

- **Yes**: Specify the diagnoses present in the immediate family:
  - **Beckwith-Wiedemann syndrome (EMG syndrome)**
  - **Nesidioblastosis**
  - **Neurofibromatosis**
  - **Trisomy 18**
  - **Other disease**

- **No**: Specify genetic disease: __________

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

- **Yes**: __________
- **No**: __________
- **Unknown**: __________

125. Specify surgery timepoint:

- **At diagnosis**: __________
- **After induction chemotherapy**: __________
- **Unknown**: __________

126. Specify the histological diagnosis of resected tissue:

- **Ganglioneuroblastoma**: __________
- **Ganglioneuroma**: __________
- **Neuroblastoma**: __________

127. Specify the site(s) of surgery:

- **Abdomen**
  - **Gross Near Subtotal Partial Biopsy**: __________
- **Head or neck**
  - **Gross Near Subtotal Partial Biopsy**: __________
- **Mediastinum**
  - **Gross Near Subtotal Partial Biopsy**: __________

129. Date of surgery: __________

CIBMTR Form 2026 (NEU) v1.0 (6–11) July 2007
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Fax this form to your designated campus (Milwaukee 414-805-0714 or Minneapolis 612-627-5895).
143. Did the recipient undergo radiotherapy as part of the initial disease treatment plan?

1 [ ] yes  
2 [ ] no  
3 [ ] unknown  

144. Primary tumor bed after resection

1 [ ] yes  
2 [ ] no  
3 [ ] unknown  

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)
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:

Month Day Year

153. Specify the date the last chemotherapy cycle began:

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 Carbo (DTIC)
159. 1 yes 2 no Etoposide (VP16)
160. 1 yes 2 no Iloprim
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

2 very good partial response (VGPR) — primary tumor decreased by 90-99%, no metastatic sites, catecholamines normal; residual 99mTc 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

168. Did neuroblastoma recur?
1 yes 2 no

169. Specify the date of recurrence:

Month Day Year

170. Specify reason:

171. Specify the date the best response to chemotherapy was determined:

Month Day Year

☐ date unknown
172. Did the recipient undergo surgery, chemotherapy or other cytotoxic treatment for persistent or recurrent disease after the initial treatment but prior to the preparative regimen?

1  yes
2  no

CIBMTR Center Number: CIBMTR Recipient ID: 

<table>
<thead>
<tr>
<th>Line of Therapy</th>
<th>1st Line of Therapy</th>
<th>2nd Line of Therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date started therapy:</td>
<td>173.</td>
<td>206.</td>
</tr>
<tr>
<td>Date stopped therapy:</td>
<td>174.</td>
<td>207.</td>
</tr>
<tr>
<td>Systemic Therapy:</td>
<td>175. yes</td>
<td>208. yes</td>
</tr>
<tr>
<td>Number of cycles:</td>
<td>176. yes</td>
<td>209. yes</td>
</tr>
<tr>
<td>Treatment:</td>
<td>177. yes</td>
<td>210. yes</td>
</tr>
<tr>
<td>Adriamycin:</td>
<td>178. yes</td>
<td>211. yes</td>
</tr>
<tr>
<td>Cisplatin:</td>
<td>179. yes</td>
<td>212. yes</td>
</tr>
<tr>
<td>Cyclophosphamide:</td>
<td>180. yes</td>
<td>213. yes</td>
</tr>
<tr>
<td>Taxol:</td>
<td>181. yes</td>
<td>214. yes</td>
</tr>
<tr>
<td>Ifosfamide (IFEX):</td>
<td>182. yes</td>
<td>215. yes</td>
</tr>
<tr>
<td>Melphalan (L-PAM):</td>
<td>183. yes</td>
<td>216. yes</td>
</tr>
<tr>
<td>Retinoids:</td>
<td>184. yes</td>
<td>217. yes</td>
</tr>
<tr>
<td>Teniposide (VM26):</td>
<td>185. yes</td>
<td>218. yes</td>
</tr>
<tr>
<td>Vincristine:</td>
<td>186. yes</td>
<td>219. yes</td>
</tr>
<tr>
<td>Other therapy:</td>
<td>187. yes</td>
<td>220. yes</td>
</tr>
<tr>
<td>Specify other therapy:</td>
<td>188.</td>
<td>221.</td>
</tr>
<tr>
<td>Radiation Therapy:</td>
<td>189. yes</td>
<td>222. yes</td>
</tr>
<tr>
<td>Primary tumor bed:</td>
<td>190. yes</td>
<td>223. yes</td>
</tr>
<tr>
<td>Specify number of fractions:</td>
<td>191. yes</td>
<td>224. yes</td>
</tr>
<tr>
<td>Specify dose / fraction:</td>
<td>192. yes</td>
<td>225. yes</td>
</tr>
<tr>
<td>Other site:</td>
<td>193. yes</td>
<td>226. yes</td>
</tr>
<tr>
<td>Specify other site:</td>
<td>194.</td>
<td>227.</td>
</tr>
<tr>
<td>Surgical Biopsy/Resection:</td>
<td>197. yes</td>
<td>230. yes</td>
</tr>
<tr>
<td>Type of surgery:</td>
<td>199. yes</td>
<td>232. yes</td>
</tr>
<tr>
<td>Histologic diagnosis:</td>
<td>200. yes</td>
<td>233. yes</td>
</tr>
<tr>
<td>Best Response to Treatment:</td>
<td>201. yes</td>
<td>234. yes</td>
</tr>
<tr>
<td>Date response evaluated:</td>
<td>202. yes</td>
<td>235. yes</td>
</tr>
<tr>
<td>Did patient relapse/progress following this line of therapy?</td>
<td>203. yes</td>
<td>236. yes</td>
</tr>
<tr>
<td>Date of relapse/progression:</td>
<td>204. yes</td>
<td>237. yes</td>
</tr>
</tbody>
</table>

