CIBMTR®
CENTER FOR INTERNATIONAL BLOOD & MARROW TRANSPLANT RESEARCH

Myelofibrosis Supplemental Pre-HCT Data

Registry Use Only
Sequence Number:

Date Received:

CIBMTR Center Number: ___ ___ ___ ___ ___

CIBMTR Research ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___

Event date: __ __ __ __ / __ __ / __ __
YYYY MM DD

HCT type (check all that apply): ☐ Autologous ☐ Allogeneic, unrelated ☐ Allogeneic, related

Product type (check all that apply):
☐ Bone marrow ☐ PBSC ☐ Single cord blood unit ☐ Multiple cord blood units ☐ Other product. Specify: _____

CIBMTR Center Number: ___ ___ ___ ___ ___ CIBMTR Research ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___

DIPSS Prognosis Score

1. Specify the maximum DIPSS score the patient ever achieved: ___

2. Specify when maximum DIPSS score was documented:
   - ☐ At diagnosis ***- Go to question 17***
   - ☐ Between diagnosis and the preparative regimen ***- Go to question 3***
   - ☐ At last evaluation prior to the start of the preparative regimen ***- Go to question 17***

Report the clinical and laboratory assessments used to determine the maximum DIPSS score:

3. WBC
   - ☐ Known →
   - ☐ Unknown

   4. ___ ___ ___ ___ ___ ___ • ___ ☐ x10⁹/L (x 10³/mm³) ☐ x10⁶/L
   5. Date sample collected: __ __ __ __ / __ __ / __ __ (YYYY / MM / DD)

6. Hemoglobin
   - ☐ Known →
   - ☐ Unknown

   7. ___ ___ ___ ___ • ___ ___ ☐ g/dL ☐ g/L ☐ mmol/L
   8. Date sample collected: __ __ __ __ / __ __ / __ __ (YYYY / MM / DD)
   9. Was RBC transfused ≤ 30 days before date of test? ☐ Yes ☐ No

10. Platelets
    - ☐ Known →
    - ☐ Unknown

    11. ___ ___ ___ ___ ___ ___ ☐ x10⁹/L (x 10³/mm³) ☐ x10⁶/L
    12. Date sample collected: __ __ __ __ / __ __ / __ __ (YYYY / MM / DD)
    13. Were platelets transfused ≤ 7 days before date of test? ☐ Yes ☐ No

14. Blasts in blood
    - ☐ Known →
    - ☐ Unknown

    15. ___ ___ ___ %
    16. Date sample collected: __ __ __ __ / __ __ / __ __ (YYYY / MM / DD)

17. Did the recipient have constitutional symptoms? (> 10% weight loss in 6 months, night sweats, unexplained fever higher than 37.5°C)
    ☐ Known ☐ Unknown

CIBMTR Center Number: ___ ___ ___ ___ ___ CIBMTR Research ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___

Pre-HCT JAK1 and JAK2 Inhibitor Therapy

18. Did the recipient receive JAK1 or JAK2 inhibitor therapy? (pre-HCT)

☐ Yes

☐ No - ***Go to question 34***

Specify therapy given:

19. Ruxolitinib (Jakafi)

☐ Yes

☐ No

20. Date therapy started

☐ Known

☐ Unknown

21. Date started: __ __ __ __ / __ __ / __ __ (YYYY / MM / DD)

22. Date therapy stopped

☐ Known

☐ Unknown

23. Date stopped: __ __ __ __ / __ __ / __ __ (YYYY / MM / DD)

24. Specify reason therapy stopped

☐ Toxicity (e.g. cytopenias)

