

INSERT V
Myelodysplasia/Myeloproliferative Disorders

FOR REGISTRY USE ONLY:
I.D. --
Date received: _____

TEAM IUBMID
(Institutional Unique Blood or Marrow Transplant Identification Number)

Registry: IBMTR ABMTR (circle one)

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

Date of report:
Month Day Year

Pretransplant Information

*** If this is a report of a second (or subsequent) transplant, check here and go to Q.67**

1. What was the date of first diagnosis of myelodysplastic/myeloproliferative disorder?
Month Day Year

2. FAB type at diagnosis (this may differ from FAB type immediately prior to conditioning):
- 51 Refractory anemia
 - 52 Refractory anemia with excess blasts (RAEB)
 - 53 Refractory anemia with excess blasts in transformation (RAEB-T)
 - 54 Chronic myelomonocytic leukemia (CMML)
 - 55 Acquired idiopathic sideroblastic anemia (RARS)
 - 56 Paroxysmal nocturnal hemoglobinuria (PNH)
 - 57 Polycythemia vera
 - 58 Essential thrombocythemia
 - 59 Myelofibrosis with myeloid metaplasia (chronic myelofibrosis - see data manual)
 - 60 Other myelofibrosis or myelosclerosis
 - 61 Other myelodysplasia or myeloproliferative disorder, specify: _____
 - 88 Unknown

3. Classification of other myelofibrosis (see data manual):

- 1 Myelofibrosis in accelerated phase or with excess blasts
- 2 Myelofibrosis in blastic transformation
- 3 Acute myelofibrosis
- 4 Myelodysplasia with myelofibrosis
- 7 Other, specify: _____

4. Was this a secondary (therapy-linked) disorder?
- 1 Yes
 - 0 No
 - 8 Unknown

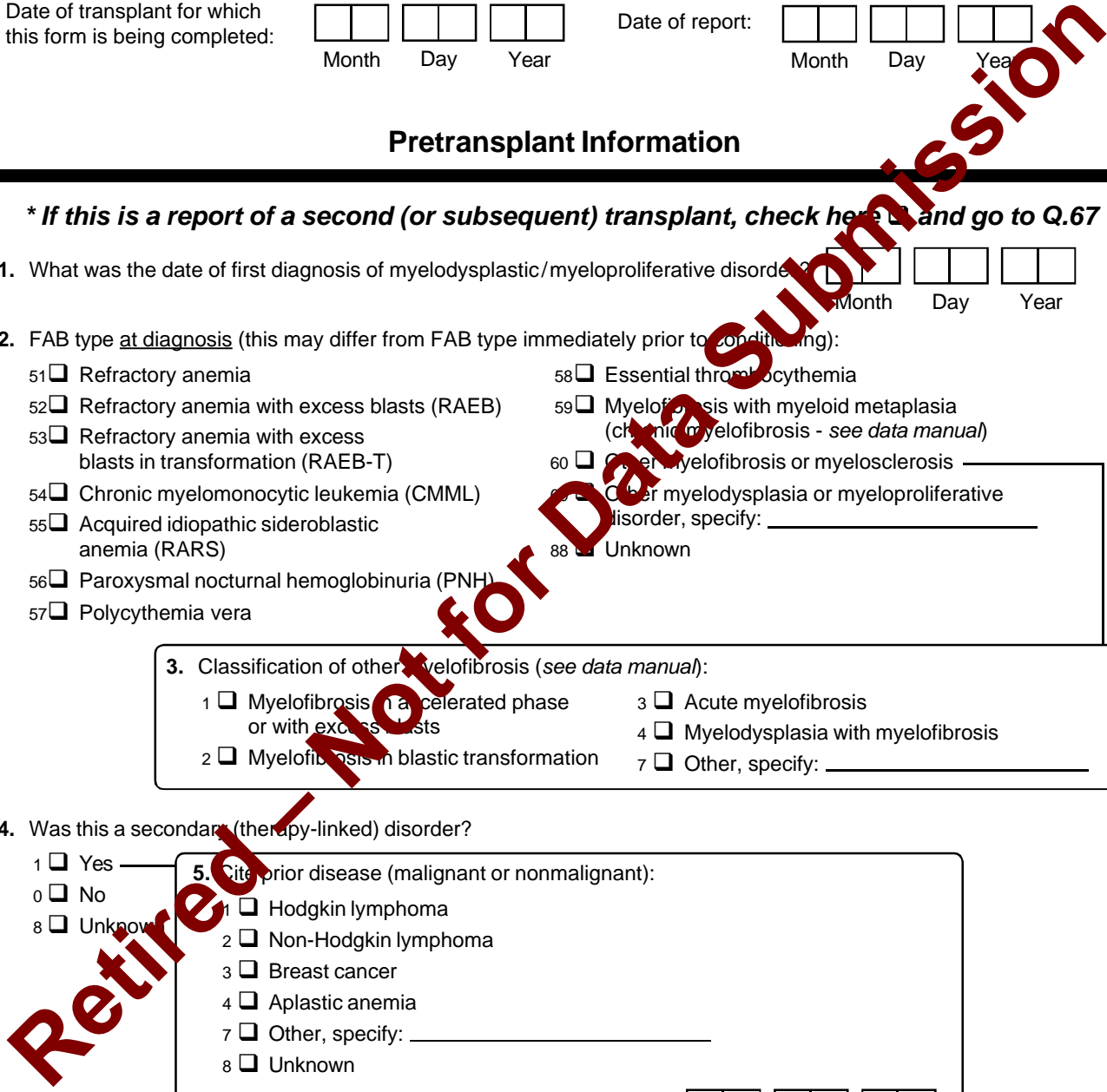
5. Cite prior disease (malignant or nonmalignant):

