National Marrow Donor Program®

# Insert XIII – Leukodystrophies

COBLT NMDP12D

**Registry Use Only**

Sequence Number:

Date Received:

**Unrelated** ID Recipient NMDP ID: ___ - ___ - ___

Recipient Last Name:

Recipient Local ID (optional):

N12DDT Today's Date: ___ Month ___ Day ___ Year

TCCODE TC Code:

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

Product type: ☐ Marrow (Form 120) ☐ PBSC (Form 520) ☐ Cord blood (Form 620)

**This form must be accompanied by Form 120, 520, 620 – Recipient Baseline and Transplant Data. All information in the box above, including the date, should be identical with the corresponding Form 120, 520, 620. 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. For which type of leukodystrophy was the transplant performed?

1 ☐ Globoid Cell Leukodystrophy →

2. Report the leukocyte galactocerebrosidase enzyme activity at diagnosis:

LGR12D Result: ___ . ___ LGU12D 1 ☐ nmol/hr/mg protein 2 ☐ pmol/hr/mg protein

LGDT12D Date tested: ___ Month ___ Day ___ Year

3. Report the **donor's** leukocyte galactocerebrosidase level:

DLGR12D Result: ___ . ___ DLGU12D 1 ☐ nmol/hr/mg protein 2 ☐ pmol/hr/mg protein

LEUK12D

2 ☐ Metachromatic Leukodystrophy →

4. Report the leukocyte arylsulfatase A enzyme activity at diagnosis:

LAR12D Result: ___ . ___ LAU12D 1 ☐ nmol/hr/mg protein 2 ☐ pmol/hr/mg protein

5. Report the urinary sulfatides at diagnosis:

USL12D Urinary level: ___ g/mL

6. Report the **donor's** leukocyte arylsulfatase A level:

DLAR12D Result: ___ . ___ DLAU12D 1 ☐ nmol/hr/mg protein 2 ☐ pmol/hr/mg protein

3 ☐ Adrenoleuko-dystrophy →

7. Report the mean fasting plasma very-long-chain fatty acid (VLCFA) C26:0 as determined at diagnosis:

MFPD12D Plasma level: ___ . ___ µg/mL


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

8. Was the mean fasting plasma very-long-chain-fatty acid level measured pre-transplant (within two weeks prior to conditioning for transplant)?
1 ☐ yes → 2 ☐ no 3 ☐ unknown MFPMP12D

9. Specify:
Plasma level: ☐.☐☐☐ µg/mL MFPLP12D
Date tested: ☐☐ Month ☐☐ Day ☐☐☐☐ Year MFPDP12D

cannot tell what this question says

[redacted]

ADREN12D
1 ☐ yes → 2 ☐ no 3 ☐ unknown

11. Specify:
a. Glucocorticoid GLUCO12D 1 ☐ yes 2 ☐ no 3 ☐ unknown
b. Mineralocorticoid MINER12D 1 ☐ yes 2 ☐ no 3 ☐ unknown

12. Was treatment given to lower plasma very-long-chain fatty acids at any time prior to transplant?
LPANY12D
1 ☐ yes → 2 ☐ no 3 ☐ unknown

13. Specify:
a. GTE:GTO oil (Lorenzo's oil) 1 ☐ yes 2 ☐ no 3 ☐ unknown LPLOR12D
b. Lovastatin or related compound 1 ☐ yes 2 ☐ no 3 ☐ unknown LPLOV12D
c. 4-phenylbutyrate 1 ☐ yes 2 ☐ no 3 ☐ unknown LP4PH12D
d. Other, specify: _____ 1 ☐ yes 2 ☐ no 3 ☐ unknown LPOTH12D

## Clinical Status Pre-Transplant

there a history of pre-transplant seizures?
1 ☐ yes
2 ☐ no
3 ☐ unknown
PTS12D

15. Was cerebrospinal fluid (CSF) testing done pre-transplant?
1 ☐ yes → 2 ☐ no 3 ☐ unknown CSF12D

16. Report results of most recent tests:

a. Opening pressure
OPEN12D
1 ☐ yes → 2 ☐ no 3 ☐ unknown
☐☐☐ cm $H_2O$ OPENV12D

b. Total protein
TPRO12D
1 ☐ yes → 2 ☐ no 3 ☐ unknown
TPROV12D ☐☐☐.☐☐
TPROU12D 1 ☐ mg/dL 2 ☐ g/L

c. **Serum** albumin
ALBU12D
1 ☐ yes → 2 ☐ no 3 ☐ unknown
ALBUV12D ☐☐.☐
ALBUU12D 1 ☐ mg/dL 2 ☐ g/L

d. **Serum** IgG
SERU12D
1 ☐ yes → 2 ☐ no 3 ☐ unknown
SERUV12D ☐☐.☐
SERUU12D 1 ☐ mg/dL 2 ☐ g/L

17. Date of most recent test: ☐☐ Month ☐☐ Day ☐☐☐☐ Year CSFDT12D


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

18. Magnetic Resonance Imaging (MRI) pre-transplant:
1 ☐ normal → 19. Date of most recent report: (*If possible, attach a copy of the report.*) Month Day Year MRIDT12D
2 ☐ abnormal →
3 ☐ unknown/ not done
MRI12D

20. Magnetic Resonance Spectroscopy pre-transplant:
1 ☐ normal → 21. Date of most recent test prior to transplant: (*If possible, attach a copy of the report.*) Month Day Year MRSDT12D
2 ☐ abnormal →
3 ☐ unknown/ not done
MRS12D

22. Were nerve conduction velocities tested pre-transplant?
1 ☐ yes → 23. Specify nerve conduction velocities:
a. Median nerve: ___ m/sec MED12D
b. Peroneal nerve: ___ m/sec PER12D
24. Date of most recent test prior to transplant: Month Day Year NCVDT12D
2 ☐ no
3 ☐ unknown
NCV12D

25. Was a Mental Development test done pre-transplant?
1 ☐ yes → 26. Indicate test instrument; report results of test done closest to transplant; report score, not percentile:
1 ☐ Bayley Scales of Infant Development
2 ☐ Stanford Binet Intelligence Scale 4th ed
3 ☐ Wechsler Preschool and Primary Scale of Intelligence (WPPSI – Revised)
4 ☐ Wechsler Intelligence Scale for Children – III (WISC – III)
5 ☐ Other, specify: _____ MDTIN12D
27. Date of test: Month Day Year MDTDT12D
28. Full scale score: MDTFS12D
29. Verbal score: MDTVS12D
30. Performance score: MDTPS12D
2 ☐ no
3 ☐ unknown
MDT12D

31. Were the Vineland Adaptive Behavior Scales done pre-transplant?
1 ☐ yes → 32. Score results:
a. Communication skills: VABCS12D
b. Daily living skills: VABDL12D
c. Socialization skills: VABSS12D
33. Date of test: Month Day Year VABDT12D
2 ☐ no
3 ☐ unknown
VAB12D


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

34. Was visual acuity tested pre-transplant?
1 ☐ yes → 35. Is patient blind?
2 ☐ no
3 ☐ unknown
VAC12D
1 ☐ yes
2 ☐ no → 36. Visual acuity:
BLIND12D
a. Right eye: VACRA12D ☐☐ / ☐☐ ← VACRB12D
b. Left eye: VACLA12D ☐☐ / ☐☐ ← VACLB12D
37. Date of test: VACDT12D ☐☐ Month ☐☐ Day ☐☐☐☐ Year

38. Was an audiologic evaluation (auditory brain stem or conditioned response) done pre-transplant?
1 ☐ yes → 39. Tympanometry results:
2 ☐ no
3 ☐ unknown
AUD12D

| | Normal | Retracted | Flat |
|---|---|---|---|
| a. Right ear: | 1 ☐ | 2 ☐ | 3 ☐ TYMRE12D |
| b. Left ear: | 1 ☐ | 2 ☐ | 3 ☐ TYMLE12D |

40. Was the hearing loss (HL) in decibels (dB) assessed at the speech threshold for 500 hertz (HZ)?
1 ☐ yes → 41. Speech Threshold results at 500 HZ:
2 ☐ no
3 ☐ unknown
HL512D

| | Normal - Mild | Moderate - Moderately Severe | Severe - Profound |
|---|---|---|---|
| a. Right ear: | 1 ☐ | 2 ☐ | 3 ☐ HL5RE12D |
| b. Left ear: | 1 ☐ | 2 ☐ | 3 ☐ HL5LE12D |

See Degree of Hearing Loss chart below for scale ranges.

