NMDP140

National Marrow Donor Program®
Six Month to Two Year Follow-Up Visit of Recipient

Registry Use Only

Sequence Number: ____

Date Received: ____

N140DT

Unrelated Recipient NMDP ID: ___ - ___ - ___

Recipient Last Name: ____

Related Unique Recipient Number (UPN): ____

Unrelated and Related 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: ☐ 6 month ☐ 1 year ☐ 2 year

Product type: ☐ Marrow (Form 140) ☐ PBSC (Form 540) ☐ Cord blood (Form 640)

Unrelated Donor Marrow Transplant and Related Donor Marrow Transplant for CML Recipient

Information should come from an actual examination by the transplant center physician, or the private physician who is following the recipient post-transplant.

1. Date of actual contact with recipient to determine medical status for this follow-up report: ___ (Month) ___ (Day) ____ (Year)

2. Did recipient receive a subsequent stem cell infusion (bone marrow, mobilized peripheral blood stem cells, cord blood) since last report? STEMCEL4
   - 1 ☐ yes → Answer questions 164–166 on page 18.
   - 2 ☐ no

3. Did recipient die since last report? DIED4
   - 1 ☐ yes → Answers to subsequent questions should reflect clinical status immediately prior to death.
   - 2 ☐ no → Answers to subsequent questions should reflect clinical status on day of actual contact for this follow-up evaluation.

4. Has recipient received an infusion of peripheral blood mononuclear cells or lymphocytes from the donor since last report?
   - 1 ☐ yes →
   - 2 ☐ no

   PBMCDR4

   5. Date the first infusion was given: ___ (Month) ___ (Day) ____ (Year) PBMCDT4
   6. Recipient weight within 2 weeks of first infusion: ___ kg PPMCWT4
   7. Total number of infusions: ___ PPMCNUM4
   8. Total dose of mononuclear cells: ___ • ___ x 10^{10} PPMCMNC4
   9. Indication for the infusion(s) of donor cells: PBMCIND4
      - 1 ☐ Relapse
      - 2 ☐ Treatment for B cell lymphoproliferative disorder
      - 3 ☐ Prophylaxis against B cell lymphoproliferative disorder
      - 4 ☐ Graft failure
      - 5 ☐ Viral infection, specify: _____
      - 6 ☐ Other, specify: _____

Mail this form to:
The NMDP Registry, Suite 500,
3433 Broadway St. N.E., Minneapolis, MN 55413
Retain a copy at the transplant center.

NMDP Form 140, 540, 640 V5 (1–18) November 1998

Recipient NMDP ID: ☐☐☐-☐☐☐-☐ Recipient Last Name: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

ıatopoietic Reconstitution Post-Transplant

10. Has the recipient received hematopoietic, lymphoid growth factors or cytokines since last report?

1 ☐ yes → 11. Specify agents given:
2 ☐ no

GCSFAD B4/E4
GMAD B4/E4
ERYTAD B4/E4
THROAD B4/E4
IL2AD
IL3AD
IL6AD
PIXYAD
SCFAD
ALPHAD
GAMMAD
BGFAD
OTHRAD

INDC4X13

	Yes	No	Date started Month	Day	Year	Date stopped Month	Day	Year	Code (below)
a. G-CSF	1 ☐	2 ☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐
b. GM-CSF	1 ☐	2 ☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐
c. Erythropoietin	1 ☐	2 ☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐
d. Thrombopoietin	1 ☐	2 ☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐
e. Interleukin – 2 (IL-2)	1 ☐	2 ☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐
f. Interleukin – 3 (IL-3)	1 ☐	2 ☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐
g. Interleukin – 6 (IL-6)	1 ☐	2 ☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐
h. PIXY – 321	1 ☐	2 ☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐
i. Stem Cell Factor (SCF)	1 ☐	2 ☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐
j. Interferon alpha	1 ☐	2 ☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐
k. Interferon gamma	1 ☐	2 ☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐
l. Blinded growth factor trial, specify agent: _____	1 ☐	2 ☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐
m. Other, specify: _____	1 ☐	2 ☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐	☐

Codes for Indication of Therapy

1. Intervention for delay/decline in absolute neutrophil count (ANC)
2. Intervention for delay/decline in platelets
3. Intervention for delay/decline in both ANC and platelets
4. Intervention for delay/decline in red blood cell counts
5. Antileukemic or tumor agent (prevention)
6. Antileukemic or tumor agent (treatment)
7. Other intervention therapy

12. After being off growth factors for at least 30 days, did the recipient receive other courses of growth factors or cytokines post-transplant?

1 ☐ yes
2 ☐ no
3 ☐ unknown

HLAFC304

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.ulopoiesis

HEMREC4

13. Did the recipient achieve an *initial* hematopoietic recovery (ANC ≥ 500/mm³ for 3 consecutive lab values obtained on different days) since last report?

1 ☐ Yes →

14. Date ANC ≥ 500/mm³ (first of 3 consecutive lab values): ANCNDT4 ☐☐ Month ☐☐ Day ☐☐☐☐ Year

15. Was ANC ≥ 1,000/mm³ achieved and sustained for 3 consecutive lab values?

1 ☐ yes →

Date (first of 3 consecutive lab values): ANCNUDT4 ☐☐ Month ☐☐ Day ☐☐☐☐ Year

2 ☐ no ANCNUYN4

Continue with 16

2 ☐ No, recipient's initial hematopoietic recovery was recorded on a previous report

Continue with 16

3 ☐ No, recipient has never achieved an ANC ≥ 500/mm³ for three consecutive lab values obtained on different days and there is no evidence of recurrent disease

Continue with 26

4 ☐ No, recipient has never achieved an ANC ≥ 500/mm³ for three consecutive lab values obtained on different days and there was documented persistent malignant disease post-transplant

Continue with 68

16. Following initial hematopoietic recovery (ANC ≥ 500/mm³ for three consecutive lab values obtained on different days) did the recipient experience a subsequent decline in ANC to < 500/mm³ for greater than three days since last report?

☐ yes →

2 ☐ no ANCYYN4

Continue with 31

17. Date of decline in ANC to < 500/mm³ for greater than 3 days (first of 3 days that ANC declined): ☐☐ Month ☐☐ Day ☐☐☐☐ Year ANCYDDT4

Actual CBC on first day of decline:

18. WBC: ☐☐☐☐.☐ x 10⁹/L ANCWBC4

19. Neutrophils: ☐☐.☐ % ANCNEU4

20. Lymphocytes: ☐☐.☐ % ANCLYM4

21. Did recipient recover and maintain ANC ≥ 500/mm³ following the decline?

1 ☐ yes →

2 ☐ no ANCRYN4

22. Date of ANC recovery: ☐☐ Month ☐☐ Day ☐☐☐☐ Year

Actual CBC on first day of recovery: ANCYRDT4

23. WBC: ☐☐☐☐.☐ x 10⁹/L ANCRWBC4

24. Neutrophils: ☐☐.☐ % ANCRNEU4

25. Lymphocytes: ☐☐.☐ % ANCRLYM4

Continue with 26

Recipient NMDP ID: ☐☐☐-☐☐☐-☐ Recipient Last Name: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

uspected etiology of failure to achieve ANC ≥ 500/mm³ or a decline in ANC:

a. Persistent disease or relapse
1 ☐ yes
2 ☐ no
ANCPDR4

b. Immune mediated rejection
1 ☐ yes →
2 ☐ no
ANCIM4X5

27. Immune mediated etiology:
a. 1 ☐ yes 2 ☐ no Cellular
b. 1 ☐ yes 2 ☐ no Antibody
c. 1 ☐ yes 2 ☐ no Third party engraftment
d. 1 ☐ yes 2 ☐ no Unknown

c. Graft versus host disease
1 ☐ yes
2 ☐ no
ANCGVHD4

d. Non-viral infection
1 ☐ yes
2 ☐ no
ANCNVI4

e. Suspected viral infection
1 ☐ yes →
2 ☐ no
ANCSV4X6

28. Suspected virus:
a. 1 ☐ yes 2 ☐ no Cytomegalovirus (CMV)
b. 1 ☐ yes 2 ☐ no Human Herpesvirus Type 6 (HHV6)
c. 1 ☐ yes 2 ☐ no Herpes Simplex Virus (HSV)
d. 1 ☐ yes 2 ☐ no Varicella
e. 1 ☐ yes 2 ☐ no Other, specify: _____

f. Documented viral infection
1 ☐ yes →
2 ☐ no
ANCDV4X6

29. Virus involved:
a. 1 ☐ yes 2 ☐ no Cytomegalovirus (CMV)
b. 1 ☐ yes 2 ☐ no Human Herpesvirus Type 6 (HHV6)
c. 1 ☐ yes 2 ☐ no Herpes Simplex Virus (HSV)
d. 1 ☐ yes 2 ☐ no Varicella
e. 1 ☐ yes 2 ☐ no Other, specify: _____

g. Antimicrobial therapy
1 ☐ yes →
2 ☐ no
ANCCAM4X4

30. Therapy:
a. 1 ☐ yes 2 ☐ no Ganciclovir
b. 1 ☐ yes 2 ☐ no Bactrim, Septra, Trimethoprim/Sulfamethoxazole
c. 1 ☐ yes 2 ☐ no Other, specify: _____

h. Undetermined
1 ☐ yes
2 ☐ no
ANCUD4

Megakaryopoiesis

The following questions relate to *initial* platelet recovery. All dates should reflect no transfusions in previous 7 days, and the first of 3 consecutive laboratory values obtained on different days.

31. Did recipient achieve an initial platelet count of ≥ 20,000 since last report? PLI2LR4

1 ☐ Yes → **Continue with 32**
2 ☐ No, recipient achieved a platelet count of ≥ 20,000 prior to current report but < 50,000 → **Continue with 34**
3 ☐ No, recipient achieved a platelet count of ≥ 50,000 prior to current report but < 100,000 → **Continue with 36**
☐ No, recipient achieved a platelet count of ≥ 100,000 prior to current report → **Continue with 40**
5 ☐ No, recipient never achieved a platelet count of ≥ 20,000 → **Continue with 49**

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Was a platelet count of ≥ 20,000 achieved? PLI2YN4

1 ☐ yes → 33. Date platelets ≥ 20,000: ☐☐ Month ☐☐ Day ☐☐☐☐ Year PLI2DT4

2 ☐ no → **Continue with 38**

34. Was a platelet count of ≥ 50,000 achieved? PLI5YN4

1 ☐ yes → 35. Date platelets ≥ 50,000: ☐☐ Month ☐☐ Day ☐☐☐☐ Year PLI5DT4

2 ☐ no → **Continue with 38**

36. Was a platelet count of ≥ 100,000 achieved? PLI10YN4

1 ☐ yes → 37. Date platelets ≥ 100,000: ☐☐ Month ☐☐ Day ☐☐☐☐ Year PLI10DT4

2 ☐ no

38. Was recipient ever platelet transfusion independent? PLITIYN4

1 ☐ yes → 39. Is the date of the last platelet transfusion known?