- 1 Hodgkin lymphoma
- 2 Non-Hodgkin lymphoma
- 3 Breast cancer
- 4 Aplastic anemia
- 7 Other, specify: _____
- 8 Unknown

6. What was the date of diagnosis of prior disease?
Month Day Year

Treatment for prior disease included:

	Yes	No	Unknown	
7.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	Radiation
8.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	Chemotherapy
9.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	Antithymocyte globulin
10.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	Other, specify: _____



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11. Did patient have other predisposing conditions prior to diagnosis of myelodysplastic/myeloproliferative disorder?

- 1 Yes
- 0 No
- 8 Unknown

12. Specify:

- 1 Fanconi anemia
- 2 Bloom syndrome
- 3 Down syndrome
- 7 Other, specify: _____

Clinical features at diagnosis of myelodysplastic/myeloproliferative disorder

13. Did patient have systemic symptoms (fever, sweats, weight loss >10%) at diagnosis?

- 1 Yes
- 0 No
- 8 Unknown

14. Did patient have splenomegaly at diagnosis?

- 1 Yes
- 0 No
- 8 Unknown

cm below left costal margin: -8 size unknown

15. Did patient have hepatomegaly at diagnosis?

- 1 Yes
- 0 No
- 8 Unknown

cm below left costal margin: -8 size unknown

Hematologic findings at diagnosis of myelodysplastic/myeloproliferative disorder

16. Hemoglobin (untransfused): g/dL -8 Unknown

17. Platelets (untransfused): x 10⁹/L (x 10³/mm³) -8 Unknown

18. WBC: x 10⁹/L (x 10³/mm³) -8 Unknown

19. Neutrophils: % -8 Unknown

20. Monocytes: % -8 Unknown

21. Blasts in blood: % -8 Unknown

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Bone marrow findings at diagnosis of myelodysplastic/myeloproliferative disorder

22. Was a bone marrow examination done at first diagnosis of myelodysplastic/myeloproliferative disorder?

- 1 Yes
- 0 No
- 8 Unknown

INCLUDE COPY OF BONE MARROW REPORT

23. Cellularity: 1 Decreased
 2 Normal
 3 Increased
 8 Unknown

24. Fibrosis: 0 Absent
 1 Mild
 2 Moderate
 3 Severe
 8 Unknown

25. Blasts in marrow: %

26. Were cytogenetics tested at first diagnosis of myelodysplastic/myeloproliferative disorder?

- 1 Yes
- 2 Yes, but no evaluable metaphases
- 0 No
- 8 Unknown

INCLUDE COPY OF CYTOGENETICS REPORT

27. Number of metaphases:

28. Was karyotype normal?

1 Yes
0 No

Specify abnormalities				
	Yes	No	Unknown	
29.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	-5/5q-
30.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	-7/7q-
31.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	-20q-
32.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	+8
33.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	+21
34.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	abnormal 3q
35.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	abnormal 11q
36.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	abnormal 16q
37.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	t (1;7)
38.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	t (5;7)
39.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	t (6;9)
40.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	t (8;16)
41.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	t (8;21)
42.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	t (9;22)
43.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	t (15;17)
44.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	Other, specify: _____

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Treatment prior to conditioning

45. Did patient receive treatment for myelodysplastic/myeloproliferative disorder prior to conditioning?

- 1 Yes
- 0 No
- 8 Unknown

	46. Date started	47. Indication	Agents	50. Response
1st treatment	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Month Year	<input type="text"/> (see codes below)	48. <input type="text"/> <input type="text"/> 49. <input type="text"/> <input type="text"/> (see codes below)	<input type="text"/> (see codes below)
2nd treatment	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Month Year	<input type="text"/> (see codes below)	53. <input type="text"/> <input type="text"/> 54. <input type="text"/> <input type="text"/> (see codes below)	<input type="text"/> (see codes below)
3rd treatment	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Month Year	<input type="text"/> (see codes below)	58. <input type="text"/> <input type="text"/> 59. <input type="text"/> <input type="text"/> (see codes below)	<input type="text"/> (see codes below)
4th treatment	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Month Year	<input type="text"/> (see codes below)	63. <input type="text"/> <input type="text"/> 64. <input type="text"/> <input type="text"/> (see codes below)	<input type="text"/> (see codes below)