Was the hearing loss (HL) in decibels (dB) assessed at the speech threshold for 2000 hertz (HZ)?
1 ☐ yes → 43. Speech Threshold results at 2000 HZ:
2 ☐ no
3 ☐ unknown
HL212D

| | Normal - Mild | Moderate - Moderately Severe | Severe - Profound |
|---|---|---|---|
| a. Right ear: | 1 ☐ | 2 ☐ | 3 ☐ HL2RE12D |
| b. Left ear: | 1 ☐ | 2 ☐ | 3 ☐ HL2LE12D |

See Degree of Hearing Loss chart below for scale ranges.

**Degree of Hearing Loss: Pure tones and speech testing**

| | | | |
|---|---|---|---|
| Normal: | 0-20 dB HL | Moderately Severe: | 60-70 dB HL |
| Mild: | 25-40 dB HL | Severe: | 75-90 dB HL |
| Moderate: | 45-55 dB HL | Profound: | > 90 dB HL |


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# Insert XIV – Mucopolysaccharidoses and Other Storage Diseases

COBLT NMDP12E

**Registry Use Only**

Sequence Number:

Date Received:

**Unrelated** ID Recipient NMDP ID: ___ - ___ - ___

Recipient Last Name:

Recipient Local ID (optional):

N12EDT Today's Date: Month ___ Day ___ Year ____

TCCODE TC Code:

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

Product type: ☐ Marrow (Form 120) ☐ PBSC (Form 520) ☐ Cord blood (Form 620)

**This form must be accompanied by Form 120, 520, 620 – Recipient Baseline and Transplant Data. All information in the box above, including the date, should be identical with the corresponding Form 120, 520, 620. 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. Which enzyme deficiency was detected at diagnosis?

ENZYM12E

**Mucopolysaccharidosis**

1 ☐ α-L-iduronidase (Hurler – MPS I)
2 ☐ Iduronate sulfatase (Hunter – MPS II)
3 ☐ Heparan N-sulfatase (Sanfilippo A – MPS IIIA)
4 ☐ α-N-acetylglucosaminidase (Sanfilippo B – MPS IIIB)
5 ☐ Acetyl CoA: α-glucosaminide acetyltransferase (Sanfilippo C – MPS IIIC)
6 ☐ N-acetylglucosamine 6-sulfatase (Sanfilippo D – MPS IIID)
7 ☐ Galactose 6-sulfatase (Morquio A – MPS IVA)
8 ☐ β-galactosidase (Morquio B – MPS IVB)
9 ☐ N-acetyl galactosamine 4-sulfatase (Maroteaux-Lamy – MPS VI)
10 ☐ β-glucuronidase (Sly syndrome – MPS VII)

**Other Storage Diseases**

11 ☐ Glucocerebrosidase (Gaucher)
12 ☐ Acid sphingomyelinase (Niemann-Pick)
13 ☐ Phosphotransferase (Mucolipidosis II or I-cell)
14 ☐ Acid lipase (Wolman)
15 ☐ α-fucosidase (Fucosidosis)
16 ☐ Neuronal ceroid-lipofuscinosis enzyme – NCL 1 (infantile): PPT-palmitoyl protein thioesterase
17 ☐ Neuronal ceroid-lipofuscinosis enzyme – NCL 2 (classic late infantile): transpeptidase
18 ☐ α- or β-mannosidase (Mannosidosis)
19 ☐ Aspartyl glucosaminidase (Aspartylglucosaminuria)
20 ☐ Hypoxanthine-guanine phosphoribosyltransferase (Lesch-Nyhan)
21 ☐ Other storage disease, specify: _____

2. Record the leukocyte enzyme levels at diagnosis:

a. Patient enzyme level: LER12E ___ . ___ LEU12E 1 ☐ nmol/hr/mg protein 2 ☐ pmol/hr/mg protein

b. Donor enzyme level: DLER12E ___ . ___ DLEU12E 1 ☐ nmol/hr/mg protein 2 ☐ pmol/hr/mg protein

NMDP Form 120, 520, 620 Insert XIV V1 (1–5) November 1999
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**Mail to NMDP Registry with Form 120, 520, 620. Retain a copy at the transplant center.**

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

3. Was treatment given for the disease between diagnosis and transplant?
1 ☐ yes → 4. Specify:
2 ☐ no
3 ☐ unknown
TRANY12E

a. Enzyme replacement 1 ☐ yes 2 ☐ no 3 ☐ unknown TRENZ12E
b. Substrate deprivation/inhibitor 1 ☐ yes 2 ☐ no 3 ☐ unknown TRSUB12E
c. Gene transfer/gene therapy 1 ☐ yes 2 ☐ no 3 ☐ unknown TRGEN12E

## Clinical Status Pre-Transplant

5. Was cerebrospinal fluid (CSF) testing done pre-transplant?
1 ☐ yes → 6. Report results of most recent tests:
2 ☐ no
3 ☐ unknown
CSF12E

a. Opening pressure
OPEN12E
1 ☐ yes → ☐☐☐ cm $H_2O$ OPENV12E
2 ☐ no
3 ☐ unknown

b. Total protein
TPRO12E
1 ☐ yes → TPROV12E ☐☐☐.☐☐ TPROU12E 1 ☐ mg/dL 2 ☐ g/L
2 ☐ no
3 ☐ unknown

c. **Serum** albumin
ALBU12E
1 ☐ yes → ALBUV12E ☐☐.☐ ALBUU12E 1 ☐ mg/dL 2 ☐ g/L
2 ☐ no
3 ☐ unknown

d. **Serum** IgG
SERU12E
1 ☐ yes → SERUV12E ☐☐.☐ SERUU12E 1 ☐ mg/dL 2 ☐ g/L
2 ☐ no
3 ☐ unknown

7. Date of most recent test: ☐☐ Month ☐☐ Day ☐☐☐☐ Year CSFDT12E

8. Magnetic Resonance Imaging (MRI) of the brain/spine pre-transplant:
1 ☐ yes → 9. Specify location of abnormalities:
2 ☐ no
3 ☐ unknown
MRI12E

*(If possible, attach a copy of the report.)*

a. Ventricular (hydrocephalus):
1 ☐ yes
2 ☐ no
3 ☐ unknown
MRIVE12E

b. Odontoid hypoplasia:
1 ☐ yes
2 ☐ no
3 ☐ unknown
MRIOD12E

10. Date of test: ☐☐ Month ☐☐ Day ☐☐☐☐ Year MRIDT12E


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

11. Was a Mental Development test done pre-transplant?
1 ☐ yes → 12
2 ☐ no
3 ☐ unknown
MDT12E

12. Indicate test instrument; report results of test done closest to transplant; report score, not percentile:
MDTIN12E
1 ☐ Bayley Scales of Infant Development
2 ☐ Stanford Binet Intelligence Scale 4th ed
3 ☐ Wechsler Preschool and Primary Scale of Intelligence (WPPSI – Revised)
4 ☐ Wechsler Intelligence Scale for Children – III (WISC – III)
5 ☐ Other, specify: _____

13. Date of test: ☐☐ Month ☐☐ Day ☐☐☐☐ Year MDTDT12E

14. Full scale score: ☐☐☐ MDTFS12E

15. Verbal score: ☐☐☐ MDTVS12E

16. Performance score: ☐☐☐ MDTPS12E

17. Were the Vineland Adaptive Behavior Scales done pre-transplant?
1 ☐ yes → 18
2 ☐ no
3 ☐ unknown
VAB12E

18. Score results:
a. Communication skills: ☐☐☐ VABCS12E
b. Daily living skills: ☐☐☐ VABDL12E
c. Socialization skills: ☐☐☐ VABSS12E