1 ☐ yes → ☐☐ Month ☐☐ Day ☐☐☐☐ Year PLITIDT4

2 ☐ no PLITIKN4

If recipient was platelet transfusion independent for ≥ 14 days and then subsequently experienced a decline in platelet count and required platelet transfusions, record date of last platelet transfusion *before decline in counts*. If recipient has not required platelet transfusions since initial platelet recovery, record date of last platelet transfusion.

2 ☐ no → **Continue with 51**

After initial recovery to platelet count ≥ 20,000 did the platelet count decline to < 20,000 for 3 consecutive laboratory values or a decline to < 20,000 for one laboratory value and the recipient received a platelet transfusion?

1 ☐ yes → PLIDYN4

41. Date of the first day platelet count declined below 20,000: ☐☐ Month ☐☐ Day ☐☐☐☐ Year PLIDDT4

42. Has platelet count recovered? PLIRYN4

1 ☐ yes → **Continue with 43**

2 ☐ no → **Continue with 49**

2 ☐ no → **Continue with 49**

The following date questions relate to *subsequent* platelet recovery following a decline of platelet count to below 20,000. All dates should reflect no transfusions in previous 7 days, and the first of 3 consecutive laboratory values.

43. Was a platelet count of ≥ 20,000 achieved?

1 ☐ yes → PLS2YN4

44. Date platelets ≥ 20,000: ☐☐ Month ☐☐ Day ☐☐☐☐ Year PLS2DT4

2 ☐ no → **Continue with 49**

45. Was a platelet count of ≥ 50,000 achieved?

1 ☐ yes → PLS5YN4

46. Date platelets ≥ 50,000: ☐☐ Month ☐☐ Day ☐☐☐☐ Year PLS5DT4

2 ☐ no → **Continue with 49**

47. Was a platelet count of ≥ 100,000 achieved?

☐ yes → PLS10YN4

2 ☐ no

48. Date platelets ≥ 100,000: ☐☐ Month ☐☐ Day ☐☐☐☐ Year PLS10DT4

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; recipient now receiving platelet transfusions?

1 ☐ yes → **Continue with 51**

2 ☐ no → 50. Is the date of the last platelet transfusion known?

PLSREC4

1 ☐ yes → ☐☐ Month ☐☐ Day ☐☐☐☐ Year PLSDT4

2 ☐ no

3 ☐ previously reported PLSKNWN4

If platelet count ≥ 100,000 achieved, continue with question 56. Otherwise continue with question 51.

51. Suspected etiology of failure to achieve a platelet count ≥ 100,000 or decline in platelet count to < 20,000:

a. Persistent disease or relapse
1 ☐ yes PLTPDR4
2 ☐ no

b. Immune mediated rejection
1 ☐ yes →
2 ☐ no
PLITIM4X5

52. Immune mediated etiology:
a. 1 ☐ yes 2 ☐ no Cellular
b. 1 ☐ yes 2 ☐ no Antibody
c. 1 ☐ yes 2 ☐ no Third party engraftment
d. 1 ☐ yes 2 ☐ no Unknown

c. Graft versus host disease
1 ☐ yes
2 ☐ no PLTGVHD4

d. Non-viral infection
1 ☐ yes
2 ☐ no PLTNVI4

e. Suspected viral infection
1 ☐ yes →
2 ☐ no
PLTSV4X6

53. Suspected virus:
a. 1 ☐ yes 2 ☐ no Cytomegalovirus (CMV)
b. 1 ☐ yes 2 ☐ no Human Herpesvirus Type 6 (HHV6)
c. 1 ☐ yes 2 ☐ no Herpes Simplex Virus (HSV)
d. 1 ☐ yes 2 ☐ no Varicella
e. 1 ☐ yes 2 ☐ no Other, specify: _____

f. Documented viral infection
1 ☐ yes →
2 ☐ no
PLTDV4X6

54. Virus involved:
a. 1 ☐ yes 2 ☐ no Cytomegalovirus (CMV)
b. 1 ☐ yes 2 ☐ no Human Herpesvirus Type 6 (HHV6)
c. 1 ☐ yes 2 ☐ no Herpes Simplex Virus (HSV)
d. 1 ☐ yes 2 ☐ no Varicella
e. 1 ☐ yes 2 ☐ no Other, specify: _____

g. Antimicrobial therapy
1 ☐ yes →
2 ☐ no
PLTAM4X4

55. Therapy:
a. 1 ☐ yes 2 ☐ no Ganciclovir
b. 1 ☐ yes 2 ☐ no Bactrim, Septra, Trimethoprim/Sulfamethoxazole
c. 1 ☐ yes 2 ☐ no Other, specify: _____

h. Veno-occlusive disease (VOD)
1 ☐ yes
2 ☐ no PLTVOD4

i. Undetermined
1 ☐ yes
2 ☐ no PLTUND4

Recipient NMDP ID: ☐☐☐-☐☐☐-☐ Recipient Last Name: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

ıropoiesis

56. Has recipient received red blood cell (RBC) transfusions within 20 days of the day of contact?
1 ☐ yes
2 ☐ no → RBCREC4

57. Is the date of the last RBC transfusion known?
1 ☐ yes → Month ☐☐ Day ☐☐ Year ☐☐☐☐ RBCDT4
2 ☐ no RBCKNWN
Continue with 58

58. Did (does) recipient have evidence of hemolysis?
1 ☐ yes →
2 ☐ no
HEMOLYS4

59. Specify criteria: _____
(e.g., fragmented red cells, spherocytes, hemoglobinuria, etc.)

Current Hematologic Findings

60. Date of most recent CBC: CBCDT4 Month ☐☐ Day ☐☐ Year ☐☐☐☐

Actual CBC results:

61. WBC: ☐☐☐☐.☐ x 10^9/L ACTWBC4
62. Neutrophils: ☐☐.☐ % ACTNEU4
Lymphocytes: ☐☐.☐ % ACTLYM4
64. Hemoglobin: ☐☐.☐ g/dL ☐ not tested ACTHGB4
65. Hematocrit: ☐☐.☐ % ☐ not tested ACTHCT4
66. Platelets: ☐☐☐☐.☐ x 10^9/L ACTPLT4

67. Were chimerism studies performed prior to date of contact? CHIMSTD4
1 ☐ yes → **Complete table on following page**
2 ☐ no → **Continue with 68**

Recipient NMDP ID: ___ - ___ - ___

Recipient Last Name:

Chim[illegible]n Studies (Provide date(s), method(s) and other information for [illegible]imerism studies performed prior to date of contact.)

Date: Month	Date: Day	Date: Year	Method (See valid list below)	Cell Type (See valid list below)	Number of Cells Examined: Total Cells	Number of Donor Cells	Number of Host Cells	Number of Unknown Origin (Third Party) Cells	Percent Donor Cells: Quant.	Percent Donor Cells: *Non-Quant.	Percent Host Cells: Quant.	Percent Host Cells: *Non-Quant.	Percent Unknown Origin (Third Party) Cells: Quant.	Percent Unknown Origin (Third Party) Cells: *Non-Quant.

* If performed by non-quantitative method, indicate the presence of donor, host, or third-party cells by (+).

Valid Method Codes

(Insert number in box above to indicate method used)

1 - Standard cytogenetics
2 - Fluorescent in situ hybridization (FISH)
3 - Restriction fragment-length polymorphisms (RFLP)
4 - Polymerase chain reaction (PCR)
5 - HLA serotyping
6 - VNTR
7 - Other, specify: _____

Valid Cell Types

(Insert number in box above to indicate cell type)

1 - Bone marrow (BM)
2 - Peripheral blood mononuclear cells (PBMC)
3 - T-cells
4 - B-cells
5 - Red cells
6 - Monocytes
7 - Neutrophils
8 - Other, specify: _____

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t vs. Host Disease (GVHD)

68. (For six month report only) Was acute GVHD present at time of 100-day post-transplant report?
1 ☐ yes → 69. Is acute GVHD still present at time of *this* report?
2 ☐ no 1 ☐ yes AGVHDNOW
3 ☐ not known 2 ☐ no
AGVHD100 3 ☐ progressed to chronic GVHD
4 ☐ not known

70. Did acute GVHD occur for the first time (or a flare-up that was more severe) after the 100-day post-transplant report or since previous report?
1 ☐ yes →
2 ☐ no AGVHDYN4
3 ☐ not known

Continue with 82

71. Maximun overall grade: 1 ☐ I 2 ☐ II 3 ☐ III 4 ☐ IV AGVHDMA4
72. Karnofsky/Lansky score at time of maximum severity of acute GVHD: ☐☐☐
(Refer to page 15 for complete scale)
73. What was the diagnosis based on? 1 ☐ Histologic evidence 2 ☐ Clinical evidence 3 ☐ Both
74. Date of onset: ☐☐ Month ☐☐ Day ☐☐☐☐ Year AGVHDEV4 AGVHDT4
75. Is acute GVHD still present at time of this report?
1 ☐ Yes
2 ☐ No AGVHDPR4
3 ☐ Progressed to chronic GVHD
4 ☐ Not known

List the maximum severity of organ involvement attributed to acute GVHD:

76. Skin
1 ☐ Stage 0 – No rash AVGSKIN4
2 ☐ Stage 1 – Maculopapular rash, < 25% of body surface
3 ☐ Stage 2 – Maculopapular rash, 25-50% of body surface
4 ☐ Stage 3 – Generalized erythroderma
5 ☐ Stage 4 – Generalized erythroderma with bulbous formation and desqamation

