Form 2026 R2.0: Neuroblastoma Pre-HSCT Data

Center: CRID:

Key Fields

Sequence Number: _____

Date Received: __ __ __ __ - __ __- __ __

CIBMTR Center Number: _____

CIBMTR Recipient ID: _____

Today's Date: __ __ __ __ - __ __- __ __

Date of HSCT for which this form is being completed: __ __ __ __ - __ __- __ __

HSCT type (check only one)

- Autologous
- Allogeneic, unrelated
- Allogeneic, related
- Syngeneic (identical twin)

Product type (check only one)

- Marrow
- PBSC
- Cord blood
- Other product

Specify: _____

- If this is a report of a second or subsequent transplant, check here and continue with question 218.

Clinical and Laboratory Characteristics at Diagnosis

Questions: 1 - 61

1 What was the date of diagnosis of Neuroblastoma? __ __ __ __ - __ __- __ __

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

2 Adrenal gland

yes no

3 Number of tumors present _____

4 Bone

yes no

5 Number of tumors present _____

6 Bone marrow

yes no

7 Number of tumors present _____

8 Cerebellum

yes no

9 Number of tumors present _____

10 Cerebrospinal fluid (CSF)

yes no

11 Number of tumors present _____

12 Cerebrum

yes no

13 Number of tumors present _____

14 Cranial nerves

yes no

15 Number of tumors present _____

16 Liver

yes no

17 Number of tumors present _____

18 Lymph nodes

yes no

19 Number of tumors present _____

20 Mediastinum

yes no

21 Number of tumors present _____

22 Paraspinal ganglion

yes no

23 Number of tumors present _____

24 Retro-orbital area

yes no

25 Number of tumors present _____

26 Skin / subcutaneous tissue

yes no

27 Number of tumors present _____

28 Other site:

yes no

29 Number of tumors present _____

30 Specify other site: _____

31 Location of primary tumor(s) unknown

yes no

32 Were metastases present at diagnosis?

yes no Unknown

Specify the site(s) of metastases:

33 Adrenal gland

yes no

34 Bone

yes no

35 Bone marrow

yes no

36 Cerebellum

yes no

37 Cerebrospinal fluid (CSF)

yes no

38 Cerebrum

yes no

39 Cranial nerves

yes no

40 Liver

yes no

41 Lymph nodes

yes no

42 Mediastinum

yes no

43 Paraspinal ganglion

yes no

44 Retro-orbital area

yes no

45 Skin / subcutaneous tissue

yes no

46 Other site:

yes no

47 Specify other site: _____

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

48 CT scan

yes no

49 Magnetic resonance imaging (MRI)

yes no

50 I-meta-iodobenzylguanidine scan (MIBG)

yes no

51 Skeletal survey

yes no

52 Technetium scan

yes no

53 Were any biopsies performed at diagnosis?

yes no

Specify the biospy site(s) postivie for neuroblastoma:

54 Bone Marrow

yes no

55 Primary tumor

yes no

56 Skin

yes no

57 Other site:

yes no

58 Specify other site: _____

59 Specify the histologic findings by Shimada classification:

stroma-rich

stroma-poor

not classified / unknown

60 Specify histology:

nodular

well differentiated / intermixed

61 Specify histology:

favorable unfavorable

Laboratory Values at Diagnosis of Neuroblastoma

Questions: 62 - 232

62 WBC:

Known Not known

63 _____ x 10^9/L (x 10^3/mm^3)

x 10^6/L

64 Hemoglobin (untransfused):

Known Not known

65 _____ g/dL g/L mmol/L

66 Platelets (untransfused):

Known Not known

67 _____ x 10^9/L (x 10^3/mm^3)

x 10^6/L

68 Hematocrit:

Known Not known

69 _____ **%**

Specify the following tumor marker analyses performed at diagnosis:

70 Homovanillic acid (HVA):

Known Not known

71 _____ **µg/mg creatinine**

72 Neuron specific enolase:

Known Not known

73 _____ **ng/mL**

74 Serum ferritin:

Known Not known

75 _____ **ng/mg or µg/L**

76 Vanilmandelic acid (VMA):

Known Not known

77 _____ **µg/mg creatinine**

78 LDH:

Known Not known

79 _____ U/L µkat/L

80 Upper limit of normal for LDH: _____

81 Other tumor marker analysis:

Known Not known

82 Specify other analysis: _____

83 Specify level and units: _____

84 Was a DNA analysis performed at diagnosis?

yes no Unknown

Specify the tissue(s) analyzed:

85 Bone marrow

yes no

86 First degree tumor

yes no

87 Other tissue

yes no

88 Specify other tissue: _____

Specify ploidy:

89 Modal number:

Known Not known

90 _____

91 DNA index:

Known Not known

92 _____

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

93 N-myc amplification:

Known Not known

94 Were proto-oncogenes detected?

yes no

95 Specify copy number: _____

96 trk A expression:

Known Not known

97 Specify expression of proto-oncogenes:

high low Absent

98 Were any other molecular abnormalities present?

yes no Unknown

99 Specify other molecular abnormality: _____

100 Is a copy of the DNA report attached?

yes no

101 Was a cytogenetic analysis performed at diagnosis?

Yes

yes, but no evaluable metaphases

No

Unknown

Specify the tissue(s) analyzed:

102 Bone marrow

yes no

103 First degree tumor

yes no

104 Other tissue

yes no

105 Specify other tissue: _____

106 Number of metaphases:

Known Not known

107 _____

108 Was the karyotype abnormal?

yes no Unknown

Specify the karyotype abnormalities:

109 1p-

yes no Unknown

110 14q-

yes no Unknown

111 17q+

yes no Unknown

112 +17

yes no Unknown

113 Other abnormality

yes no Unknown

114 Specify: _____

115 Is a copy of the cytogenetic report attached?

yes no

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

- 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)
- Stage 2A - localized tumor with incomplete gross excision; representative ipsilateral nonadherent lymph nodes negative for tumor microscopically
- 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
- 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
- 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)
- 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.
- Unknown

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

117 Specify the POG Stage:

- 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.
- B - incomplete gross resection of primary. Lymph nodes and liver must be histologically free of tumor.
- C - complete or incomplete gross resection of primary. Intracavitary nodes (cavity of primary) histologically positive for tumor. Liver histologically free of tumor.
- D - disseminated disease beyond intracavitary nodes in bone marrow, bone, liver, skin or lymph nodes beyond cavity containing primary tumor.
- Unknown

118 Specify the Evans Stage:

- I - tumor confined to the organ structure of origin
- 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.
- 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.
- IV - remote disease involving skeleton, soft tissues, distant lymph node groups, etc.
- 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)
- Unknown

119 Are other family members known to have neuroblastoma or ganglioneuroma?

yes no Unknown

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

120 Father

yes no Unknown

121 Mother

yes no Unknown

122 Sister

yes no Unknown

123 Specify the number of sisters affected: _____ Number of affected sisters unknown

124 Brother

yes no Unknown

125 Specify the number of brothers affected: _____ Number of affected brothers unknown

126 Other relative

yes no Unknown

127 Specify relationship: _____

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

yes no Unknown

Specify the diagnoses present in the immediate family:

129 Beckwith-Wiedemann syndrome (EMG syndrome)

yes no Unknown

130 Nesidioblastosis

yes no Unknown

131 Neurofibromatosis

yes no Unknown

132 Trisomy 18

yes no Unknown

133 Other disease

yes no Unknown

134 Specify genetic disease: _____

135 Did spontaneous regression of the recipient's tumor occur?

yes no Unknown

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

yes no

137 Specify surgery timepoint:

at diagnosis

after induction chemotherapy

Unknown

138 Specify the histological diagnosis of resected tissue:

ganglioneuroblastoma ganglioneuroma neuroblastoma

Specify the site(s) of surgery:

139 Abdomen

yes no Unknown

140 Extent of surgery:

Gross Near Subtotal Partial Biopsy

141 Date of surgery: __ __ __ __ - __ __- __ __

142 Head or neck

yes no Unknown

143 Extent of surgery:

- Gross **->95% resection, no radiographic residual tumor**
- Near **-90-95% resection, minimal radiographic residual tumor**
- Subtotal **-51-89% resection, moderate radiographic residual tumor**
- Partial **-10-50% resection, significant radiographic residual tumor**
- Biopsy **-<10% resection, no radiographic change post-op from pre-op**