19. Date of test: ☐☐ Month ☐☐ Day ☐☐☐☐ Year VABDT12E

20. Was an eye exam done pre-transplant?
1 ☐ yes → 21
2 ☐ no
3 ☐ unknown
EYE12E

21. Visual acuity:
a. Right eye: ☐☐ / ☐☐☐ VACRA12E VACRB12E
b. Left eye: ☐☐ / ☐☐☐ VACLA12E VACLB12E

22. Was corneal clouding present?
1 ☐ yes
2 ☐ no
3 ☐ unknown
VACCC12E

23. Date of most recent test: ☐☐ Month ☐☐ Day ☐☐☐☐ Year VACDT12E


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

24. Was an audiologic evaluation (auditory brain stem or conditioned response) done pre-transplant?
1 ☐ yes → 25. Tympanometry results:

| | Normal | Retracted | Flat | |
|---|---|---|---|---|
| a. Right ear: | 1 ☐ | 2 ☐ | 3 ☐ | TYMRE12E |
| b. Left ear: | 1 ☐ | 2 ☐ | 3 ☐ | TYMLE12E |

2 ☐ no
3 ☐ unknown
AUD12E

26. Was the hearing loss (HL) in decibels (dB) assessed at the speech threshold for 500 hertz (HZ)?
1 ☐ yes → 27. Speech Threshold results at 500 HZ:

| | Normal - Mild | Moderate - Moderately Severe | Severe - Profound | |
|---|---|---|---|---|
| a. Right ear: | 1 ☐ | 2 ☐ | 3 ☐ | HL5RE12E |
| b. Left ear: | 1 ☐ | 2 ☐ | 3 ☐ | HL5LE12E |

See Degree of Hearing Loss chart below for scale ranges.

2 ☐ no
3 ☐ unknown
HL512E

28. Was the hearing loss (HL) in decibels (dB) assessed at the speech threshold for 2000 hertz (HZ)?
1 ☐ yes → 29. Speech Threshold results at 2000 HZ:

| | Normal - Mild | Moderate - Moderately Severe | Severe - Profound | |
|---|---|---|---|---|
| a. Right ear: | 1 ☐ | 2 ☐ | 3 ☐ | HL2RE12E |
| b. Left ear: | 1 ☐ | 2 ☐ | 3 ☐ | HL2LE12E |

See Degree of Hearing Loss chart below for scale ranges.

2 ☐ no
3 ☐ unknown
HL212E

**Degree of Hearing Loss: Pure tones and speech testing**

| | | | |
|---|---|---|---|
| Normal: | 0-20 dB HL | Moderately Severe: | 60-70 dB HL |
| Mild: | 25-40 dB HL | Severe: | 75-90 dB HL |
| Moderate: | 45-55 dB HL | Profound: | > 90 dB HL |

Was pulmonary function testing done pre-transplant?
1 ☐ yes → 31. Oxygen saturation on room air: ☐☐☐ % PULOS12E

32. Results of most recent pulmonary function test:
*(If possible, attach a copy of the report.)*
1 ☐ normal
2 ☐ abnormal
3 ☐ not done
→ PULRS12E

2 ☐ no
3 ☐ unknown
PUL12E


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33. Was an echocardiogram done pre-transplant?
1 ☐ yes → 34. Valvular insufficiency:
2 ☐ no
3 ☐ unknown
ECH12E

a. Tricuspid:
1 ☐ none
2 ☐ mild or trivial
3 ☐ moderate or severe
4 ☐ valve replacement
ECHTR12E

b. Mitral:
1 ☐ none
2 ☐ mild or trivial
3 ☐ moderate or severe
4 ☐ valve replacement
ECHMI12E

c. Aortic:
1 ☐ none
2 ☐ mild or trivial
3 ☐ moderate or severe
4 ☐ valve replacement
ECHAO12E

d. Pulmonary:
1 ☐ none
2 ☐ mild or trivial
3 ☐ moderate or severe
4 ☐ valve replacement
ECHPU12E

35. Date of test: ☐☐ Month ☐☐ Day ☐☐☐☐ Year ECHDT12E

36. Was the cardiac contractility tested pre-transplant?
☐ yes → 37. Ejection fraction: ☐☐ % CAREJ12E
2 ☐ no
3 ☐ unknown
CAR12E

38. Shortening fraction: ☐☐ % CARSH12E


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**100-Day Follow-Up Visit of Recipient**

COBLT NMDP130

**Registry Use Only**

Sequence Number

Date Received

**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

Product type: ☐ Marrow (Form 130) ☐ PBSC (Form 530) ☐ Cord blood (Form 630)

## 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. Research blood samples from recipients receiving marrow from *unrelated* donors should be collected and sent to Blood Centers of the Pacific, Irwin Center. See Manual of Operations for detailed instructions.**

1. Date of actual contact with recipient to determine medical status for this follow-up report: A130DT [ ][ ] Month [ ][ ] Day [ ][ ][ ][ ] Year

2. Did recipient receive a subsequent stem cell infusion (bone marrow, mobilized peripheral blood stem cells, cord blood) prior to day 100 after the transplant for which this form is being completed? STEMCLL3

   ☐ yes → Answers to subsequent questions should reflect clinical status immediately prior to start of conditioning for subsequent stem cell infusion. Be sure to answer questions 167–169 on page 18.

   no

3. Did recipient die prior to day 100 after the transplant for which this form is being completed? DIED3

   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 (approximately 100 days post-transplant).

4. Has recipient received an infusion of peripheral blood mononuclear cells or lymphocytes from the original donor? PBMCDR3

   1 ☐ yes →

   2 ☐ no

   5. Date the first infusion was given: [ ][ ] Month [ ][ ] Day [ ][ ][ ][ ] Year PBMCDT3

   6. Recipient weight within 2 weeks of first infusion: [ ][ ][ ] kg PBMCWT3

   7. Total number of infusions: [ ][ ] PBMCNUM3

   8. Total dose of mononuclear cells: [ ][ ][ ] • [ ] x $10^{10}$ PBMCMNC3

   9. Indication for the infusion(s) of donor cells: PBMCIND3
      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 130, 530, 630 V8 (1–18) November 1998
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Recipient NMDP ID: ___ - ___ - ___ Recipient Last Name: _____

## H topoietic Reconstitution Post-Transplant

10. Has the recipient received hematopoietic, lymphoid growth factors or cytokines post-transplant? HL6FC3

1 ☐ yes → 2 ☐ no

11. Specify agents given as *planned* therapy to promote engraftment, per protocol:

PLAN3X7

| | | Yes | No | Date started Month | Day | Year | Date stopped Month | Day | Year | |
|---|---|---|---|---|---|---|---|---|---|---|
| PLAN31 | a. G-CSF | 1 ☐ | 2 ☐ | | | | | | | GCSFPDE3 |
| PLAN32 | b. GM-CSF GMPDB3 | 1 ☐ | 2 ☐ | | | | | | | GMPDE3 |
| PLAN33 | c. PIXY – 321 PIXYPDB3 | 1 ☐ | 2 ☐ | | | | | | | PIXYPDE3 |
| PLAN34 | d. Interleukin – 3 (IL-3) IL3PDB3 | 1 ☐ | 2 ☐ | | | | | | | IL3PDE3 |
| PLAN35 | e. Stem Cell Factor (SCF) SCFPDB3 | 1 ☐ | 2 ☐ | | | | | | | SCFPDE3 |
| PLAN36 | f. Blinded growth factor trial, specify agent: BGFPDB3 | 1 ☐ | 2 ☐ | | | | | | | BGFPDE3 |
| PLAN37 | g. Other, specify: OTHRPDB3 | 1 ☐ | 2 ☐ | | | | | | | OTHRPDE3 |