77. Intestinal tract (use ml/day for adult recipients and ml/m²/day for pediatric recipients)
1 ☐ Stage 0 – No diarrhea AVGINTE4
2 ☐ Stage 0 – Diarrhea ≤ 500 ml/day or < 280 ml/m²/day
3 ☐ Stage 1 – Diarrhea > 500 but ≤ 1000 ml/day or 280-555 ml/m²/day
4 ☐ Stage 2 – Diahrrea > 1000 but ≤ 1500 ml/day or 556-833 ml/m²/day
5 ☐ Stage 3 – Diarrhea > 1500 ml/day or > 833 ml/m²/day
6 ☐ Stage 4 – Severe abdominal pain, with or without ileus

78. Liver AVGLIVE4
1 ☐ Stage 0 – Bilirubin < 2.0 mg/dL (< 34 µmol/L)
2 ☐ Stage 1 – Bilirubin 2.0-3.0 mg/dL (34-51 µmol/L)
3 ☐ Stage 2 – Bilirubin 3.1-6.0 mg/dL (51.1-102 µmol/L)
4 ☐ Stage 3 – Bilirubin 6.1-15.0 mg/dL (102.1-255 µmol/L)
5 ☐ Stage 4 – Bilirubin > 15.0 mg/dL (> 255 µmol/L)
6 ☐ **Not evaluable, other liver process present**

79. Other organ involvement?
1 ☐ yes →
2 ☐ no AGOTH4XY
a. 1 ☐ yes 2 ☐ no Upper GI tract
b. 1 ☐ yes 2 ☐ no Lung
c. 1 ☐ yes 2 ☐ no Other, specify: _____

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80. Was specific therapy used to *treat* acute GVHD?
1 ☐ yes → 2 ☐ no

TRAG4X13

81. For each agent listed below indicate whether or not it was used to treat AGVHD (if recipient was already receiving agent, indicate if dose was increased):

	yes	no	increasd	
a.	1 ☐	2 ☐	3 ☐	Methotrexate
b.	1 ☐	2 ☐	3 ☐	Cyclosporine
c.	1 ☐	2 ☐	3 ☐	Systemic corticosteroids
d.	1 ☐	2 ☐	3 ☐	Topical corticosteroids
e.	1 ☐	2 ☐	3 ☐	ALS, ALG, ATS, ATG
f.	1 ☐	2 ☐	3 ☐	Azathioprine
g.	1 ☐	2 ☐	3 ☐	Cyclophosphamide
h.	1 ☐	2 ☐	3 ☐	Thalidomide
i.	1 ☐	2 ☐	3 ☐	In vivo anti T-lymphocyte monoclonal antibody, specify: _____
j.	1 ☐	2 ☐	3 ☐	In vivo immunotoxin, specify: _____
k.	1 ☐	2 ☐	3 ☐	Blinded randomized trial, specify agent: _____
l.	1 ☐	2 ☐	3 ☐	Other agents, specify: _____

82. Did recipient have chronic GVHD at time of last report?
☐ yes → **Continue with 89** CGVHDLR4
☐ no

83. Has recipient developed clinical chronic GVHD since last report?
1 ☐ yes →
2 ☐ no CGVHDYN4 → **Continue with 96**

84. Date of onset: ☐☐ Month ☐☐ Day ☐☐☐☐ Year CGVHDDT4

85. Karnofsky/Lansky score at diagnosis of chronic GVHD: ☐☐☐ (Refer to page 15 for complete scale) CGVHDKL4

86. Platelet count at diagnosis of chronic GVHD: ☐☐☐☐.☐ x 10^9/L CGVHDPL4

87. Total serum bilirubin at diagnosis of chronic GVHD: ☐☐.☐ Unit of measurement: 1 ☐ mg/dL 2 ☐ µmol/L CGVHDBT4

88. What was the diagnosis based on? CGVHDBS4
1 ☐ Histologic evidence
2 ☐ Clinical evidence
3 ☐ Both

89. Maximum grade of chronic GVHD: CGVHDEV4
1 ☐ Limited (Localized skin involvement and/or hepatic dysfunction due to chronic GVHD)
2 ☐ Extensive (Generalized skin involvement or localized skin involvement and/or hepatic dysfunction due to chronic GVHD, plus;
- Liver histology showing chronic aggressive hepatitis, bridging necrosis or cirrhosis; or,
- Involvement of eye: Schirmer's test with < 5 mm wetting; or
- Involvement of minor salivary glands or oral mucosa demonstrated on labial biopsy; or
- Involvement of any other target organ

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ıdicate if there was organ involvement with chronic GVHD from list below:

CGVH4X17

a. 1 ☐ yes 2 ☐ no Cutaneous involvement
b. 1 ☐ yes 2 ☐ no Xerophthalmia (dry eyes)
c. 1 ☐ yes 2 ☐ no Oral involvement
d. 1 ☐ yes 2 ☐ no Mucositis, specify site: _____
e. 1 ☐ yes 2 ☐ no Esophogeal involvement
f. 1 ☐ yes 2 ☐ no Chronic nausea/vomiting
g. 1 ☐ yes 2 ☐ no Chronic diarrhea
h. 1 ☐ yes 2 ☐ no Other GI tract involvement
i. 1 ☐ yes 2 ☐ no Weight loss
j. 1 ☐ yes 2 ☐ no Hepatitis/hepatic involvement
k. 1 ☐ yes 2 ☐ no Arthritis/arthralgia (joint pain)
l. 1 ☐ yes 2 ☐ no Contractures
m. 1 ☐ yes 2 ☐ no Obstructive lung disease
n. 1 ☐ yes 2 ☐ no Serositis, specify site: _____
o. 1 ☐ yes 2 ☐ no Myositis/myalgia (tenderness/pain in muscles)
p. 1 ☐ yes 2 ☐ no Thrombocytopenia
q. 1 ☐ yes 2 ☐ no Other, specify: _____

91. Was specific therapy used to *treat* chronic GVHD?
1 ☐ yes →
2 ☐ no

92. For each agent listed below indicate whether or not it was used to treat chronic GVHD:

TRCG4X12

	Yes, still taking	Dose increased, still taking	Yes, no longer taking	No
a. ALS, ALG, ATS, ATG	1 ☐	2 ☐	3 ☐	4 ☐
b. Azathioprine	1 ☐	2 ☐	3 ☐	4 ☐
c. Cyclosporine	1 ☐	2 ☐	3 ☐	4 ☐
d. Systemic corticosteroids	1 ☐	2 ☐	3 ☐	4 ☐
e. Topical corticosteroids	1 ☐	2 ☐	3 ☐	4 ☐
f. Cyclophosphamide	1 ☐	2 ☐	3 ☐	4 ☐
g. Thalidomide	1 ☐	2 ☐	3 ☐	4 ☐
h. In vivo anti T-lymphocyte monoclonal antibody, specify: _____	1 ☐	2 ☐	3 ☐	4 ☐
i. In vivo immunotoxin, specify: _____	1 ☐	2 ☐	3 ☐	4 ☐
j. Blinded randomized trial, specify agent: _____	1 ☐	2 ☐	3 ☐	4 ☐
k. Other, specify: _____	1 ☐	2 ☐	3 ☐	4 ☐

93. Is the recipient still receiving treatment for chronic GVHD?

TRCGVN4

1 ☐ yes
2 ☐ no →

94. Date final treatment administered:

TRCGDT4

☐☐ Month ☐☐ Day ☐☐☐☐ Year

95. Is chronic GVHD still present?

CGVHDPR4

1 ☐ yes
2 ☐ no
3 ☐ no symptoms, recipient still receiving treatment

Recipient NMDP ID: ☐☐☐-☐☐☐-☐ Recipient Last Name: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

:r Function Post-Transplant

Pulmonary Function

96. Has recipient developed interstitial pneumonitis since last report? (Interstitial pneumonitis is characterized by hypoxia and diffuse interstitial infiltrates on chest x-ray not caused by fluid overload.)

1 ☐ yes → 2 ☐ no

PRYN4

97. Date of onset: ☐☐ Month ☐☐ Day ☐☐☐☐ Year PNDT4

98. Were diagnostic tests done?

1 ☐ yes → 2 ☐ no

PNTEST4

99. Diagnosis was evaluated by: PNDI4X5

a. 1 ☐ yes 2 ☐ no Bronchoalveolar lavage
b. 1 ☐ yes 2 ☐ no Transbronchial biopsy
c. 1 ☐ yes 2 ☐ no Open lung biopsy
d. 1 ☐ yes 2 ☐ no Autopsy
e. 1 ☐ yes 2 ☐ no Other, specify: _____

100. Was an organism isolated?

1 ☐ yes → 2 ☐ no (idiopathic)

PNOI4X9

101. Etiology:

a. 1 ☐ yes 2 ☐ no Pneumocystis carinii
b. 1 ☐ yes 2 ☐ no Aspergillus
c. 1 ☐ yes 2 ☐ no Cytomegalovirus
d. 1 ☐ yes 2 ☐ no Herpes simplex
e. 1 ☐ yes 2 ☐ no Adenovirus
f. 1 ☐ yes 2 ☐ no Human Herpesvirus Type 6 (HHV6)
g. 1 ☐ yes 2 ☐ no Other virus, specify: _____
h. 1 ☐ yes 2 ☐ no Other, specify: _____

102. Has interstitial pneumonitis resolved?

1 ☐ yes 2 ☐ no PNRESLV4

103. Did recipient develop pulmonary abnormalities other than interstitial pneumonitis since the last report?

1 ☐ yes → 2 ☐ no PAYN4

Continue with 118

104. Did recipient develop Acute Respiratory Distress Syndrome (ARDS)?

1 ☐ yes → 2 ☐ no ARYN4

105. Date of onset: ☐☐ Month ☐☐ Day ☐☐☐☐ Year ARDT4

106. Were diagnostic tests done?

1 ☐ yes → 2 ☐ no ARTEST4

107. Diagnosis was evaluated by: ARDIA4X5

a. 1 ☐ yes 2 ☐ no Bronchoalveolar lavage
b. 1 ☐ yes 2 ☐ no Transbronchial biopsy
c. 1 ☐ yes 2 ☐ no Open lung biopsy
d. 1 ☐ yes 2 ☐ no Autopsy
e. 1 ☐ yes 2 ☐ no Other, specify: _____

Recipient NMDP ID: ☐☐☐-☐☐☐-☐ Recipient Last Name: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

108. Did recipient develop bronchiolitis obliterans?
1 ☐ yes → 109. Date of onset: ☐☐ Month ☐☐ Day ☐☐☐☐ Year BODT4
2 ☐ no
BOYN4