Indication codes:

- 1 Bone marrow failure (anemia, thrombocytopenia, neutropenia)
- 2 Early evidence of progression to leukemia (increasing percentage of blasts or RAEB-T)
- 3 To induce complete remission (prior to bone marrow failure or evolution)
- 7 Other (specify in space below box)

Agent codes:

- 1 Androgens
- 2 Corticosteroids
- 3 Interferon
- 4 G-CSF
- 5 GM-CSF
- 6 IL3
- 7 Stem cell factor
- 8 Other cytokine (specify in space below box)
- 9 Splenic radiation
- 10 Splenectomy
- 11 Low-dose chemotherapy
- 12 Intensive chemotherapy
- 90 Other (specify in space below box)

Response codes:

- 1 Complete remission
- 2 Bone marrow function* improved
- 3 Improved bone marrow biopsy (specify in space below box)
- 4 No response to therapy
- 5 Bone marrow function* worse
- 7 Other (specify in space below box)

*as assessed by transfusion requirements, number of infections, etc.

66. ADDITIONAL TREATMENTS WERE GIVEN PRIOR TO TRANSPLANT 1 Yes 0 No

If more than 4 treatments were used prior to transplant, please copy the form for 1st – 4th treatments and complete as appropriate, indicating each sequential therapy.

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Clinical features just prior to conditioning

67. Were cytogenetics tested at any time after diagnosis?

- 1 Yes
- 2 Yes, but no evaluable metaphases
- 0 No
- 8 Unknown

INCLUDE COPY OF CYTOGENETICS REPORT

68. Date tested: 69. Number of metaphases:

Month Day Year

70. Was karyotype normal?

- 1 Yes
- 0 No

Specify abnormalities:

	Yes	No	
71.	<input type="checkbox"/>	<input type="checkbox"/>	-5/5q-
72.	<input type="checkbox"/>	<input type="checkbox"/>	-7/7q-
73.	<input type="checkbox"/>	<input type="checkbox"/>	-20q-
74.	<input type="checkbox"/>	<input type="checkbox"/>	+8
75.	<input type="checkbox"/>	<input type="checkbox"/>	+21
76.	<input type="checkbox"/>	<input type="checkbox"/>	abnormal 3q
77.	<input type="checkbox"/>	<input type="checkbox"/>	abnormal 11q
78.	<input type="checkbox"/>	<input type="checkbox"/>	abnormal 16q
79.	<input type="checkbox"/>	<input type="checkbox"/>	t (1;7)
80.	<input type="checkbox"/>	<input type="checkbox"/>	t (5;7)
81.	<input type="checkbox"/>	<input type="checkbox"/>	t (6;9)
82.	<input type="checkbox"/>	<input type="checkbox"/>	t (8;11)
83.	<input type="checkbox"/>	<input type="checkbox"/>	t (9;21)
84.	<input type="checkbox"/>	<input type="checkbox"/>	t (11;22)
85.	<input type="checkbox"/>	<input type="checkbox"/>	t (15;17)
86.	<input type="checkbox"/>	<input type="checkbox"/>	Other, specify: _____

87. Did patient transform to a different FAB classification or stage after diagnosis and prior to conditioning?

- 1 Yes
- 2 Yes, with subsequent complete remission
- 0 No

88. Indicate FAB classification or stage at time of transplant or, if in complete remission, the most recent stage:

51 <input type="checkbox"/> Refractory anemia	57 <input type="checkbox"/> Polycythemia vera
52 <input type="checkbox"/> Refractory anemia with excess blasts (RAEB)	58 <input type="checkbox"/> Essential thrombocythemia
53 <input type="checkbox"/> Refractory anemia with excess blasts in transformation (RAEB-T)	59 <input type="checkbox"/> Myelofibrosis with myeloid metaplasia (chronic myelofibrosis - <i>see data manual</i>)
54 <input type="checkbox"/> Chronic myelomonocytic leukemia (CMML)	60 <input type="checkbox"/> Other myelofibrosis or myelosclerosis
55 <input type="checkbox"/> Acquired idiopathic sideroblastic anemia (RARS)	69 <input type="checkbox"/> Other myelodysplasia or myeloproliferative disorder, specify: _____
56 <input type="checkbox"/> Paroxysmal nocturnal hemoglobinuria (PNH)	70 <input type="checkbox"/> Acute leukemia (<i>Go to Q.111 and complete Insert I</i>)
	88 <input type="checkbox"/> Unknown

89. Classification of myelofibrosis:

1 <input type="checkbox"/> Myelofibrosis in accelerated phase or with excess blasts	3 <input type="checkbox"/> Acute myelofibrosis
2 <input type="checkbox"/> Myelofibrosis in blastic transformation	4 <input type="checkbox"/> Myelodysplasia with myelofibrosis
	7 <input type="checkbox"/> Other, specify: _____

90. Date of most recent transformation:

Month Day Year

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91. Did patient have systemic symptoms (fever, sweats, weight loss >10%) just prior to conditioning?