12. Specify additional agents given: ADDL3X13

**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

| | | Yes | No | Date started Month | Day | Year | Date stopped Month | Day | Year | Indication (above) | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| ADDL31 | a. G-CSF GCSFADB3 | 1 ☐ | 2 ☐ | | | | GCSFADE3 | | | | INDC3 |
| ADDL32 | b. GM-CSF GMADDB3 | 1 ☐ | 2 ☐ | | | | GMADE3 | | | | INDC3 |
| ADDL33 | c. Erythropoietin ERYTADB3 | 1 ☐ | 2 ☐ | | | | ERYTADE3 | | | | INDC |
| ADDL34 | d. Thrombopoietin THRDADB3 | 1 ☐ | 2 ☐ | | | | THRDADE3 | | | | INDC |
| ADDL35 | e. Interleukin – 2 (IL-2) IL2ADB3 | 1 ☐ | 2 ☐ | | | | IL2ADE3 | | | | INDC |
| ADDL36 | f. Interleukin – 3 (IL-3) IL3ADB3 | 1 ☐ | 2 ☐ | | | | IL3ADE3 | | | | INDC |
| ADDL37 | g. Interleukin – 6 (IL-6) IL6ADB3 | 1 ☐ | 2 ☐ | | | | IL6ADE3 | | | | INDC |
| ADDL38 | h. PIXY – 321 PIXYADB3 | 1 ☐ | 2 ☐ | | | | PIXYADE3 | | | | INDC |
| ADDL39 | i. Stem Cell Factor (SCF) SCFADB3 | 1 ☐ | 2 ☐ | | | | SCFADE3 | | | | INDC |
| ADDL310 | j. Interferon alpha ALPHADB3 | 1 ☐ | 2 ☐ | | | | ALPHADE3 | | | | INDC |
| ADDL311 | k. Interferon gamma GAMMDDB3 | 1 ☐ | 2 ☐ | | | | GAMMADE3 | | | | INDC |
| ADDL312 | l. Blinded growth factor trial, specify agent: BGFADB3 | 1 ☐ | 2 ☐ | | | | BGFADE3 | | | | INDC |
| ADDL313 | m. Other, specify: GTHRADB3 | 1 ☐ | 2 ☐ | | | | GTHRADE3 | | | | INDC |


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## G[illegible]opoiesis

HEMREC3

13. [illegible] (was) there evidence of hematopoietic recovery following the initial bone marrow infusion? (Check only one)

1 ☐ Yes, ANC ≥ 500/mm³ achieved and sustained for 3 consecutive lab values with no subsequent decline →

14. Date ANC > 500/mm³ (first of 3 consecutive lab values taken on different days): ANCNDT3 ☐☐ Month ☐☐ Day ☐☐☐☐ Year

15. Was ANC > 1,000/mm³ achieved and sustained for 3 consecutive lab values taken on different days? ANCNUYN3

1 ☐ yes → Date (first of 3 consecutive lab values taken on different days): ANCNUDT3 ☐☐ Month ☐☐ Day ☐☐☐☐ Year

2 ☐ no

**Continue with 32**

2 ☐ Yes, ANC ≥ 500/mm³ for 3 consecutive lab values with subsequent decline in ANC to < 500/mm³ for greater than 3 days →

16. Date ANC > 500/mm³ (first of 3 consecutive days): ANCYDT3 ☐☐ Month ☐☐ Day ☐☐☐☐ Year

17. Was ANC > 1,000/mm³ achieved and sustained for 3 consecutive days? ANCYUYN3

1 ☐ yes → Date (first of 3 consecutive days): ANCYUDT3 ☐☐ Month ☐☐ Day ☐☐☐☐ Year

2 ☐ no

18. Date of decline in ANC to < 500/mm³ for greater than 3 days (first of 3 days that ANC declined): ANCYDDT3 ☐☐ Month ☐☐ Day ☐☐☐☐ Year

Actual CBC on first day of decline:

19. WBC: ☐☐☐☐.☐ x 10³/L ANCWBC3

20. Neutrophils: ☐☐.☐ % ANCNEU3

21. Lymphocytes: ☐☐.☐ % ANCLYM3

22. Did recipient recover and maintain ANC ≥ 500/mm³ following the decline? ANCYRYN3

1 ☐ yes → 23. Date of ANC recovery: ANCYRDT3 ☐☐ Month ☐☐ Day ☐☐☐☐ Year

Actual CBC on first day of recovery:

24. WBC: ☐☐☐☐.☐ x 10³/L ANCRWBC3

25. Neutrophils: ☐☐.☐ % ANCRNEU3

26. Lymphocytes: ☐☐.☐ % ANCRLYM3

2 ☐ no

**Continue with 27**

3 ☐ No, ANC ≥ 500/mm³ was not achieved and there was no evidence of recurrent disease in the bone marrow → **Continue with 27**

ANCNPDR3

4 ☐ No, ANC ≥ 500/mm³ was not achieved and there was documented persistent disease in the bone marrow post-transplant → **Continue with 68**


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27. Suspected etiology of failure to achieve ANC > 500/mm³ or a decline in ANC: ANCPDR3

Persistent disease or relapse
1 ☐ yes
2 ☐ no

b. Immune mediated rejection ANCIM3X5
1 ☐ yes → 28. Immune mediated etiology: ANCIM31
2 ☐ no
- a. 1 ☐ yes 2 ☐ no Cellular ANCIM32
- b. 1 ☐ yes 2 ☐ no Antibody ANCIM33
- c. 1 ☐ yes 2 ☐ no Third party engraftment ANCIM34
- d. 1 ☐ yes 2 ☐ no Unknown ANCIM35

c. Graft versus host disease ANCGUHD3
1 ☐ yes
2 ☐ no

d. Non-viral infection ANCNVI3
1 ☐ yes
2 ☐ no

e. Suspected viral infection
1 ☐ yes → 29. Suspected virus: ANCSV3X6 ANCSV31
2 ☐ no
- a. 1 ☐ yes 2 ☐ no Cytomegalovirus (CMV) ANCSV32
- b. 1 ☐ yes 2 ☐ no Human Herpesvirus Type 6 (HHV6) ANCSV33
- c. 1 ☐ yes 2 ☐ no Herpes Simplex Virus (HSV) ANCSV34
- d. 1 ☐ yes 2 ☐ no Varicella ANCSV35
- e. 1 ☐ yes 2 ☐ no Other, specify: ANCSV36

f. Documented viral infection ANCDV3X6
1 ☐ yes → 30. Virus involved: ANCDV31
2 ☐ no
- a. 1 ☐ yes 2 ☐ no Cytomegalovirus (CMV) ANCDV32
- b. 1 ☐ yes 2 ☐ no Human Herpesvirus Type 6 (HHV6) ANCDV33
- c. 1 ☐ yes 2 ☐ no Herpes Simplex Virus (HSV) ANCDV34
- d. 1 ☐ yes 2 ☐ no Varicella ANCDV35
- e. 1 ☐ yes 2 ☐ no Other, specify: ANCDV36

g. Antimicrobial therapy ANCAM3X4
1 ☐ yes → 31. Therapy:
2 ☐ no ANCAM31
- a. 1 ☐ yes 2 ☐ no Ganciclovir ANCAM32
- b. 1 ☐ yes 2 ☐ no Bactrim, Septra, Trimethoprim/Sulfamethoxazole ANCAM33
- c. 1 ☐ yes 2 ☐ no Other, specify: ANCAM34

h. Undetermined
1 ☐ yes
2 ☐ no ANCUND3

## 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.

32. Was a platelet count of ≥ 20,000 achieved? PL12YN3
1 ☐ yes → 33. Date platelets ≥ 20,000: ☐☐ Month ☐☐ Day ☐☐☐☐ Year PL12DT3
2 ☐ no → **Continue with 38**


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3 s a platelet count of ≥ 50,000 achieved? PL15Y N3

1 ☐ yes → 35. Date platelets ≥ 50,000: ☐☐ Month ☐☐ Day ☐☐☐☐ Year PL15DT3

2 ☐ no → **Continue with 38**

36. Was a platelet count of ≥ 100,000 achieved? PL110Y N3

1 ☐ yes → 37. Date platelets ≥ 100,000: ☐☐ Month ☐☐ Day ☐☐☐☐ Year PL110DT3

2 ☐ no → **Continue with 38**

38. Was recipient ever platelet transfusion independent? PL1T1Y N3

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

1 ☐ yes → ☐☐ Month ☐☐ Day ☐☐☐☐ Year PL1T1KN3

2 ☐ no

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**

40. 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? PL1T1DT3

1 ☐ yes → 41. Date of the first day platelet count declined below 20,000: PL1DYN3 ☐☐ Month ☐☐ Day ☐☐☐☐ Year PL1DDT3