110. Were diagnostic tests done?
1 ☐ yes → 111. Diagnosis was evaluated by: BODIA4XS
2 ☐ no
BOTEST4

a. 1 ☐ yes 2 ☐ no Bronchoalveolar lavage
b. 1 ☐ yes 2 ☐ no Transbronchial biopsy
c. 1 ☐ yes 2 ☐ no Open lung biopsy
d. 1 ☐ yes 2 ☐ no Autopsy
e. 1 ☐ yes 2 ☐ no Other, specify: _____

112. Did recipient develop pulmonary hemorrhage?
1 ☐ yes → 113. Date of onset: ☐☐ Month ☐☐ Day ☐☐☐☐ Year PHDT4
2 ☐ no
PHYN4

114. Were diagnostic tests done?
1 ☐ yes → 115. Diagnosis was evaluated by: PHDIA4XS
2 ☐ no
PHTEST4

a. 1 ☐ yes 2 ☐ no Bronchoalveolar lavage
b. 1 ☐ yes 2 ☐ no Transbronchial biopsy
c. 1 ☐ yes 2 ☐ no Open lung biopsy
d. 1 ☐ yes 2 ☐ no Autopsy
e. 1 ☐ yes 2 ☐ no Other, specify: _____

PAOTHER4

116. Did recipient develop other pulmonary abnormalities sice last report?
1 ☐ yes → 117. Specify: _____
2 ☐ no

Liver Function

118. Recipient's maximum known total bilirubin: ☐☐☐.☐ Unit of measurement: MAXBMEA4
1 ☐ mg/dL *or* 2 ☐ µmol/L ☐ not tested
MAXBQTY4

119. Date of maximum known total bilirubin: ☐☐ Month ☐☐ Day ☐☐☐☐ Year MAXBDT4

120. Recipient's most recent bilirubin: ☐☐☐.☐ Unit of measurement:
1 ☐ mg/dL *or* 2 ☐ µmol/L CONBMEA4
CONBQTY4

121. Date of most recent bilirubin: ☐☐ Month ☐☐ Day ☐☐☐☐ Year CONBDT4

122. Did the recipient develop any of the following clinical signs/symptoms of abnormal liver function since the last report?
ALFYXL
a. 1 ☐ yes 2 ☐ no Jaundice
b. 1 ☐ yes 2 ☐ no Hepatomegaly
c. 1 ☐ yes 2 ☐ no Right upper quadrant pain
d. 1 ☐ yes 2 ☐ no Ascites
e. 1 ☐ yes 2 ☐ no Weight gain (> 5%)
f. 1 ☐ yes 2 ☐ no Other, specify: _____

Recipient NMDP ID: ☐☐☐-☐☐☐-☐ Recipient Last Name: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Did recipient develop liver toxicity since the last report?

1 ☐ yes → 2 ☐ no

LTYN4

124. Date of onset: ☐☐ Month ☐☐ Day ☐☐☐☐ Year LTDT4

125. Etiology:
- 1 ☐ Veno-occlusive disease (VOD) LTETIOL4
- 2 ☐ Other, specify: _____
- 3 ☐ VOD and other, specify: _____
- 4 ☐ Unknown

126. Diagnosis was based on:
- a. 1 ☐ yes 2 ☐ no Clinical signs and symptoms LTDIA4XS
- b. 1 ☐ yes 2 ☐ no Elevated liver enzymes
- c. 1 ☐ yes 2 ☐ no Biopsy
- d. 1 ☐ yes 2 ☐ no Autopsy
- e. 1 ☐ yes 2 ☐ no Other, specify: _____

127. Has liver toxicity resolved?
- 1 ☐ yes
- 2 ☐ no LTRSLV4

Kidney Function

128. Recipient's most recent serum creatinine: ☐☐.☐ mg/dL SERCREA4

129. Date of serum creatinine: ☐☐ Month ☐☐ Day ☐☐☐☐ Year SERCRDT4

r Organ Impairmant/Disorder

130. Since the last reported contact has the recipient developed any other clinically significant organ impairment or disorder?

1 ☐ yes → 2 ☐ no

IDYN4

131. From the list below, indicate what organ impairment/disorder occurred:
- a. 1 ☐ yes 2 ☐ no Renal failure requiring dialysis
- b. 1 ☐ yes 2 ☐ no TTP/HUS or similar syndrome IDOR4X10
- c. 1 ☐ yes 2 ☐ no Hemorrhage, specify site: _____
- d. 1 ☐ yes 2 ☐ no Seizures
- e. 1 ☐ yes 2 ☐ no Cataracts
- f. 1 ☐ yes 2 ☐ no Hypothyroidism
- g. 1 ☐ yes 2 ☐ no Gonadal dysfunction
- h. 1 ☐ yes 2 ☐ no Growth disturbance/growth hormone deficiency
- i. 1 ☐ yes 2 ☐ no Hemorraghic cystitis
- j. 1 ☐ yes 2 ☐ no Other, specify: _____

New Malignancy

132. Did a *new* malignancy, lymphoproliferative or myeloproliferative disorder appear since the last report?

1 ☐ yes → 2 ☐ no

NMYN4

133. Diagnosis:
- a. 1 ☐ yes 2 ☐ no AML/MDS NMDIA4X6
- b. 1 ☐ yes 2 ☐ no B-cell lymphoproliferative disorder
- c. 1 ☐ yes 2 ☐ no Other lymphoma, specify: _____
- d. 1 ☐ yes 2 ☐ no Skin cancer, specify: _____
- e. 1 ☐ yes 2 ☐ no Solid tumor, specify: _____
- f. 1 ☐ yes 2 ☐ no Other, specify, including site: _____

134. Date of diagnosis: ☐☐ Month ☐☐ Day ☐☐☐☐ Year NMDT4

Recipient NMDP ID: ☐☐☐-☐☐☐-☐ Recipient Last Name: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Was the recipient alive on the day of contact? (If recipient died on date of contact, check "no.")

1 ☐ yes → 136. If the recipient was alive on the day of contact, complete the Karnofsky Scale for recipients 16 years or older and the Lansky Scale for recipients younger than 16. Rate activity of recipients hospitalized for therapy according to how they were functioning before hospitalization.

2 ☐ no

ALIVEYN4

ALIVEKL4 **KARNOFSKY SCALE ≥ 16 yrs**

Check the phrase in the Karnofsky Scale which best describes the activity status of the recipient:

Able to carry on normal activity; no special care is needed

1 ☐ 100 Normal; no complaints; no evidence of disease
2 ☐ 90 Able to carry on normal activity
3 ☐ 80 Normal activity with effort

Unable to work; able to live at home, cares for most personal needs; a varying amount of assistance is needed

4 ☐ 70 Cares for self; unable to carry on normal activity or to do active work
5 ☐ 60 Requires occasional assistance but is able to care for most needs
6 ☐ 50 Requires considerable assistance and frequent medical care

Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly

7 ☐ 40 Disabled; requires special care and assistance
8 ☐ 30 Severely disabled; hospitalization indicated, although death not imminent
9 ☐ 20 Very sick; hospitalization necessary
10 ☐ 10 Moribund; fatal process progressing rapidly

LANSKY SCALE < 16 yrs

Select the phrase in the Lansky Play-Performance Scale which best describes the activity status of the recipient:

Able to carry on normal activity; no special care is needed

1 ☐ 100 Fully active
2 ☐ 90 Minor restriction in physically strenuous play
3 ☐ 80 Restricted in strenuous play, tires more easily, otherwise active

Mild to moderate restriction

4 ☐ 70 Both greater restrictions of, and less time spent in, active play
5 ☐ 60 Ambulatory up to 50% of time, limited active play with assistance/supervision
6 ☐ 50 Considerable assistance required for any active play; fully able to engage in quiet play

Moderate to severe restriction

7 ☐ 40 Able to initiate quiet activities
8 ☐ 30 Needs considerable assistance for quiet activity
9 ☐ 20 Limited to very passive activity initiated by others (e.g., TV)
10 ☐ 10 Completely disabled, not even passive play

Disease Status and Treatment Post-Transplant

Questions 137–163 are disease specific questions. For this section, only answer the questions that pertain to the disease that was reported for this recipient on the Form 120, 520, 620.

Leukemia, Lymphoma, MDS, Other Malignancy (If recipient's original diagnosis was CML only answer questions 143-160.)

137. What is (was) the status of recipient's disease at time of this report or at time of death?

1 ☐ First complete remission post transplant (no hematologic evidence of disease) → **Continue with 164**

LLSTATY4

2 ☐ Therapy-induced complete remission after persistent disease or relapse post transplant →

3 ☐ Relapse or persistent disease →

138. Date of first relapse: ☐☐ Month ☐☐ Day ☐☐☐☐ Year

LLRELDTY4

139. Site of relapse:

a. 1 ☐ yes 2 ☐ no Blood and/or bone marrow
b. 1 ☐ yes 2 ☐ no CNS
c. 1 ☐ yes 2 ☐ no Testes
d. 1 ☐ yes 2 ☐ no Other, specify: _____

LLRSYXY4

Recipient NMDP ID: ☐☐☐-☐☐☐-☐ Recipient Last Name: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

140. Was recipient treated for post-transplant relapse?
1 ☐ yes → 141. What treatments were given? LLRTYX10
2 ☐ no

a. 1 ☐ yes 2 ☐ no Interferon gamma
b. 1 ☐ yes 2 ☐ no Interferon alpha
c. 1 ☐ yes 2 ☐ no Chemotherapy
d. 1 ☐ yes 2 ☐ no Withdrawal of immunosuppression
e. 1 ☐ yes 2 ☐ no Immunotoxins
f. 1 ☐ yes 2 ☐ no Donor leukocytes
g. 1 ☐ yes 2 ☐ no Second transplant
h. 1 ☐ yes 2 ☐ no Growth factors, specify: _____
i. 1 ☐ yes 2 ☐ no Other, specify: _____

142. Did the recipient acheive a hematologic remission? LLHEMREM
1 ☐ yes
2 ☐ no
3 ☐ not applicable

Continue with 164

CML Only

143. Did Chronic Myelogenous Leukemia recur (include clinical and/or cytogenetic relapse) post-transplant?
1 ☐ yes →
2 ☐ no CMRECYN4 ↓

