National Marrow Donor Program®
Insert IX – Hemphagocytic Lymphohistiocytosis Post-Transplant Follow-Up Form

Registry Use Only

Sequence Number:

Date Received:

Unrelated

Recipient NMDP ID: ☐☐☐ - ☐☐☐ - ☐

Recipient Last Name: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Recipient Local ID (optional): ☐☐☐☐☐☐☐☐☐☐

Today's Date: ☐☐ Month ☐☐ Day ☐☐ Year TC Code: ☐☐☐

Date of Transplant for which this form is being completed: ☐☐ Month ☐☐ Day ☐☐ Year

Visit: ☐ 100 day ☐ 6 month ☐ 1 year ☐ 2 year

Product type: ☐ Marrow (Form 130/140) ☐ PBSC (Form 530/540) ☐ Cord blood (Form 630/640)

This form must be accompanied by Form 130, 530, 630 – 100-Day Follow-up Visit of Recipient or Form 140, 540, 640 – Six Month to Two Year Follow-up Visit of Recipient. All information in the box above, including the date, should be identical with the corresponding Form 130, 530, 630 or Form 140, 540, 640. Information should come from an actual examination by the Transplant Center physician or the physician who is following the recipient post transplant, or abstraction of the recipient's medical records.

1. Clinical status post-transplant:
   a. Splenomegaly (> 3 cm below left costal margin) 1 ☐ present 2 ☐ absent 3 ☐ unknown
   b. Hepatomegaly (> 3 cm below right costal margin) 1 ☐ present 2 ☐ absent 3 ☐ unknown
   c. Hypofibrinogenemia (< 150 mg/dL) 1 ☐ present 2 ☐ absent 3 ☐ unknown
   d. Hypertriglyceridemia (> 200 mg/dL) 1 ☐ present 2 ☐ absent 3 ☐ unknown

2. Cerebrospinal fluid findings:
   a. WBC count: 1 ☐ ≤ 5 cells/µl 2 ☐ > 5 cells/µl 3 ☐ not tested
   b. Neopterin level: 1 ☐ normal 2 ☐ elevated 3 ☐ not tested
   c. Protein: 1 ☐ normal 2 ☐ elevated 3 ☐ not tested

3. Clinical neurologic status post-transplant:
   1 ☐ normal
   2 ☐ abnormal →

4. Specify neurologic dysfunction:

	Improvement in Pre-Transplant Abnormalities	Stable Pre-Transplant Abnormalities	Deterioration of Pre-Transplant Abnormalities	Abnormalities Developed Post-transplant
a. Seizures	1 ☐ yes 2 ☐ no	3 ☐ yes 4 ☐ no	5 ☐ yes 6 ☐ no	7 ☐ yes 8 ☐ no
b. Mental retardation	1 ☐ yes 2 ☐ no	3 ☐ yes 4 ☐ no	5 ☐ yes 6 ☐ no	7 ☐ yes 8 ☐ no
c. Developmental delay	1 ☐ yes 2 ☐ no	3 ☐ yes 4 ☐ no	5 ☐ yes 6 ☐ no	7 ☐ yes 8 ☐ no
d. Abnormal gait	1 ☐ yes 2 ☐ no	3 ☐ yes 4 ☐ no	5 ☐ yes 6 ☐ no	7 ☐ yes 8 ☐ no
e. Motor weakness	1 ☐ yes 2 ☐ no	3 ☐ yes 4 ☐ no	5 ☐ yes 6 ☐ no	7 ☐ yes 8 ☐ no
f. Sensory deficits	1 ☐ yes 2 ☐ no	3 ☐ yes 4 ☐ no	5 ☐ yes 6 ☐ no	7 ☐ yes 8 ☐ no
g. Other, specify: _____	1 ☐ yes 2 ☐ no	3 ☐ yes 4 ☐ no	5 ☐ yes 6 ☐ no	7 ☐ yes 8 ☐ no

Mail to NMDP Registry with Form 130/140, 530/540, 630/640.
Retain a copy at the transplant center.

NMDP Form 130, 530, 630 / 140, 540, 640 Insert IX v1 (1–2) December 2001

For internal use only: Document F00049 12/21/2001 Replaces: n/a

Recipient NMDP ID: | | | | - | | | | - | |

Recipient Last Name: | | | | | | | | | | | | | | | |

5. MRI or CT CNS findings post-transplant: *(Please attach a copy of the report, and note that it pertains to question 5.)*
   1 ☐ Improvement in pre-transplant abnormalities
   2 ☐ Stable pre-transplant abnormalities
   3 ☐ Worsening of pre-transplant abnormalities
   4 ☐ MRI / CT not performed

6. Clinical status post-transplant of natural killer cell activity:
   1 ☐ absent (< 10% normal)
   2 ☐ decreased
   3 ☐ normal
   4 ☐ increased
   5 ☐ not tested

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