42. Did platelet count recover? PL1RYN3

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? PLS2YN3

1 ☐ yes → 44. Date platelets ≥ 20,000: ☐☐ Month ☐☐ Day ☐☐☐☐ Year PLS2DT3

2 ☐ no → **Continue with 49**

45. Was a platelet count of ≥ 50,000 achieved? PLS5YN3

1 ☐ yes → 46. Date platelets ≥ 50,000: ☐☐ Month ☐☐ Day ☐☐☐☐ Year PLS5DT3

2 ☐ no → **Continue with 49**

47. Was a platelet count of ≥ 100,000 achieved? PLS10YN3

1 ☐ yes → 48. Date platelets ≥ 100,000: ☐☐ Month ☐☐ Day ☐☐☐☐ Year PLS10DT3

2 ☐ no

49. Is recipient now receiving platelet transfusions? PLSREC3

1 ☐ yes → **Continue with 51**

2 ☐ no → 50. Is the date of the last platelet transfusion known? PLSKNWN3

1 ☐ yes → ☐☐ Month ☐☐ Day ☐☐☐☐ Year → PLSDT3

2 ☐ no

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


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spected etiology of failure to achieve a platelet count ≥ 100,000 or decline in platelet count to < 20,000

a. Persistent disease or relapse PLTPDR3
1 ☐ yes
2 ☐ no

b. Immune mediated rejection PLTIM3X5
1 ☐ yes →
2 ☐ no

52. Immune mediated etiology: PLTIM31
- a. 1 ☐ yes 2 ☐ no Cellular PLTIM32
- b. 1 ☐ yes 2 ☐ no Antibody PLTIM33
- c. 1 ☐ yes 2 ☐ no Third party engraftment PLTIM34
- d. 1 ☐ yes 2 ☐ no Unknown PLTIM35

c. Graft versus host disease PLTGVHD3
1 ☐ yes
2 ☐ no

d. Non-viral infection PLTNVI3
1 ☐ yes
2 ☐ no

e. Suspected viral infection PLTSV3X6
1 ☐ yes →
2 ☐ no

53. Suspected virus: PLTSV31
- a. 1 ☐ yes 2 ☐ no Cytomegalovirus (CMV) PLTSV32
- b. 1 ☐ yes 2 ☐ no Human Herpesvirus Type 6 (HHV6) PLTSV33
- c. 1 ☐ yes 2 ☐ no Herpes Simplex Virus (HSV) PLTSV34
- d. 1 ☐ yes 2 ☐ no Varicella ~~PLTSV34~~ PLTSV35
- e. 1 ☐ yes 2 ☐ no Other, specify: PLTSV36

f. Documented viral infection PLTDV3X6
1 ☐ yes →
2 ☐ no

54. Virus involved: PLTDV31
- a. 1 ☐ yes 2 ☐ no Cytomegalovirus (CMV) PLTDV32
- b. 1 ☐ yes 2 ☐ no Human Herpesvirus Type 6 (HHV6) PLTDV33
- c. 1 ☐ yes 2 ☐ no Herpes Simplex Virus (HSV) PLTDV34
- d. 1 ☐ yes 2 ☐ no Varicella PLTDV35
- e. 1 ☐ yes 2 ☐ no Other, specify: PLTDV36

g. Antimicrobial therapy PLTAM3X4
1 ☐ yes →
2 ☐ no

55. Therapy: PLTAM31
- a. 1 ☐ yes 2 ☐ no Ganciclovir PLTAM32
- b. 1 ☐ yes 2 ☐ no Bactrim, Septra, Trimethoprim/Sulfamethoxazole PLTAM33
- c. 1 ☐ yes 2 ☐ no Other, specify: PLTAM34

h. Veno-occlusive disease (VOD) PLTVOD3
1 ☐ yes
2 ☐ no

i. Undetermined PLTUND3
1 ☐ yes
2 ☐ no


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## Erythropoiesis

56. Has recipient received red blood cell (RBC) transfusions within 20 days of the day of contact? RBCREC3
1 ☐ yes
2 ☐ no →

57. Is the date of the last RBC transfusion known? RBCKNWN3
1 ☐ yes → Month ☐☐ Day ☐☐ Year ☐☐☐☐ RBCDT3
2 ☐ no
**Continue with 58**

58. Did (does) recipient have evidence of hemolysis? HEMOLYS3
1 ☐ yes →
2 ☐ no

59. Specify criteria: _____

## Current Hematologic Findings

60. Date of most recent CBC: Month ☐☐ Day ☐☐ Year ☐☐☐☐ CBCDT3

Actual CBC values:

61. WBC: ☐☐☐☐ • ☐ x $10^9$/L ACTWBC3
62. Neutrophils: ☐☐ • ☐ % ACTNEU3
63. Lymphocytes: ☐☐ • ☐ % ACTLYM3
64. Hemoglobin: ☐☐ • ☐ g/dL ACTHGB3
65. Hematocrit: ☐☐ • ☐ % ACTHCT3
66. Platelets: ☐☐☐☐ • ☐ x $10^9$/L ACTPLT3

67. Were chimerism studies performed prior to date of contact? CHIMSTD3
1 ☐ yes → **Complete table on following page**
2 ☐ no → **Continue with 68**


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## Acute Graft vs. Host Disease (GVHD)

6 Is specific therapy used post transplant to *prevent* acute GVHD or promote engraftment? PRAG3X11

1 ☐ yes → 69. For each agent listed below indicate whether or not it was used to prevent acute GVHD or promote engraftment: PRAG31

a. 1 ☐ 2 ☐ Methotrexate PRAG32
b. 1 ☐ 2 ☐ Cyclosporine PRAG33
c. 1 ☐ 2 ☐ Corticosteroids PRAG34
d. 1 ☐ 2 ☐ ALS, ALG, ATS, ATG PRAG35
e. 1 ☐ 2 ☐ Azathioprine PRAG36
f. 1 ☐ 2 ☐ Cyclophosphamide PRAG37
g. 1 ☐ 2 ☐ In vivo anti T-lymphocyte monoclonal antibody, specify: PRAG38
h. 1 ☐ 2 ☐ In vivo immunotoxin, specify: PRAG39
i. 1 ☐ 2 ☐ Blinded randomized trial, specify agent: PRAG310
j. 1 ☐ 2 ☐ Other, specify: PRAG311

2 ☐ no

70 Did acute GVHD occur? AGVHD4N3

1 ☐ yes →

71. Maximun overall grade: 1 ☐ I 2 ☐ II 3 ☐ III 4 ☐ IV AGVHDMG3

72. Karnofsky/Lansky score at time of maximum severity of acute GVHD: ☐☐☐ (Refer to page 15 for complete scale) AGVHDKL3

73. What was the diagnosis based on? 1 ☐ Histologic evidence 2 ☐ Clinical evidence 3 ☐ Both AGVHDEV3

74. Date of onset: ☐☐ Month ☐☐ Day ☐☐☐☐ Year AGVHDDT3

75. Is acute GVHD still present at time of this report? AGVHDPR3
1 ☐ Yes
2 ☐ No
3 ☐ Progressed to chronic GVHD
4 ☐ Not known

2 ☐ no → **Continue with 82**

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

76. Skin AGSKIN3
1 ☐ Stage 0 – No rash
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 desquamation

77. Intestinal tract (use ml/day for adult recipients and ml/m²/day for pediatric recipients) AGINTE3
1 ☐ Stage 0 – No diarrhea
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 AGLIVE3
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)
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


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## Chim[illegible]m Studies (Provide date(s), method(s) and other information fr[illegible]himerism studies performed prior to date of contact.)