Continue with 160

144. Was post-transplant relapse extramedullary only? CMEMDTM
1 ☐ yes →
2 ☐ no CMEMYN4

145. Date of extramedullary relapse: ☐☐ Month ☐☐ Day ☐☐☐☐ Year

146. Site of relapse, specify: _____

Continue with 154

147. Was *initial* post-transplant relapse cytogenetic *only*?
1 ☐ yes →
2 ☐ no CMCYYN4

148. Date of cytogenetic relapse: CMBNDTM ☐☐ Month ☐☐ Day ☐☐☐☐ Year

149. Did hematologic evidence of CML *subsequently* appear?
1 ☐ yes →
2 ☐ no CMHEYN4 ↓

Cont. with 154

150. Date of hematologic relapse: CMHEDTM ☐☐ Month ☐☐ Day ☐☐☐☐ Year

151. *Initial hematologic* relapse findings were consistent with: CMHECON4
1 ☐ Chronic phase
2 ☐ Acccelerated phase
3 ☐ Blast phase

Continue with 154

152. Were initial post-transplant relapse hematologic findings consistent with:
1 ☐ Chronic phase →
2 ☐ Accelerated or blast phase → CMPTCON4

153. Date of relapse: CMPTDTM ☐☐ Month ☐☐ Day ☐☐☐☐ Year

Recipient NMDP ID: ☐☐☐-☐☐☐-☐ Recipient Last Name: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

154. Was recipient treated for post-transplant relapse?
1 ☐ yes → 155
2 ☐ no

CMTRYN4

155. What treatments were given?
a. 1 ☐ yes 2 ☐ no Interferon gamma
b. 1 ☐ yes 2 ☐ no Interferon alpha
c. 1 ☐ yes 2 ☐ no Chemotherapy
d. 1 ☐ yes 2 ☐ no Withdrawal of immunosuppression
e. 1 ☐ yes 2 ☐ no Immunotoxins
f. 1 ☐ yes 2 ☐ no Donor leukocytes
g. 1 ☐ yes 2 ☐ no Second transplant
h. 1 ☐ yes 2 ☐ no Growth factors, specify: _____
i. 1 ☐ yes 2 ☐ no Other, specify: _____

@MTRT4X9

156. Did recipient achieve hematologic remission?
1 ☐ yes
2 ☐ no
3 ☐ not applicable

CMHEMR#4

157. Did recipient achieve cytogenetic remission?
1 ☐ yes → 158
2 ☐ no → 158
3 ☐ not applicable, extramedullary relapse only
4 ☐ not tested

CMCRYN4

158. Date bone marrow examined: CMCRDT4
Month ☐☐ Day ☐☐ Year ☐☐☐☐

159. Did recipient achieve chronic phase?
1 ☐ yes
2 ☐ no
3 ☐ not applicable, cytogenetic relapse only

CMCRCP4

Continue with 160

Cont. with 160

160. At the time of this report, CML was (check one box only):
1 ☐ Absent
2 ☐ Present on cytogenetic testing only
3 ☐ In chronic phase
4 ☐ In accelerated phase
5 ☐ In blast phase

CMLSTAT4

Continue with 164

Aplastic Anemia, Nonmalignant Hematologic Disorders, Inborn Errors of Metabolism

161. What was the status of original disease at the time of this report?
1 ☐ Cured
2 ☐ Improved
3 ☐ Unchanged
4 ☐ Worse
5 ☐ Unknown

NHDSTAT4

Continue with 164

Recipient NMDP ID: ☐☐☐-☐☐☐-☐ Recipient Last Name: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

I' inodeficiency Disease (For SCIDS complete Insert I; for WAS complete Insert II, and answer questions 162 and 163.)

162. What was the status of T-cell function at this visit or at the time of death?
1 ☐ Absent (≤ 10% normal response)
2 ☐ Normal
3 ☐ Partial
4 ☐ Unknown

IDSTAT4

163. What was the status of B-cell function at this visit or at the time of death?
1 ☐ Absent (≤ 10% normal response)
2 ☐ Normal
3 ☐ Partial
4 ☐ Unknown

IDBSTAT4

Subsequent Stem Cell Infusion

Complete this section if recipient has received a subsequent stem cell infusion. If the donor is a second unrelated donor, complete a new Form 120, 520, 620 for baseline information relative to the subsequent infusion.

164. Date of subsequent stem cell infusion: ☐☐ Month ☐☐ Day ☐☐☐☐ Year

SCIDT4

165. What was the indication for subsequent stem cell infusion?
1 ☐ Graft failure/rejection
2 ☐ Recurrence of disease
3 ☐ Other, specify: _____

SCIIND4

1' ource of stem cells:
1 ☐ Autologous

SCISRCA4

1 ☐ Cryopreserved bone marrow
2 ☐ Cryopreserved peripheral blood stem cells
2 ☐ Allogeneic, unrelated

SCISRCB4

1 ☐ Fresh, original donor bone marrow
2 ☐ Cryopreserved original donor bone marrow
3 ☐ Fresh, second donor bone marrow
4 ☐ Fresh, original donor *mobilized* peripheral blood stem cells
5 ☐ Cryopreserved original donor *mobilized* peripheral blood stem cells
6 ☐ Fresh, second donor *mobilized* peripheral blood stem cells
7 ☐ **NMDP cord blood**
8 ☐ **Non-NMDP cord blood**
3 ☐ Allogeneic, related
1 ☐ Bone marrow
2 ☐ Peripheral blood
3 ☐ Cord blood

167. Signed: _____
Person completing form
Please print name: _____
Phone: (_____) _____
Fax: (_____) _____
E-mail address: _____

COBLT NMDP131

National Marrow Donor Program®
Post-Transplant Follow-up Form
Insert I – Severe Combined Immunodeficiency (SCIDS)

ID
MONTHNO
M13IDT+

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)

Registry Use Only

Sequence Number:

Date Received:

COBLT NMDP131

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.

Status of Hematologic Engraftment

1. What is the status of T-cell engraftment? TCELSTAT
   1 ☐ predonimantly or completely donor (> 80% donor chimerism)
   2 ☐ only host T-cells detected
   3 ☐ mixed chimerism (5–80% donor)
   ☐ unknown

2. What is the status of B-cell engraftment? BCELSTAT
   1 ☐ predonimantly or completely donor (> 80% donor chimerism)
   2 ☐ only host T-cells detected
   3 ☐ mixed chimerism (5–80% donor)
   4 ☐ unknown

3. What is the status of myeloid engraftment? MYENSTAT
   1 ☐ completely donor
   2 ☐ host only
   3 ☐ mixed chimerism
   4 ☐ unknown

4. Since the last report, has the recipient developed an EBV associated B-cell lymphoproliferative disorder?
   1 ☐ yes → 5. Date of diagnosis: [ ][ ] Month [ ][ ] Day [ ][ ][ ][ ] Year LYMDISDT
   2 ☐ no
   3 ☐ unknown
   LYMDISYN

Continue with question 165 on Form 130, 530, 630 or question 162 on Form 140, 540, 640.

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

COBLT | NMDP132

National Marrow Donor Program®
Post-Transplant Follow-up Form
Insert II – Wiscott Aldrich Syndrome (WAS)

KEYS:
(COBLT) ID MONTHNO

Registry Use Only N132DT

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. What was the platelet count at most recent follow-up? PLATECNT
   1 ☐ normal
   2 ☐ decreased
   3 ☐ unknown

2. What was the platelet size at most recent follow-up? PLATESIZ
   1 ☐ normal
   2 ☐ decreased
   3 ☐ unknown

3. Since the last report, has the recipient developed an EBV associated B-cell lymphoproliferative disorder? LYMDISYN
   1 ☐ yes → 4. Date of diagnosis: ☐☐ Month ☐☐ Day ☐☐☐☐ Year LYMDISDT
   2 ☐ no
   3 ☐ unknown

Continue with question 165 on Form 130, 530, 630 or question 162 on Form 140, 540, 640.

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

COBLT NMDP133

National Marrow Donor Program®
Insert III – Post-Transplant Information for Hodgkin and Non-Hodgkin Lymphoma

Registry Use Only N133DT

Sequence Number:

Date Received:

KEYS:
COBLT = ID MONTH NO

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:
☐ Form 130 — 100 day
☐ Form 140 — ☐ 6 month ☐ 1 year ☐ 2 year
☐ Form 150 — ☐☐ year

Product type: ☐ Marrow (Form 130/140/150) ☐ PBSC (Form 530/540/550) ☐ Cord blood (Form 630/640/650)

This form must be accompanied by Form 130, 530, 630 – 100-Day Follow-Up Visit, Form 140, 540, 640 – 6-Month to 2-Year Follow-Up Visit, or Form 150, 550, 650 – Yearly Follow-Up for Greater Than Two Years Post-Transplant. All information in the box above, including the date, should be identical to the corresponding Form 130/140/150, 530/540/550, 630/640/650. 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. What was the patient's best response to transplant not including planned post-transplant treatment? RSPCODNI
   1 ☐ Continued Complete Remission (for patients transplanted in CR)
   2 ☐ Complete Remission (CR): complete disappearance of all known disease for ≥ 4 weeks
   3 ☐ Complete Remission Undetermined (CRU): as above with the exception of persistant scan abnormalities of unknown significance
   4 ☐ Partial Remission (PR): ≥ 50% reductions in greatest diameter of all sites of known disease and no new sites
   5 ☐ No response/progressive disease: < 50% reduction in greatest diameter of all sites of known disease, or increase in size of known disease, or new sites of disease
   6 ☐ Not evaluable, specify reason: _____

2. Was planned treatment (not for progressive disease) given *post-transplant*? (For 100-day, 6-month, and first annual report only.)
   1 ☐ yes → Specify treatment given:
   2 ☐ no PLANTRT

3. Chemotherapy
   1 ☐ yes → Specify:
   2 ☐ no PCHEMO

4. Radiation
   1 ☐ yes → Specify sites:
   2 ☐ no PRADIAT

5. Immune therapy
   1 ☐ yes →
   2 ☐ no PTIMMTH

   6. IL-2
      1 ☐ yes
      2 ☐ no PTIMMIL2

   7. Linomide
      1 ☐ yes
      2 ☐ no PTIMMLIN

   8. Other immune therapy
      1 ☐ yes → Specify:
      2 ☐ no PTIMMOTH

9. Other treatment
   1 ☐ yes → Specify:
   2 ☐ no PTOTHER

Mail to NMDP Registry with Form 130/140/150, 530/540/550, 630/640/650. Retain a copy at the transplant center.