144 Date of surgery: __ __ __ __ - __ __- __ __

145 Mediastinum

yes no Unknown

146 Extent of surgery:

Gross Near Subtotal Partial Biopsy

147 Date of surgery: __ __ __ __ - __ __- __ __

148 Pelvis

yes no Unknown

149 Extent of surgery:

Gross Near Subtotal Partial Biopsy

150 Date of surgery: __ __ __ __ - __ __- __ __

151 Other site:

yes no Unknown

152 Extent of surgery:

Gross Near Subtotal Partial Biopsy

153 Date of surgery: __ __ __ __ - __ __- __ __

154 Specify other surgery site: _____

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

yes no Unknown

Specify the site(s) of radiotherapy:

156 Primary tumor bed after resection

yes no

157 Specify total number of fractions given: _____

158 Specify the dose per fraction: _____ **cGy (rads)**

159 Other site:

yes no

160 Specify other radiotherapy site: _____

161 Specify total number of fractions given: _____

162 Specify the dose per fraction: _____ **cGy (rads)**

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

yes no Unknown

164 Specify the date the first chemotherapy cycle began: __ __ __ __ - __ __- __ __ Date the first chemotherapy cycle began unknown

165 Specify the date the last chemotherapy cycle began: __ __ __ __ - __ __- __ __ Date the last chemotherapy cycle began unknown

166 Specify the total number of chemotherapy cycles given: _____ Number of chemotherapy cycles given unknown

Specify the treatment(s) given:

167 Adriamycin

yes no

168 Cisplatin

yes no

169 Cyclophosphamide

yes no

170 Dacarbazine (DTIC)

yes no

171 Etoposide (VP16)

yes no

172 Ifosfamide

yes no

173 Melphalan (L-PAM)

yes no

174 Retinoids

yes no

175 Teniposide (VM26)

yes no

176 Vincristine

yes no

177 Other treatment

yes no

178 Specify treatment: _____

179 Specify the best response to chemotherapy:

(Internationl Neuroblastoma Response Criteria)

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

very good partial response (VGPR) - primary tumor decreased by 90-99%, no metastatic sites, catecholamines normal; residual ^{99}Tc bone changes allowed

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 positve marrow aspirate or biopsy allowed if this represents a decrease from the number of postive sites at diagnosis

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

no response (NR) - no new lesions; < 50% reduction but < 25% increase in any existing lesion

progressive disease (PD) - any new lesions; increase of any measurable lesion by > 25%; previous negative marrow positive for tumor

not evaluable (NE)

not tested / unknown

180 Did neuroblastoma recur?

yes no

181 Specify the date of recurrence: __ __ __ __ - __ __- __ __

182 Specify reason: _____

183 Specify the date of the best response to chemotherapy was determined __ __ __ __ - __ __- __ __ Date best response to chemotherapy was determined unknown

184 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?

yes no

Line of Therapy (1) **Questions: 185 - 217**

185 Date therapy started: __ __ __ __ - __ __- __ __

186 Date therapy stopped: __ __ __ __ - __ __- __ __

187 Systemic Therapy:

yes no

188 Number of cycles _____ Number of cycles unknown/not applicable

Treatment:

189 Adriamycin:

yes no

190 Cisplatin:

yes no

191 Cyclophosphamide:

yes no

192 Dacarbazine (DTIC):

yes no

193 Etoposide (VP-16)

yes no

194 Ifosfamide (IFEX):

yes no

195 Melphalan (L-PAM):

yes no

196 Retinoids:

yes no

197 Teniposide (VM26):

yes no

198 Vincristine:

yes no

199 Other therapy:

yes no

200 Specify other therapy _____

201 Radiation Therapy:

yes no

202 Primary tumor bed:

yes no

203 Specify number of fractions: _____ **cGy (rads)**

204 Specify dose / fraction: _____ **cGy (rads)**

205 Other site:

yes no

206 Specify other site: _____

207 Specify number of fractions: _____ **cGy (rads)**

208 Specify dose / fraction: _____ **cGy (rads)**

209 Surgical Biopsy/Resection:

yes no

210 Specify site: _____

211 Type of surgery:

gross total near total subtotal partial biopsy

212 Histologic diagnosis:

neuroblastoma ganglioneuroblastoma ganglioneuroma

213 Best response to line of therapy:

CR **-Complete response-no primary tumor, no metastatic sites, catecholamines normal**