| Date | | | Method (See valid list below) | Cell Type (See valid list below) | Number of Cells Examined | Number of Donor Cells | Number of Host Cells | Number of Unknown Origin (Third Party) Cells | Percent Donor Cells | | Percent Host Cells | | Percent Unknown Origin (Third Party) Cells | |
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| Month | Day | Year | | | Total Cells | | | | Quant | *Non-Quant | Quant | *Non-Quant | Quant | *Non-Quant |
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* 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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7? ...er organ involvement? AGOTH3X4

1 ☐ yes → 2 ☐ no

a. 1 ☐ yes 2 ☐ no Upper GI tract AGOTH32
b. 1 ☐ yes 2 ☐ no Lung AGOTH33
c. 1 ☐ yes 2 ☐ no Other, specify: AGOTH34

80. Was specific therapy used to *treat* acute GVHD? TRAG3X13

1 ☐ yes → 2 ☐ no

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): TRAG31

| | yes | no | increasd | |
|---|---|---|---|---|
| a. | 1 ☐ | 2 ☐ | 3 ☐ | Methotrexate TRAG32 |
| b. | 1 ☐ | 2 ☐ | 3 ☐ | Cyclosporine TRAG33 |
| c. | 1 ☐ | 2 ☐ | 3 ☐ | Systemic corticosteroids TRAG34 |
| d. | 1 ☐ | 2 ☐ | 3 ☐ | Topical corticosteroids TRAG35 |
| e. | 1 ☐ | 2 ☐ | 3 ☐ | ALS, ALG, ATS, ATG TRAG36 |
| f. | 1 ☐ | 2 ☐ | 3 ☐ | Azathioprine TRAG37 |
| g. | 1 ☐ | 2 ☐ | 3 ☐ | Cyclophosphamide TRAG38 |
| h. | 1 ☐ | 2 ☐ | 3 ☐ | Thalidomide TRAG39 |
| i. | 1 ☐ | 2 ☐ | 3 ☐ | In vivo anti T-lymphocyte monoclonal antibody, specify: TRAG310 |
| j. | 1 ☐ | 2 ☐ | 3 ☐ | In vivo immunotoxin, specify: TRAG311 |
| k. | 1 ☐ | 2 ☐ | 3 ☐ | Blinded randomized trial, specify agent: TRAG312 |
| l. | 1 ☐ | 2 ☐ | 3 ☐ | Other, specify: TRAG313 |

## Chronic Graft vs. Host Disease

82. Has recipient developed clinical chronic GVHD? CGVHDYN3

1 ☐ yes → 2 ☐ no

**Continue with 95**

83. Date of onset: ☐☐ Month ☐☐ Day ☐☐☐☐ Year CGVHDDT3

84. Karnofsky/Lansky score at diagnosis of chronic GVHD: ☐☐☐ CGVHDKL3
(Refer to page 15 for complete scale)

85. Platelet count at diagnosis of chronic GVHD: ☐☐☐☐.☐ x $10^9$/L CGVHDPL3

86. Total serum bilirubin at diagnosis of chronic GVHD: ☐☐.☐ Unit of measurement CGVHDBU3
1 ☐ mg/dL 2 ☐ µmol/L
CGVHDBT3

87. What was the diagnosis based on?
1 ☐ Histologic evidence
2 ☐ Clinical evidence CGVHDEV3
3 ☐ Both

88. Maximum grade of chronic GVHD: CGVHDMG3
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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CGVH3X17

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

a. 1 ☐ yes 2 ☐ no Cutaneous involvement CGVH31
b. 1 ☐ yes 2 ☐ no Xerophthalmia (dry eyes) CGVH32
c. 1 ☐ yes 2 ☐ no Oral involvement CGVH33
d. 1 ☐ yes 2 ☐ no Mucositis, specify site: CGVH34
e. 1 ☐ yes 2 ☐ no Esophogeal involvement CGVH35
f. 1 ☐ yes 2 ☐ no Chronic nausea/vomiting CGVH36
g. 1 ☐ yes 2 ☐ no Chronic diarrhea CGVH37
h. 1 ☐ yes 2 ☐ no Other GI tract involvement CGVH38
i. 1 ☐ yes 2 ☐ no Weight loss CGVH39
j. 1 ☐ yes 2 ☐ no Hepatitis/hepatic involvement CGVH310
k. 1 ☐ yes 2 ☐ no Arthritis/arthralgia (joint pain) CGVH311
l. 1 ☐ yes 2 ☐ no Contractures CGVH312
m. 1 ☐ yes 2 ☐ no Obstructive lung disease CGVH313
n. 1 ☐ yes 2 ☐ no Serositis, specify site: CGVH314
o. 1 ☐ yes 2 ☐ no Myositis/myalgia (tenderness/pain in muscles) CGVH315
p. 1 ☐ yes 2 ☐ no Thrombocytopenia CGVH316
q. 1 ☐ yes 2 ☐ no Other, specify: CGVH317

90. Was specific therapy used to *treat* chronic GVHD? TRCG3X12

1 ☐ yes → 91. For each agent listed below indicate whether or not it was used to treat chronic GVHD: TRCG31

| | Yes, still taking | Dose increased, still taking | Yes, no longer taking | No |
|---|---|---|---|---|
| a. ALS, ALG, ATS, ATG TRCG32 | 1 ☐ | 2 ☐ | 3 ☐ | 4 ☐ |
| b. Azathioprine TRCG33 | 1 ☐ | 2 ☐ | 3 ☐ | 4 ☐ |
| c. Cyclosporine TRCG34 | 1 ☐ | 2 ☐ | 3 ☐ | 4 ☐ |
| d. Systemic corticosteroids TRCG35 | 1 ☐ | 2 ☐ | 3 ☐ | 4 ☐ |
| e. Topical corticosteroids TRCG36 | 1 ☐ | 2 ☐ | 3 ☐ | 4 ☐ |
| f. Cyclophosphamide TRCG37 | 1 ☐ | 2 ☐ | 3 ☐ | 4 ☐ |
| g. Thalidomide TRCG38 | 1 ☐ | 2 ☐ | 3 ☐ | 4 ☐ |
| h. In vivo anti T-lymphocyte monoclonal antibody, specify: TRCG39 | 1 ☐ | 2 ☐ | 3 ☐ | 4 ☐ |
| i. In vivo immunotoxin, specify: TRCG310 | 1 ☐ | 2 ☐ | 3 ☐ | 4 ☐ |
| j. Blinded randomized trial, specify agent: TRCG311 | 1 ☐ | 2 ☐ | 3 ☐ | 4 ☐ |
| k. Other, specify: TRCG312 | 1 ☐ | 2 ☐ | 3 ☐ | 4 ☐ |

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

1 ☐ yes
2 ☐ no → 93. Date final treatment was administered:

TRCGDT3→ ☐☐ Month ☐☐ Day ☐☐☐☐ Year

94. Is chronic GVHD still present?

1 ☐ yes
2 ☐ no CGVHDPR3
3 ☐ no symptoms, recipient still receiving treatment


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

## O' Treatment and Clinical Status Post-Transplant

95 Were transfusions given at any time after the start of conditioning to present? TRANS4N3

1 ☐ yes → 96. Did recipient receive only CMV seronegative blood products?
- 1 ☐ yes
- 2 ☐ no CMVNEG3

97. Were blood products filtered to reduce leukocytes?
- 1 ☐ yes
- 2 ☐ no BPFILT3

2 ☐ no

98. Did recipient receive any of the following agents for infection prophylaxis after start of conditioning to present? INPR3X14