Recipient NMDP ID: ☐☐☐-☐☐☐-☐ Recipient Last Name: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

RSPCODIP

10. What was the patient's best response to transplant *including* planned post-transplant treatment?
- 1 ☐ Continued Complete Remission (for patients transplanted in CR)
- 2 ☐ Complete Remission (CR): complete disappearance of all known disease for ≥ 4 weeks
- 3 ☐ Complete Remission Undetermined (CRU): as above with the exception of persistant scan abnormalities of unknown significance
- 4 ☐ Partial Remission (PR): ≥ 50% reductions in greatest diameter of all sites of known disease and no new sites
- 5 ☐ No response/progressive disease: < 50% reduction in greatest diameter of all sites of known disease, or increase in size of known disease, or new sites of disease
- 6 ☐ Not evaluable, specify reason: _____

11. Was a Gallium scan done post-transplant?
- 1 ☐ yes →
- 2 ☐ no

GALLS133

12. Date of scan: ☐☐ Month ☐☐ Day ☐☐☐☐ Year GALLD133

13. Results:
- 1 ☐ negative
- 2 ☐ positive
- 3 ☐ indeterminate / equivocal

GALLR133

14. Sites: _____

15. What is the status of lymphoma at the time of last contact or at time of death?
- 1 ☐ Free of lymphoma with no recurrence post-transplant
- 2 ☐ Free of lymphoma except for persistent scan abnormalities of unknown significance, no recurrence post-transplant
- 3 ☐ Persistent lymphoma without progression (never achieved remission)
- 4 ☐ Progressive disease (never achieved remission) →
- 5 ☐ Recurrent disease (relapse after complete remission) →
- 6 ☐ Free of lymphoma after post-transplant recurrence →
- 7 ☐ Not evaluable, explain: _____

STATLYMP

16. Date of recurrence/progression: ☐☐ Month ☐☐ Day ☐☐☐☐ Year RECPRGDT
- ☐ Date of first recurrence/ progression previously reported

17. Specify site(s) of first progression:
- ☐ Sites previously reported

Nodal sites:

	yes	no	unknown		
1	☒	2 ☐	3 ☐	Waldeyer's ring	NWYLDEY
1	☐	2 ☐	3 ☐	Cervical	NCERVIC
1	☐	2 ☐	3 ☐	Supraclavicular	NSUPRAC
1	☐	2 ☐	3 ☐	Axillary	NAXILLA
1	☐	2 ☐	3 ☐	Hilar	NHILAR
1	☐	2 ☐	3 ☐	Mediastinal	NMEDIAS
1	☐	2 ☐	3 ☐	Retroperitoneal	NRETROP
1	☐	2 ☐	3 ☐	Intra-abdominal	NINTRAA
1	☐	2 ☐	3 ☐	Inguinal	NINGUIN
1	☐	2 ☐	3 ☐	Spleen	NSPLEEN
1	☐	2 ☐	3 ☐	Periaortic	NPERIAO
1	☐	2 ☐	3 ☐	Illiac	NILIAC
1	☐	2 ☐	3 ☐	Other, specify:	NOTHER

Extranodal sites:

	yes	no	unknown		
1	☐	2 ☐	3 ☐	Lung	ELUNG
1	☐	2 ☐	3 ☐	Pleura	EPLEU
1	☐	2 ☐	3 ☐	Liver	ELIVR
1	☐	2 ☐	3 ☐	Kidney	EKIDN
1	☐	2 ☐	3 ☐	Brain	EBRAI
1	☐	2 ☐	3 ☐	CSF	ECSF
1	☐	2 ☐	3 ☐	Epidural space	EEPSP
1	☐	2 ☐	3 ☐	Bone	EBONE
1	☐	2 ☐	3 ☐	Bone marrow	EBM
1	☐	2 ☐	3 ☐	Skin	ESKIN
1	☐	2 ☐	3 ☐	GI tract	EGITR
1	☐	2 ☐	3 ☐	Other, specify:	EOTHR

18. Date status established: ☐☐ Month ☐☐ Day ☐☐☐☐ Year

National Marrow Donor Program®
Yearly Follow-Up for Greater Than Two Years Post-Transplant

Registry Use Only

Sequence Number:

Date Received:

Unrelated ID

Recipient NMDP ID: ___ - ___ - ___

Recipient Last Name:

Recipient Local ID (optional):

Today's Date: Month ___ Day ___ Year ____ TC Code: ___

Follow-up Visit for which this form is being completed: MONTHNO

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

Product type: ☐ Marrow (Form 150) ☐ PBSC (Form 550) ☐ Cord blood (Form 650) N150DT

COBLT NMDP150

Survival Status

1. Is the recipient alive?

1 ☐ yes → 2. Give date of most recent contact: Month ___ Day ___ Year ____ RECCNTDT

RECALVYN

2 ☐ no → 3. Give date of death: Month ___ Day ___ Year ____ DEATHDT

Complete Form 190 and continue with question 16

Answers to subsequent questions should reflect clinical status just prior to death.

Functional Status

NSKARLAN

4. Complete the Karnofsky Scale for recipients 16 years or older and the Lansky Scale for recipients younger than 16.

KARNOFSKY SCALE ≥ 16 yrs

Check the phrase in the Karnofsky Scale which best describes the activity status of the recipient:

Able to carry on normal activity; no special care is needed

1 ☐ 100 Normal; no complaints; no evidence of disease
2 ☐ 90 Able to carry on normal activity
3 ☐ 80 Normal activity with effort

Unable to work; able to live at home, cares for most personal needs; a varying amount of assistance is needed

4 ☐ 70 Cares for self; unable to carry on normal activity or to do active work
5 ☐ 60 Requires occasional assistance but is able to care for most needs
6 ☐ 50 Requires considerable assistance and frequent medical care

Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly

7 ☐ 40 Disabled; requires special care and assistance
8 ☐ 30 Severely disabled; hospitalization indicated, although death not imminent
9 ☐ 20 Very sick; hospitalization necessary
10 ☐ 10 Moribund; fatal process progressing rapidly

LANSKY SCALE < 16 yrs

Select the phrase in the Lansky Play-Performance Scale which best describes the activity status of the recipient:

Able to carry on normal activity; no special care is needed

1 ☐ 100 Fully active
2 ☐ 90 Minor restriction in physically strenuous play
3 ☐ 80 Restricted in strenuous play, tires more easily, otherwise active

Mild to moderate restriction

4 ☐ 70 Both greater restrictions of, and less time spent in, active play
5 ☐ 60 Ambulatory up to 50% of time, limited active play with assistance/supervision
6 ☐ 50 Considerable assistance required for any active play; fully able to engage in quiet play

Moderate to severe restriction

7 ☐ 40 Able to initiate quiet activities
8 ☐ 30 Needs considerable assistance for quiet activity
9 ☐ 20 Limited to very passive activity initiated by others (e.g., TV)
10 ☐ 10 Completely disabled, not even passive play

Mail a copy of this form to:
The NMDP Registry, Suite 500, 3001 Broadway St. N.E. Minneapolis, MN 55413
Retain original at the transplant center.

NMDP Form 150, 550, 650 v3 (1–6) December 2001

Recipient NMDP ID: ☐☐☐-☐☐☐-☐ Recipient Last Name: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

5. Was the recipient (age ≥ 6 and ≤ 18 years) attending school on the day of contact? ATSCHOOL

- ☐ yes → 6. Specify student attendance status: STATSTAT
  - 1 ☐ part time
  - 2 ☐ full time
  - 3 ☐ attendance status unknown
  - 7. Date recipient returned to school: SCHOOLDT ☐☐ Month ☐☐ Day ☐☐☐☐ Year; 1 ☐ date unknown; 2 ☐ date previously reported
- ☐ no
- 3 ☐ unknown
- 4 ☐ not applicable, recipient age > 18
- 5 ☐ not applicable, recipient age < 6

Continue with 16

8. Was the recipient employed outside the home prior to current illness? PREVEMPL

- 1 ☐ yes → 9. Has the recipient returned to work? RETWORK
  - 1 ☐ yes → 10. Date recipient returned to work: RETWRKDT ☐☐ Month ☐☐ Day ☐☐☐☐ Year; 1 ☐ date unknown; 2 ☐ date previously reported
  - 2 ☐ no → 11. Is recipient able to work but not currently employed? ABLEBUT 1 ☐ yes 2 ☐ no
  - 3 ☐ no change since last report
  - 4 ☐ unknown
- ☐ no →
- 3 ☐ no change since last report
- 4 ☐ unknown
- 5 ☐ not applicable, recipient age is < 18 years

12. Has the recipient resumed all usual household activities?

- 1 ☐ yes → 13. Date recipient resumed activities: RESHOMDT ☐☐ Month ☐☐ Day ☐☐☐☐ Year; 1 ☐ date unknown; 2 ☐ date previously reported
- 2 ☐ no
- 3 ☐ no change since last report RESHOME
- 4 ☐ unknown

14. Is the recipient currently employed outside the home? NOWWORK

- 1 ☐ yes → 15. Date recipient began work: NOWWRKDT ☐☐ Month ☐☐ Day ☐☐☐☐ Year; 1 ☐ date unknown; 2 ☐ date previously reported
- 2 ☐ no
- 3 ☐ no change since last report
- 4 ☐ unknown

Chronic GVHD

16. Did the recipient have chronic GVHD at the time of the last report? CHRNGVHD

- 1 ☐ yes → **Continue with question 19**
- 2 ☐ no

17. Did the recipient develop chronic GVHD since the last report?

- 1 ☐ yes → 18. Date of onset: CGVHDNDT ☐☐ Month ☐☐ Day ☐☐☐☐ Year
- CGVHD NEW
- ☐ no → **Continue with question 25**

Recipient NMDP ID: ☐☐☐-☐☐☐-☐ Recipient Last Name: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

19. Indicate the maximum grade of GVHD since the last report: CGVHMDM45
- ☐ limited (localized skin involvement and/or hepatic dysfunction due to chronic GVHD)
- ☐ extensive (generalized skin involvement or localized skin involvement and/or hepatic dysfunction due to chronic GVHD)
  - liver histology showing chronic aggressive hepatitis, bridging necrosis or cirrhosis; or,
  - involvement of eye: Schirmer's test with < 5 mm wetting; or
  - involvement of minor salivary glands or oral mucosa demonstrated on lip biopsy; or
  - involvement of any other target organ