- 1 Yes
- 0 No
- 8 Unknown

92. Did patient have splenomegaly just prior to conditioning?

- 1 Yes ————— cm below left costal margin:
- 0 No
- 7 Splenectomy
- 8 Unknown

93. Did patient have hepatomegaly just prior to conditioning?

- 1 Yes ————— cm below left costal margin:
- 0 No
- 8 Unknown

Hematologic findings just prior to conditioning

94. Hemoglobin (untransfused): g/dL Patient transfused

95. Platelets (untransfused): x 10⁹/L (x 10⁹/mm³) or Patient transfused

96. WBC: x 10⁹/L (x 10⁹/mm³)

97. Neutrophils: %

98. Monocytes: %

99. Blasts in blood: %

Bone marrow findings just prior to conditioning

100. Date of most recent bone marrow examination just prior to conditioning:
Month Day Year

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101. Cellularity: 1 Decreased
2 Normal
3 Increased
8 Unknown

102. Fibrosis: 0 Absent
1 Mild
2 Moderate
3 Severe
8 Unknown

103. Blasts in marrow: %

104. Indication for bone marrow transplant:

- 1 Bone marrow failure (anemia, thrombocytopenia, neutropenia)
- 2 Early evidence of progression to leukemia (increasing percentage of blasts or RAEB-T)
- 3 To induce complete remission (prior to bone marrow failure or evolution)
- 7 Other, specify: _____

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Posttransplant Information

To be completed ≥ 100 days posttransplant or at time of death if death occurred less than 100 days posttransplant.

105. Best posttransplant response (indicate one only):

- 1 Complete remission
- 2 Persistent disease
- 7 Other, specify: _____

106. Most recent posttransplant disease status:

- 1 Continuous complete remission
- 2 Persistent disease
- 3 Relapse _____
- 4 Complete remission after posttransplant relapse

107. Date of relapse:
Month Day Year

108. Date of relapse:
Month Day Year

109. Treatment given: _____

110. Date of remission:
Month Day Year

111. For patients with marrow fibrosis prior to conditioning, marrow fibrosis posttransplant:

- 1 Remained unchanged
- 2 Improved
- 3 Completely resolved

112. Most recent posttransplant bone marrow examination:
Month Day Year

INCLUDE COPY OF BONE MARROW REPORT

113. Cellularity: 1 Decreased
 Normal
 Increased
8 Unknown

114. Fibrosis: 0 Absent
1 Mild
2 Moderate
3 Severe
8 Unknown

115. Blasts in marrow: %

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Appendix: Classification of Myelofibrosis

I. Chronic myelofibrosis (classical myeloid metaplasia with agnogenic metaplasia):

- Clinically:
 - Splenomegaly
- Blood:
 - Leukoerythroblastic picture
 - <1% blasts
- Bone Marrow:
 - Fibrosis
 - Trilineage proliferation
 - No foci of blasts on marrow biopsy or <5% blasts on touch preps

II. Myelofibrosis in "accelerated phase" or "with excess of blasts":

- Clinically:
 - Splenomegaly
- Blood:
 - Leukoerythroblastic picture
 - ≤30% blasts
- Bone Marrow:
 - Fibrosis
 - Trilineage proliferation
 - Presence of foci of blasts on marrow biopsy or ≤ 30 blasts on touch preps

III. Myelofibrosis in blastic transformation:

- Clinically:
 - Splenomegaly
 - History of "chronic phase"
- Blood:
 - Leukoerythroblastic picture
 - >30% blasts
- Bone Marrow:
 - Fibrosis
 - Diffuse blastic infiltration on marrow biopsy or >30 blasts on touch preps

IV. Acute Myelofibrosis:

- Clinically:
 - Splenomegaly, if present usually mild
 - No history of "chronic phase"
- Blood:
 - > 30% blasts (not necessarily megakaryoblasts)
- Bone Marrow:
 - Fibrosis
 - Blastic marrow (not necessarily megakaryoblasts), >30% blasts

V. MDS with myelofibrosis:

- Clinically:
 - Absence of or barely palpable spleen
- Blood:
 - Leukoerythroblastic picture
 - <1% blasts
- Bone Marrow:
 - Fibrosis
 - Trilineage proliferation with marked dysplasia
 - No foci of blasts or <5% blasts on touch preps