1 ☐ yes → 99. Specify: INPR31

| | | | |
|---|---|---|---|
| a. | 1 ☐ yes 2 ☐ no | Polyclonal IV gamma globulin (not ATG) | INPR32 |
| b. | 1 ☐ yes 2 ☐ no | IV amphotericin | INPR33 |
| c. | 1 ☐ yes 2 ☐ no | Fluconazole | INPR34 |
| d. | 1 ☐ yes 2 ☐ no | Itraconazole | INPR35 |
| e. | 1 ☐ yes 2 ☐ no | Other systemic antifungal agent, specify: | INPR36 |
| f. | 1 ☐ yes 2 ☐ no | Acyclovir | INPR37 |
| g. | 1 ☐ yes 2 ☐ no | Ganciclovir | INPR38 |
| h. | 1 ☐ yes 2 ☐ no | Foscarnet | INPR39 |
| i. | 1 ☐ yes 2 ☐ no | Other antiviral agent, specify: | INPR310 |
| j. | 1 ☐ yes 2 ☐ no | Trimethoprim/sulfamethoxazole (Bactrim, Septra) | INPR311 |
| k. | 1 ☐ yes 2 ☐ no | Pentamidine | INPR312 |
| l. | 1 ☐ yes 2 ☐ no | Other pneumocystis prophylaxis, specify: | NIPR313 |
| m. | 1 ☐ yes 2 ☐ no | Other, specify: | INPR314 |

2 ☐ no

## Organ Function

### Pulmonary Function

100. Did recipient develop interstitial pneumonitis after the start of conditioning to present? (Interstitial pneumonitis is characterized by hypoxia and diffuse interstitial infiltrates on chest x-ray not caused by fluid overload.) PNYN3

1 ☐ yes → 101. What was the date of onset? (Month ___ Day ___ Year ____) PNDT3

2 ☐ no

102. Were diagnostic tests done? PNTEST3

1 ☐ yes → 103. Diagnosis was evaluated by: PNDIA3X5

| | | | |
|---|---|---|---|
| a. | 1 ☐ yes 2 ☐ no | Bronchoalveolar lavage | PNDIA31 |
| b. | 1 ☐ yes 2 ☐ no | Transbronchial biopsy | PNDIA32 |
| c. | 1 ☐ yes 2 ☐ no | Open lung biopsy | PNDIA33 |
| d. | 1 ☐ yes 2 ☐ no | Autopsy | PNDIA34 |
| e. | 1 ☐ yes 2 ☐ no | Other, specify: | PNDIA35 |

104. Was an organism isolated? PNO13X9

1 ☐ yes → 105. Etiology: PNO131

| | | | |
|---|---|---|---|
| a. | 1 ☐ yes 2 ☐ no | Pneumocystis carinii | PNO132 |
| b. | 1 ☐ yes 2 ☐ no | Aspergillus | PNO133 |
| c. | 1 ☐ yes 2 ☐ no | Cytomegalovirus | PNO134 |
| d. | 1 ☐ yes 2 ☐ no | Herpes simplex | PNO135 |
| e. | 1 ☐ yes 2 ☐ no | Adenovirus | PNO136 |
| f. | 1 ☐ yes 2 ☐ no | Human Herpesvirus Type 6 (HHV6) | PNO137 |
| g. | 1 ☐ yes 2 ☐ no | Other virus, specify: | PNO138 |
| h. | 1 ☐ yes 2 ☐ no | Other, specify: | PNO139 |

2 ☐ no (idiopathic)

106. Has interstitial pneumonitis resolved? 1 ☐ yes 2 ☐ no PNRESLN3

**Continue with 107**


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107. recipient develop pulmonary abnormalities other than interstitial pneumonitis after the start of conditioning to present? PAYN3

1 ☐ yes → 108. Did recipient develop Acute Respiratory Distress Syndrome (ARDS)? PAYN3

2 ☐ no

ARYN3

1 ☐ yes → 109. Date of onset: ☐☐ Month ☐☐ Day ☐☐☐☐ Year ARDT3

2 ☐ no

110. Were diagnostic tests done? ARTEST3

1 ☐ yes → 111. Diagnosis was evaluated by: ARDIA3X5

- a. 1 ☐ yes 2 ☐ no Bronchoalveolar lavage ARDIA31
- b. 1 ☐ yes 2 ☐ no Transbronchial biopsy ARDIA32
- c. 1 ☐ yes 2 ☐ no Open lung biopsy ARDIA33
- d. 1 ☐ yes 2 ☐ no Autopsy ARDIA34
- e. 1 ☐ yes 2 ☐ no Other, specify: ARDIA35

2 ☐ no

**Continue with 122**

112. Did recipient develop bronchiolitis obliterans? BOYN3

1 ☐ yes → 113. Date of onset: ☐☐ Month ☐☐ Day ☐☐☐☐ Year BODT3

2 ☐ no

114. Were diagnostic tests done? BOTEST3

1 ☐ yes → 115. Diagnosis was evaluated by: BODIA3X5

- a. 1 ☐ yes 2 ☐ no Bronchoalveolar lavage BODIA31
- b. 1 ☐ yes 2 ☐ no Transbronchial biopsy BODIA32
- c. 1 ☐ yes 2 ☐ no Open lung biopsy BODIA33
- d. 1 ☐ yes 2 ☐ no Autopsy BODIA34
- e. 1 ☐ yes 2 ☐ no Other, specify: BODIA35

2 ☐ no

116. Did recipient develop pulmonary hemorrhage? PHYN3

1 ☐ yes → 117. Date of onset: ☐☐ Month ☐☐ Day ☐☐☐☐ Year PHDT3

2 ☐ no

118. Were diagnostic tests done? PHTEST3

1 ☐ yes → 119. Diagnosis was evaluated by: PHDIA3X5

- a. 1 ☐ yes 2 ☐ no Bronchoalveolar lavage PHDIA31
- b. 1 ☐ yes 2 ☐ no Transbronchial biopsy PHDIA32
- c. 1 ☐ yes 2 ☐ no Open lung biopsy PHDIA33
- d. 1 ☐ yes 2 ☐ no Autopsy PHDIA34
- e. 1 ☐ yes 2 ☐ no Other, specify: PHDIA35

2 ☐ no

120. Did recipient develop other pulmonary abnormalities? PAOTHER3

1 ☐ yes → 121. Specify: _____

2 ☐ no

**Liver Function**

MAXBQT3

122. Recipient's maximum known total bilirubin: ☐☐☐.☐ Unit of measurement: 1 ☐ mg/dL *or* 2 ☐ µmol/L MAXBMEA3

123. Date of maximum known total bilirubin: ☐☐ Month ☐☐ Day ☐☐☐☐ Year MAXBDT3

124. Recipient's bilirubin on day of contact: ☐☐☐.☐ Unit of measurement: 1 ☐ mg/dL *or* 2 ☐ µmol/L CONBMEA3

CONBQTY3


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12[illegible] the recipient develop any of the following clinical signs/symptoms of abnormal liver function after the start of conditioning to ent? ALF3X6

a. 1 ☐ yes 2 ☐ no Jaundice ALF31
b. 1 ☐ yes 2 ☐ no Hepatomegaly ALF32
c. 1 ☐ yes 2 ☐ no Right upper quadrant pain ALF33
d. 1 ☐ yes 2 ☐ no Ascites ALF34
e 1 ☐ yes 2 ☐ no Weight gain (> 5%) ALF35
f. 1 ☐ yes 2 ☐ no Other, specify: ALF36

126. Did recipient develop liver toxicity after the start of conditioning to present? LTYN3

1 ☐ yes → 127. Date of onset: ☐☐ Month ☐☐ Day ☐☐☐☐ Year LTDT3

128. Etiology: LTETIOL3
1 ☐ Veno-occlusive disease (VOD)
2 ☐ Other, specify: _____
3 ☐ VOD and other, specify: _____
4 ☐ Unknown

129. Diagnosis was based on: LTDIA3X5
a. 1 ☐ yes 2 ☐ no Clinical signs and symptoms LTDIA31
b. 1 ☐ yes 2 ☐ no Elevated liver enzymes LTDIA32
c. 1 ☐ yes 2 ☐ no Biopsy LTDIA33
d. 1 ☐ yes 2 ☐ no Autopsy LTDIA34
e. 1 ☐ yes 2 ☐ no Other, specify: LTDIA35