20. Overall severity of chronic GVHD as reported by the Transplant Center: OVSEVCHR
1 ☐ mild – signs and symptoms of chronic GVHD do not interfere substantially with function and do not progress once appropriately treated with local therapy or standard systemic therapy (steroids and/or cyclosporine or FK 506)
2 ☐ moderate – signs and symptoms of chronic GVHD interfere somewhat with function despite appropriate therapy or are progressive through first line systemic therapy defined as steroids and/or cyclosporine or FK 506
3 ☐ severe – signs and symptoms of chronic GVHD limit function substantially despite appropriate therapy or are progressive through second line therapy

21. Indicate if there was organ involvement with chronic GVHD from list below:

Skin / hair

a. 1 ☐ yes 2 ☐ no subclinical (biopsy findings only) CGVHSUBC
b. 1 ☐ yes 2 ☐ no rash CGVHRASH
c. 1 ☐ yes 2 ☐ no scleroderma CGVHSCL
d. 1 ☐ yes 2 ☐ no dyspigmentation CGVHDYSP
e. 1 ☐ yes 2 ☐ no alopecia CGVHALOP
f. 1 ☐ yes 2 ☐ no body surface area, specify percent of BSA involved: ☐☐☐ % CGVHBSUR/CGVHBSUP
g. 1 ☐ yes 2 ☐ no lichenoid skin changes CGVHLICS
h. 1 ☐ yes 2 ☐ no other skin or hair involvement, specify: _____ CGVHSKIN

Eyes

i. 1 ☐ yes 2 ☐ no xerophthalmia (dry eyes) CGVHXERO
j. 1 ☐ yes 2 ☐ no abnormal Schirmer's test CGVHSCH
k. 1 ☐ yes 2 ☐ no corneal erosion / conjunctivitis CGVHCORN
1 ☐ yes 2 ☐ no other eye involvement, specify: _____ CGVHEYE

Mouth

m. 1 ☐ yes 2 ☐ no lichenoid changes CGVHLICH
n. 1 ☐ yes 2 ☐ no mucositis / ulcers CGVHMUCO
o. 1 ☐ yes 2 ☐ no other mouth involvement, specify: _____ CGVHMOUT

Lung

p. 1 ☐ yes 2 ☐ no bronchiolitis obliterans CGVHBRON
q. 1 ☐ yes 2 ☐ no other lung involvement, specify: _____ CGVHLUNG

Gastrointestinal tract

r. 1 ☐ yes 2 ☐ no esophageal involvement CGVHESOP
s. 1 ☐ yes 2 ☐ no chronic nausea / vomiting CGVHNAUS
t. 1 ☐ yes 2 ☐ no chronic diarrhea CGVHDIAR
u. 1 ☐ yes 2 ☐ no malabsorption CGVHMALA
v. 1 ☐ yes 2 ☐ no abnormal pain / cramps CGVHPAIN
w. 1 ☐ yes 2 ☐ no other GI tract involvement, specify: _____ CGVHGAST

Liver

x. 1 ☐ yes 2 ☐ no liver involvement, specify: _____ CGVHLIVR

Genitourinary tract

y. 1 ☐ yes 2 ☐ no vaginitis / stricture CGVHVAG
z. 1 ☐ yes 2 ☐ no other GU tract involvement, specify: _____ CGVHGENI

Musculoskeletal

aa. 1 ☐ yes 2 ☐ no arthritis CGVHARTH
bb. 1 ☐ yes 2 ☐ no contractures CGVHCONT
cc. 1 ☐ yes 2 ☐ no myositis CGVHMYOS
dd. 1 ☐ yes 2 ☐ no myasthenia CGVHMYAS
ee. 1 ☐ yes 2 ☐ no other musculoskeletal involvement, specify: _____ CGVHMUSC

Recipient NMDP ID: ___ - ___ - ___ Recipient Last Name: _____

Hematologic

ii. 1 ☐ yes 2 ☐ no thrombocytopenia (< 100,000 x 10^9/L) CGVHTHRO
jj. 1 ☐ yes 2 ☐ no eosinophilia CGVHEOSI
kk. 1 ☐ yes 2 ☐ no autoantibodies CGVHAUTO
ll. 1 ☐ yes 2 ☐ no other hematologic involvement, specify: CGVHHEMA

Other

mm. 1 ☐ yes 2 ☐ no serositis, specify site: CGVHSERO
nn. 1 ☐ yes 2 ☐ no weight loss CGVHWGHT
oo. 1 ☐ yes 2 ☐ no other, specify: CGVHOTHR

22. Was specific therapy used to treat chronic GVHD?

1 ☐ yes → 23. For each agent listed below, indicate whether or not it was used to treat chronic GVHD:
2 ☐ no

TRCGSPTH

	Yes, agent continued	Yes, agent started	No, not used		
a.	1 ☐	2 ☐	3 ☐	ALS, ALG, ATS, ATG	TRCGALS
b.	1 ☐	2 ☐	3 ☐	azathioprine	TRCGAZAT
c.	1 ☐	2 ☐	3 ☐	cyclosporine	TRCGCYCL
d.	1 ☐	2 ☐	3 ☐	systemic corticosteroids	TRCGSCOR
e.	1 ☐	2 ☐	3 ☐	topical corticosteroids	TRCGTCOR
f.	1 ☐	2 ☐	3 ☐	thalidomide	TRCGTHAL
g.	1 ☐	2 ☐	3 ☐	tacrolimus (FK506, Prograf)	TRCGTACR
h.	1 ☐	2 ☐	3 ☐	mycophenolate mofetil (MMF, CellCept)	TRCGMYCO
i.	1 ☐	2 ☐	3 ☐	PUVA (Psoralen and UVA)	TRCGPUVA
j.	1 ☐	2 ☐	3 ☐	ECP (extra-corporeal photopheresis)	TRCGECP
k.	1 ☐	2 ☐	3 ☐	sirolimus (rapamycin)	TRCGSIRO
l.	1 ☐	2 ☐	3 ☐	etretinate	TRCGETRE
m.	1 ☐	2 ☐	3 ☐	lamprene (clofazimine)	TRCGLAMP
n.	1 ☐	2 ☐	3 ☐	etanercept	TRCGETAN
o.	1 ☐	2 ☐	3 ☐	zenapax (daclizumab)	TRCGZENA
p.	1 ☐	2 ☐	3 ☐	chloroquine phosphate	TRCGCHLO & TRCGTLYM
q.	1 ☐	2 ☐	3 ☐	in vivo anti T-lymphocyte monoclonal antibody, specify:	TRCGIMMU
r.	1 ☐	2 ☐	3 ☐	in vivo immunotoxin, specify:	TRCGIMMT
s.	1 ☐	2 ☐	3 ☐	blinded randomized trial, specify agent:	TRCGBRT
t.	1 ☐	2 ☐	3 ☐	other, specify:	TRCGOTHR

24. Is chronic GVHD still present at the time of this report?

1 ☐ yes
2 ☐ no GVHDPRES

25. Is recipient still taking immunosuppressive agents (including PUVA) to treat or prevent GVHD?

1 ☐ yes
2 ☐ no → 26. Date final treatment administered: ☐☐ Month ☐☐☐☐ Year FINIMMDT

STILLIMM

Recipient NMDP ID: ☐☐☐-☐☐☐-☐ Recipient Last Name: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

New Malignancies

27. Did a new malignancy, lymphoproliferative or myeloproliferative disorder appear?

- ☐ yes → 28. Diagnosis:
-] no

NMYNS

a. AML/MDS
1 ☐ yes NMDIAS1
2 ☐ no

b. B-cell lymphoproliferative disorder NMBCEPVP
1 ☐ yes → 29. Is the recipient EBV positive? 1 ☐ yes 2 ☐ no
2 ☐ no NMDIAS2

c. other lymphoma
1 ☐ yes, specify: _____ NMDIAS3
2 ☐ no

d. skin cancer
1 ☐ yes, specify: _____ NMDIASH
2 ☐ no

e. solid tumor
1 ☐ yes, specify: _____ NMDIASS
2 ☐ no

f. other
1 ☐ yes, specify, including site: _____ NMDIAS6
2 ☐ no

30. Date of diagnosis: NMDTS ☐☐ Month ☐☐ Day ☐☐☐☐ Year

Other Organ Impairment/Disorder

31. Since the last reported contact has the recipient developed any other clinically significant organ impairment or disorder?

1 ☐ yes → 32. From the list below, indicate what organ impairment/disorder occurred:
2 ☐ no ORIMPAIR

a. 1 ☐ yes 2 ☐ no renal failure requiring dialysis ORRENAL
b. 1 ☐ yes 2 ☐ no TTP/HUS or similar syndrome ORTTPHUS
c. 1 ☐ yes 2 ☐ no hemorrhage, specify site: _____ ORHEMORR
d. 1 ☐ yes 2 ☐ no seizures ORSEIZUR
e. 1 ☐ yes 2 ☐ no cataracts ORCATAR
f. 1 ☐ yes 2 ☐ no hypothyroidism ORHYPOTH
g. gonadal dysfunction ORGONAD
   1 ☐ yes → 33. Specify:
   2 ☐ no
      a. 1 ☐ yes 2 ☐ no menopause ORGDMENO
      b. 1 ☐ yes 2 ☐ no low sperm count ORGDSPER
      c. 1 ☐ yes 2 ☐ no low testosterone ORGDTEST
      d. 1 ☐ yes 2 ☐ no other, specify: _____ ORGDOTHR
h. 1 ☐ yes 2 ☐ no growth disturbance/growth hormone deficiency ORGROWTH
i. 1 ☐ yes 2 ☐ no hemorraghic cystitis ORCYSTT
j. 1 ☐ yes 2 ☐ no other, specify: _____ OROTHER

Disease Status Post-Transplant

Only answer this section if the diagnosis listed on Form 120, 520, 620 is an acute or chronic leukemia or other malignancy.

34. What is the recipient's current disease status? ACUTCHRN

1 ☐ complete remission
2 ☐ therapy induced remission after persistent disease or relapse post-transplant →
3 ☐ hematologic relapse →
☐ cytogenetic relapse →
5 ☐ extramedullary relapse →
6 ☐ BCR / ABL positive →

35. Date of first relapse for this type of relapse: ACUTCHDT
☐☐ Month ☐☐ Day ☐☐☐☐ Year
☐ first relapse date for this type of relapse previously reported

Recipient NMDP ID: ☐☐☐-☐☐☐-☐ Recipient Last Name: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Subsequent Stem Cell Infusion

Complete this section if recipient received a subsequent stem cell infusion. If no subsequent stem cell infusions were done, continue with the signature lines at question 39. If multiple stem cell infusions occured in the same reporting period, copy this page and complete these questions for each infusion.