VGPR **-Very good partial response-primary tumor decreased by 90-99%, no metastatic sites catecholamines normal; residual 99Tc bone changes allowed**

PR **-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**

MR **-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**

NR **-No response-no new lesions; <50% reduction but <25% increase in any existing lesion**

PD **-Progressive disease-any new lesions; increase of any measurable lesion by >25%; previous negative marrow positive for tumor**

NE **-Not evaluable**

Unk **-Unknown**

214 Specify reason: _____

215 Date response evaluated: __ __ __ __ - __ __- __ __

216 Did the patient relapse/progress following this line of therapy?

yes no

217 Date of relapse/progression: __ __ __ __ - __ __- __ __

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.)*

218 Adrenal gland

yes no

219 Bone

yes no

220 Bone marrow

yes no

221 Cerebellum

yes no

222 Cerebrospinal fluid (CSF)

yes no

223 Cerebrum

yes no

224 Cranial nerves

yes no

225 Liver

yes no

226 Lymph nodes

yes no

227 Mediastinum

yes no

228 Paraspinal ganglion

yes no

229 Retro-orbital area

yes no

230 Skin / subcutaneous tissue

yes no

231 Other site:

yes no

232 Specify other site: _____

Disease Status Immediately Prior to Preparative Regiman

Questions: 233 - 271

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

yes no

Specify the following tumor marker analyses performed:

234 Homovanillic acid (HVA):

Known Not known

235 _____ **µg/mg creatinine**

236 Date of analysis: __ __ __ __ - __ __- __ __

237 Neuron specific enolase:

Known Not known

238 _____ **ng/mL**

239 Date of analysis: __ __ __ __ - __ __- __ __

240 Serum ferritin:

Known Not known

241 _____ **ng/mg or µg/L**

242 Date of analysis: __ __ __ __ - __ __- __ __

243 Vanilmandelic acid (VMA):

Known Not known

244 _____ **µg/mg creatinine**

245 Date of analysis: __ __ __ __ - __ __- __ __

246 Other tumor marker analysis:

Known Not known

247 Specify other analysis: _____

248 Specify level and units: _____

249 Specify the disease status immediately prior to the preparative regimen:

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

very good partial response (VGPR) - primary tumor decreased by 90-99%, no metastatic sites, catecholamines normal; residual ^{99}Tc bone changes allowed

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 positve marrow aspirate or biopsy allowed if this represents a decrease from the number of postive sites at diagnosis

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

no response (NR) - no new lesions; < 50% reduction but < 25% increase in any existing lesion

progressive disease (PD) - any new lesions; increase of any measurable lesion by > 25%; previous negative marrow positive for tumor

not evaluable (NE)

not tested / unknown

250 Specify the total number of complete remissions: _____

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

251 Adrenal gland

yes no

252 Bone

yes no

253 Bone Marrow

yes no

Specify the method(s) used to evaluate the disease status immediately prior to the preparative regimen:

254 Bone marrow morphology

yes no

255 Flow cytometric analysis

yes no

256 Immunofluorescence

yes no

257 Cerebellum

yes no

258 Cerebrospinal fluid (CSF)

yes no

259 Cerebrum

yes no

260 Cranial nerves

yes no

261 Liver

yes no

262 Lymph nodes

yes no

263 Mediastinum

yes no

264 Paraspinal ganglion

yes no

265 Retro-orbital area

yes no

266 Skin / subcutaneous tissue

yes no

267 Other site:

yes no

268 Specify other site: _____

269 Specify the percent of cells positive for neuroblastoma: _____ %

270 Specify reason: _____

271 Specify the date the disease status was determined: __ __ __ __ - __ __- __ __

First Name: _____ Last Name: _____

Phone: _____ Fax number: _____

E-mail address: _____