130. Has liver toxicity resolved? LTRESLV3
1 ☐ yes
2 ☐ no

2 ☐ no

**Kidney Function**

131. Recipient's serum creatinine on day of contact: ☐☐.☐ mg/dL SERCREA3

**New Malignancy**

132. Did a *new* malignancy, lymphoproliferative or myeloproliferative disorder appear? NMYN3

1 ☐ yes → 133. Diagnosis: NMDIA3X6
a. 1 ☐ yes 2 ☐ no AML/MDS NMDIA31
b. 1 ☐ yes 2 ☐ no B-cell lymphoproliferative disorder NMDIA32
c. 1 ☐ yes 2 ☐ no Other lymphoma, specify: NMDIA33
d. 1 ☐ yes 2 ☐ no Skin cancer, specify: NMDIA34
e. 1 ☐ yes 2 ☐ no Solid tumor, specify: NMDIA35
f. 1 ☐ yes 2 ☐ no Other, specify, including site: NMDIA36

134. Date of diagnosis: ☐☐ Month ☐☐ Day ☐☐☐☐ Year NMDT3

2 ☐ no

## Survival and Functional Status

135. Was recipient discharged from hospital after transplant? DISCHYN3

1 ☐ yes → 136. Date of first discharge from hospital after transplant: DISCHDT3 ☐☐ Month ☐☐ Day ☐☐☐☐ Year

137. Total number of inpatient days in first 100 days post-transplant: ☐☐☐ DAYSINP3

2 ☐ no


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137. Is the recipient alive on the day of contact? ALIVEYN3
1 ☐ yes → 139. 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

**KARNOFSKY SCALE ≥ 16 yrs** ALIVE

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** KNL

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 140–166 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 146-163.)

140. What is (was) the status of recipient's disease at time of this report or at time of death? LLSTAT3

1 ☐ First complete remission post transplant (no hematologic evidence of disease) → **Continue with 167**

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

141. Date of first relapse: ☐☐ Month ☐☐ Day ☐☐☐☐ Year LLRELDT3

142. Site of relapse: LLRS3XY
- a. 1 ☐ yes 2 ☐ no Blood and/or bone marrow LLRS31
- b. 1 ☐ yes 2 ☐ no CNS LLRS32
- c. 1 ☐ yes 2 ☐ no Testes LLRS33
- d. 1 ☐ yes 2 ☐ no Other, specify: LLRS34 _____


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143. Was patient treated for post-transplant relapse? LLRT3X10
1 ☐ yes → 144. What treatments were given? LLRT31
2 ☐ no
a. 1 ☐ yes 2 ☐ no Interferon gamma LLRT32
b. 1 ☐ yes 2 ☐ no Interferon alpha LLRT33
c. 1 ☐ yes 2 ☐ no Chemotherapy LLRT34
d. 1 ☐ yes 2 ☐ no Withdrawal of immunosuppression LLRT35
e. 1 ☐ yes 2 ☐ no Immunotoxins LLRT36
f. 1 ☐ yes 2 ☐ no Donor leukocytes LLRT37
g. 1 ☐ yes 2 ☐ no Second transplant LLRT38
h. 1 ☐ yes 2 ☐ no Growth factors, specify: LLRT39
i. 1 ☐ yes 2 ☐ no Other, specify: LLRT310

145. Did the patient acheive a hematologic remission? LLHEMRE3
1 ☐ yes
2 ☐ no
3 ☐ not applicable

**Continue with 167**

## CML Only

146. Did Chronic Myelogenous Leukemia recur (include clinical and/or cytogenetic relapse) post-transplant? CMRECYN3
1 ☐ yes →
2 ☐ no

**Continue with 163**

147. Was post-transplant relapse extramedullary only? CMEMYN3
1 ☐ yes →
2 ☐ no

148. Date of extramedullary relapse: CMEMDT3 ☐☐ Month ☐☐ Day ☐☐☐☐ Year
149. Site of relapse, specify: _____

**Continue with 157**

150. Was *initial* post-transplant relapse cytogenetic *only*? CMCYYN3
1 ☐ yes →
2 ☐ no

151. Date of cytogenetic relapse: CMBMDT3 ☐☐ Month ☐☐ Day ☐☐☐☐ Year
152. Did hematologic evidence of CML *subsequently* appear? CMHEYN3
1 ☐ yes →
2 ☐ no

153. Date of hematologic relapse: CMHEDT3 ☐☐ Month ☐☐ Day ☐☐☐☐ Year
154. *Initial hematologic* relapse findings were consistent with: CMHECON3
1 ☐ Chronic phase
2 ☐ Acccelerated phase
3 ☐ Blast phase

**Continue with 157**

**Cont. with 157**

155. Were initial post-transplant relapse hematologic findings consistent with: CMPTCON3
1 ☐ Chronic phase →
2 ☐ Accelerated or blast phase →

153. Date of relapse: CMPTDT3 ☐☐ Month ☐☐ Day ☐☐☐☐ Year


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157. Was recipient treated for post-transplant relapse? CMTRYN3
- 1 ☐ yes →
- 2 ☐ no

158. What treatments were given? CMTRT3X9
- a. 1 ☐ yes 2 ☐ no Interferon gamma CMTRT31
- b. 1 ☐ yes 2 ☐ no Interferon alpha CMTRT32
- c. 1 ☐ yes 2 ☐ no Chemotherapy CMTRT33
- d. 1 ☐ yes 2 ☐ no Withdrawal of immunosuppression CMTRT34
- e. 1 ☐ yes 2 ☐ no Immunotoxins CMTRT35
- f. 1 ☐ yes 2 ☐ no Donor leukocytes CMTRT36
- g. 1 ☐ yes 2 ☐ no Second transplant CMTRT37
- h. 1 ☐ yes 2 ☐ no Growth factors, specify: CMTRT38
- i. 1 ☐ yes 2 ☐ no Other, specify: CMTRT39

159. Did recipient achieve hematologic remission? CMHEMRE3
- 1 ☐ yes
- 2 ☐ no
- 3 ☐ not applicable

160. Did recipient achieve cytogenetic remission? CMCRYN3
- 1 ☐ yes →
- 2 ☐ no →
- 3 ☐ not applicable, extramedullary relapse only
- 4 ☐ not tested

161. Date bone marrow examined: CMCRDT3
Month ☐☐ Day ☐☐ Year ☐☐☐☐

162. Did recipient achieve chronic phase? CMCRCP3
- 1 ☐ yes
- 2 ☐ no
- 3 ☐ not applicable, cytogenetic relapse only

Continue with 163

Cont. with 163

163. At the time of this report, CML was (check one box only): CMLSTAT3
- 1 ☐ Absent
- 2 ☐ Present on cytogenetic testing only
- 3 ☐ In chronic phase
- 4 ☐ In accelerated phase
- 5 ☐ In blast phase

Continue with 167

## Aplastic Anemia, Nonmalignant Hematologic Disorders, Inborn Errors of Metabolism

164. What was the status of original disease at the time of this report? NHDSTAT3
- 1 ☐ Cured
- 2 ☐ Improved
- 3 ☐ Unchanged
- 4 ☐ Worse
- 5 ☐ Unknown

Continue with 167


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**Immunodeficiency Disease** (For SCIDS complete Insert I; for WAS complete Insert II, and answer questions 165 and 166.)

165. What was the status of T-cell function at this visit or at the time of death? IDTSTAT3
- 1 ☐ Absent (≤ 10% normal response)
- 2 ☐ Normal
- 3 ☐ Partial
- 4 ☐ Unknown

166. What was the status of B-cell function at this visit or at the time of death? IDBSTAT3
- 1 ☐ Absent (≤ 10% normal response)
- 2 ☐ Normal
- 3 ☐ Partial
- 4 ☐ Unknown

## 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.

167. Date of subsequent stem cell infusion: ☐☐ Month ☐☐ Day ☐☐☐☐ Year SCIDT3

168. What was the indication for subsequent stem cell infusion? SCIIND3
- 1 ☐ Graft failure/rejection
- 2 ☐ Recurrence of disease
- 3 ☐ Other, specify: _____

169. Source of stem cells: SCISRCA3
- 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

170. Signed: _____ Person completing form

Please print name: _____

Phone: (_____) _____

(_____) _____

E-mail address: _____


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