36. Date of subsequent stem cell infusion: ☐☐ Month ☐☐ Day ☐☐☐☐ Year SCIDTS

37. What was the indication for the subsequent stem cell infusion? SCIINDS

1 ☐ no engraftment
2 ☐ partial engraftment
3 ☐ graft failure/rejection after achieving initial engraftment
4 ☐ persistent malignancy
5 ☐ recurrent malignancy
6 ☐ secondary malignancy
7 ☐ planned second transplant, per protocol
8 ☐ other, specify: _____

38. Source of stem cells: SCISRCAS

1 ☐ autologous
2 ☐ allogeneic, unrelated
  1 ☐ fresh, original donor bone marrow *(Complete a new Form 120 – Recipient Baseline and Transplant Data)*
  2 ☐ cryopreserved original donor bone marrow
  3 ☐ fresh, second donor bone marrow *(Complete a new Form 120 – Recipient Baseline and Transplant Data)*
  4 ☐ non-NMDP donor bone marrow
  5 ☐ fresh, original donor mobilized peripheral blood stem cells *(Complete a new Form 520 – Recipient Baseline and Transplant Data)*
  6 ☐ cryopreserved original donor mobilized peripheral blood stem cells
  7 ☐ fresh, second donor mobilized peripheral blood stem cells *(Complete a new Form 520 – Recipient Baseline and Transplant Data)*
  8 ☐ non-NMDP donor mobilized peripheral blood stem cells
  9 ☐ NMDP cord blood *(Complete a new Form 620 – Recipient Baseline and Transplant Data)*
  10 ☐ non-NMDP cord blood
3 ☐ allogeneic, related

SCISRCAS

39. Signed: _____
Person completing form

Please print name: _____

Phone number: (_____) _____

Fax number: (_____) _____

E-mail address: _____

National Marrow Donor Program®

Leukemia and MDS Yearly Follow-Up for Relapse Post-Stem Cell Transplant

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

Follow-up Visit for which this form is being completed: ☐☐

Product type: ☐ Marrow (Form 160) ☐ PBSC (Form 560) ☐ Cord blood (Form 660)

COBLT NMDP160

Survival Status

1. Is the recipient alive?

1 ☐ yes →

2. Give date of most recent contact: ☐☐ Month ☐☐ Day ☐☐☐☐ Year

Continue with question 4

2 ☐ no →

3. Give date of death: ☐☐ Month ☐☐ Day ☐☐☐☐ Year

Complete Form 190 and continue with question 5

Answers to subsequent questions should reflect clinical status just prior to death.

Functional Status

Complete the Karnofsky Scale for recipients 16 years or older and the Lansky Scale for recipients younger than 16. Rate activity of recipients hospitalized for therapy according to how they were functioning before hospitalization.

KARNOFSKY SCALE ≥ 16 yrs

Check the phrase in the Karnofsky Scale which best describes the activity status of the recipient:

Able to carry on normal activity; no special care is needed

- 1 ☐ 100 Normal; no complaints; no evidence of disease
- 2 ☐ 90 Able to carry on normal activity
- 3 ☐ 80 Normal activity with effort

Unable to work; able to live at home, cares for most personal needs; a varying amount of assistance is needed

- 4 ☐ 70 Cares for self; unable to carry on normal activity or to do active work
- 5 ☐ 60 Requires occasional assistance but is able to care for most needs
- 6 ☐ 50 Requires considerable assistance and frequent medical care

Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly

- 7 ☐ 40 Disabled; requires special care and assistance
- 8 ☐ 30 Severely disabled; hospitalization indicated, although death not imminent
- 9 ☐ 20 Very sick; hospitalization necessary
- 10 ☐ 10 Moribund; fatal process progressing rapidly

LANSKY SCALE < 16 yrs

Select the phrase in the Lansky Play-Performance Scale which best describes the activity status of the recipient:

Able to carry on normal activity; no special care is needed

- 1 ☐ 100 Fully active
- 2 ☐ 90 Minor restriction in physically strenuous play
- 3 ☐ 80 Restricted in strenuous play, tires more easily, otherwise active

Mild to moderate restriction

- 4 ☐ 70 Both greater restrictions of, and less time spent in, active play
- 5 ☐ 60 Ambulatory up to 50% of time, limited active play with assistance/supervision
- 6 ☐ 50 Considerable assistance required for any active play; fully able to engage in quiet play

Moderate to severe restriction

- 7 ☐ 40 Able to initiate quiet activities
- 8 ☐ 30 Needs considerable assistance for quiet activity
- 9 ☐ 20 Limited to very passive activity initiated by others (e.g., TV)
- 10 ☐ 10 Completely disabled, not even passive play

Mail this form to:
The NMDP Registry, Suite 500, 3433 Broadway St. N.E.
Minneapolis, MN 55413
Retain a copy at the transplant center.

NMDP Form 160, 560, 660 V1 (1–2) November 1998

Recipient NMDP ID: ☐☐☐-☐☐☐-☐ Recipient Last Name: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

T nent

5. Did the recipient receive treatment for relapse since the last report?
   1 ☐ yes →
   2 ☐ no

6. Treatments given:
   a. 1 ☐ yes 2 ☐ no Interferon alpha
   b. 1 ☐ yes 2 ☐ no Chemotherapy
   c. 1 ☐ yes 2 ☐ no Withdrawal of immunosuppression
   d. 1 ☐ yes 2 ☐ no Immunotoxins
   e. 1 ☐ yes 2 ☐ no Infusion of donor leukocytes
   f. 1 ☐ yes 2 ☐ no Growth factors, specify: _____
   g. 1 ☐ yes 2 ☐ no Other, specify: _____

Subsequent Stem Cell Infusion

7. Did the recipient receive a subsequent infusion of stem cells?
   1 ☐ yes →
   2 ☐ no

8. Date of subsequent infusion: ☐☐ Month ☐☐ Day ☐☐☐☐ Year

9. Source of stem cells:
   1 ☐ Autologous
      1 ☐ Cryopreserved bone marrow
      2 ☐ Cryopreserved peripheral blood stem cells
   2 ☐ Allogeneic, unrelated
      1 ☐ Fresh, original donor bone marrow
      2 ☐ Cryopreserved original donor bone marrow
      3 ☐ Fresh, second donor bone marrow
      4 ☐ Fresh, original donor *mobilized* peripheral blood stem cells
      5 ☐ Cryopreserved original donor *mobilized* peripheral blood stem cells
      6 ☐ Fresh, second donor *mobilized* peripheral blood stem cells
      7 ☐ NMDP cord blood
      8 ☐ Non-NMDP cord blood
   3 ☐ Allogeneic, related
      1 ☐ Bone marrow
      2 ☐ Peripheral blood
      3 ☐ Cord blood

Disease Status

10. What was the status of the recipient's disease at the time of this report or at the time of death?
    1 ☐ Therapy induced complete remission →
    2 ☐ Relapse

11. Date of remission: ☐☐ Month ☐☐ Day ☐☐☐☐ Year

12. Signed: _____
Person completing form

Please print name: _____

Phone number: (_____) _____

Fax number: (_____) _____

E-mail address: _____

National Marrow Donor Program®
Recipient Death Information

Registry Use Only

Reference Number:

Date Received:

Unrelated ID

Recipient NMDP ID: ___ - ___ - ___

Recipient Last Name:

Recipient Local ID (optional):

Today's Date: Month ___ Day ___ Year ____ TC Code: ___

Product type for first transplant: ☐ Marrow (Form 190) ☐ PBSC (Form 590) ☐ Cord blood (Form 690)

COBLT DEATH

To be completed in conjunction with a 100-Day Follow-Up Form (Form 130, 530, 630), Six Month to Two Year Follow-Up Form (Form 140, 540, 640), or Greater Than Two Year Follow-Up Form (Form 150, 550, 650).

1. Date of death: Month ___ Day ___ Year ____ DEATHDT

2. Was cause of death confirmed by autopsy?
   1 ☐ yes
   2 ☐ no
   3 ☐ pending
   AUTOPSY

3. Cause of death: *(Enter appropriate cause of death code below. List in order of decreasing severity, i.e., primary cause first. If a code number for "Other, specify" is entered, write the cause in the space provided.)*

   Primary: ___.___ Specify: _____ DCAUSE1

   ___.___ Specify: _____ DCAUSE2

   ___.___ Specify: _____ DCAUSE3

   ___.___ Specify: _____ DCAUSE4

   ___.___ Specify: _____ DCAUSE5

   ___.___ Specify: _____ DCAUSE6

4. Signed: _____
   Person completing form

   Please print name: _____

   Phone number: (_____) _____

   Fax number: (_____) _____

   E-mail address: _____

Send a copy of this form to:
The NMDP Registry, Suite 500,
3001 Broadway Street N.E., Minneapolis, MN 55413
Retain original at the transplant center.

Cause of Death Codes

1.0	Graft rejection or failure
	Infection (other than interstitial pneumonia)
2.1	Bacterial
2.2	Fungal
2.3	Viral
2.4	Protozoal
2.5	Organism not identified
2.6	Other, specify
	Interstitial pneumonia
3.1	Viral, CMV
3.2	Viral, other
3.3	Pneumocystis
3.4	Idiopathic
3.5	Other, specify
4.0	Adult Respiratory Distress Syndrome
5.0	Acute GVHD
6.0	Chronic GVHD
7.0	Recurrence or persistence of leukemia/malignancy/MDS
	Organ failure (not due to GVHD or infection)
8.1	Liver
8.2	Cardiac (Cardiomyopathy)
8.3	Pulmonary
8.4	CNS
8.5	Renal
8.6	Multiple organ failure, specify
8.7	Other, specify
9.0	Secondary malignancy
	Hemorrhage
10.1	Pulmonary
10.2	Intracranial
10.3	Gastrointestinal
10.4	Hemorrhage not specified
10.5	Other, specify
	Vascular
11.1	Thromboembolic
11.2	Disseminated intravascular coagulation (DIC)
11.3	Gastrointestinal
11.4	Thrombotic thrombocytopenic purpura
11.5	Vascular not specified
11.6	Other, specify
12.0	Accidental death
13.0	Other, specify

NMDP Form 190, 590, 690 v5 (1–1) December 2001