Copy and complete this page to report more than 2 lines of therapy.
Specify any sites of tumor involvement at any time after diagnosis but prior to the preparative regimen:
(For subsequent HSCT reports, list sites between last HSCT and the preparative regimen for subsequent HSCT.)

<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>239</td>
<td>yes</td>
<td>2</td>
<td>no</td>
<td>Adrenal gland</td>
<td></td>
</tr>
<tr>
<td>240</td>
<td>yes</td>
<td>2</td>
<td>no</td>
<td>Bone</td>
<td></td>
</tr>
<tr>
<td>241</td>
<td>yes</td>
<td>2</td>
<td>no</td>
<td>Bone marrow</td>
<td></td>
</tr>
<tr>
<td>242</td>
<td>yes</td>
<td>2</td>
<td>no</td>
<td>Cerebellum</td>
<td></td>
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<tr>
<td>243</td>
<td>yes</td>
<td>2</td>
<td>no</td>
<td>Cerebrospinal fluid (CSF)</td>
<td></td>
</tr>
<tr>
<td>244</td>
<td>yes</td>
<td>2</td>
<td>no</td>
<td>Cerebrum</td>
<td></td>
</tr>
<tr>
<td>245</td>
<td>yes</td>
<td>2</td>
<td>no</td>
<td>Cranial nerves</td>
<td></td>
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<tr>
<td>246</td>
<td>yes</td>
<td>2</td>
<td>no</td>
<td>Liver</td>
<td></td>
</tr>
<tr>
<td>247</td>
<td>yes</td>
<td>2</td>
<td>no</td>
<td>Lymph nodes</td>
<td></td>
</tr>
<tr>
<td>248</td>
<td>yes</td>
<td>2</td>
<td>no</td>
<td>Mediastinum</td>
<td></td>
</tr>
<tr>
<td>249</td>
<td>yes</td>
<td>2</td>
<td>no</td>
<td>Paraspinal ganglion</td>
<td></td>
</tr>
<tr>
<td>250</td>
<td>yes</td>
<td>2</td>
<td>no</td>
<td>Retro-orbital area</td>
<td></td>
</tr>
<tr>
<td>251</td>
<td>yes</td>
<td>2</td>
<td>no</td>
<td>Skin / subcutaneous tissue</td>
<td></td>
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<tr>
<td>252</td>
<td>yes</td>
<td>2</td>
<td>no</td>
<td>Other site</td>
<td></td>
</tr>
</tbody>
</table>

Disease Status Immediately Prior to the Preparative Regimen

254. Were tumor marker analyses performed immediately prior to the preparative regimen?

1. [ ] yes
   2. [ ] no

Specify the following tumor marker analyses performed:

- 255. Homovanillic acid (HVA):
  1. [ ] known
  2. [ ] not known

- 257. Neuron specific enolase:
  1. [ ] known
  2. [ ] not known

- 259. Serum ferritin:
  1. [ ] known
  2. [ ] not known

- 261. Vanilmandelic acid (VMA):
  1. [ ] known
  2. [ ] not known

- Other tumor marker analysis:
  1. [ ] known
  2. [ ] not known

Specify other analysis:

Specify level and units:

Fax this form to your designated campus (Milwaukee 414-805-0714 or Minneapolis 612-627-5895).
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

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 marrow
270. 1 ☐ yes 2 ☐ no Bone
271. 1 ☐ yes 2 ☐ no Bone marrow morphology
272. 1 ☐ yes 2 ☐ no Flow cytometric analysis
273. 1 ☐ yes 2 ☐ no Immunofluorescence
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
285. Specify other site:

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

287. Specify reason:

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

288. Specify the date the disease status was determined:

Month Day Year

289. Signed: ____________________________

Person completing form

Please print name: ____________________________

Phone: (____________) ____________________________

Fax: (____________) ____________________________

E-mail address: ____________________________