☐ Not tolerable

☐ Lack of response

☐ Disease progression

☐ Other

☐ Unknown

25. Specify other reason: _____

26. Other JAK1 or JAK2 inhibitor

☐ Yes

☐ No

27. Specify other JAK1 or JAK2 inhibitor: _____

28. Date therapy started

☐ Known

☐ Unknown

29. Date started: __ __ __ __ / __ __ / __ __ (YYYY / MM / DD)

30. Date therapy stopped

☐ Known

☐ Unknown

31. Date stopped: __ __ __ __ / __ __ / __ __ (YYYY / MM / DD)

Copy and complete questions 26-31 to report multiple other therapies

32. Response to therapy:

- ☐ Clinical improvement: defined as 50% improvement in palpable spleen length for spleen palpable by 10 cm, or complete resolution of splenomegaly for palpable spleen <10 cm
- ☐ Stable disease
- ☐ Non-splenic disease progression: increase in blasts to 10% to 19%, intolerance to treatment due to hematologic/non-hematologic side effects, or new onset transfusion-requiring anemia
- ☐ Splenic disease progression: appearance of new splenomegaly palpable 5 cm below costal margin (BCM) or 100% increase in palpable distance BCM for baseline splenomegaly of 5 cm to 10 cm BCM, 50% increase in palpable distance BCM for baseline splenomegaly of 10 cm BCM, loss of spleen response, or symptomatic splenomegaly requiring splenectomy
- ☐ Transformation to leukemia: peripheral blood or bone marrow blast count of 20%

33. Date assessed: __ __ __ __ / __ __ / __ __ (YYYY / MM / DD)

Laboratory Studies Prior to Therapy

Specify the laboratory values immediately prior to JAK1 / JAK2 inhibitor therapy. If no JAK1 / JAK2 inhibitor therapy was given, report results at last evaluation prior to the start of the preparative regimen:

34. Was presence of somatic mutations tested? (immediately prior to JAK1 / JAK2 inhibitor therapy initiation)

- ☐ Yes →
- ☐ No
- ☐ Unknown

35. Date sample collected: __ __ __ __ / __ __ / __ __ (YYYY / MM / DD)

36. Specify sample source ☐ Bone marrow ☐ Peripheral blood

37.	JAK 2	☐ Positive	☐ Negative	☐ Not done
38.	CALR1	☐ Positive	☐ Negative	☐ Not done
39.	CALR2	☐ Positive	☐ Negative	☐ Not done
40.	MPL	☐ Positive	☐ Negative	☐ Not done
41.	ASXL1	☐ Positive	☐ Negative	☐ Not done
42.	SRSF2	☐ Positive	☐ Negative	☐ Not done
43.	EZH2	☐ Positive	☐ Negative	☐ Not done
44.	IDH1	☐ Positive	☐ Negative	☐ Not done
45.	IDH2	☐ Positive	☐ Negative	☐ Not done
46.	LNK	☐ Positive	☐ Negative	☐ Not done
47.	CBL	☐ Positive	☐ Negative	☐ Not done
48.	TET2	☐ Positive	☐ Negative	☐ Not done
49.	IKZF1	☐ Positive	☐ Negative	☐ Not done
50.	DNMT3A	☐ Positive	☐ Negative	☐ Not done
51.	TP53	☐ Positive	☐ Negative	☐ Not done
52.	SF3B1	☐ Positive	☐ Negative	☐ Not done
53.	U2AF1	☐ Positive	☐ Negative	☐ Not done
54.	FLT3	☐ Positive	☐ Negative	☐ Not done

55. Other gene mutation

- ☐ Positive →
- ☐ Negative →
- ☐ Not done

56. Specify other gene mutation: _____

Copy and complete questions 55-56 to report multiple other gene mutations

57. WBC

☐ Known → 58. ___ ___ ___ ___ ___ ___ • ___ ☐ x10⁹/L (x 10³/mm³) ☐ x10⁶/L

☐ Unknown 59. Date sample collected: __ __ __ __ / __ __ / __ __ (YYYY / MM / DD)

60. Hemoglobin

☐ Known → 61. ___ ___ ___ ___ • ___ ___ ☐ g/dL ☐ g/L ☐ mmol/L

☐ Unknown 62. Date sample collected: __ __ __ __ / __ __ / __ __ (YYYY / MM / DD)

63. Was RBC transfused ≤ 30 days before date of test? ☐ Yes ☐ No

64. Platelets

☐ Known → 65. ___ ___ ___ ___ ___ ___ ☐ x10⁹/L (x 10³/mm³) ☐ x10⁶/L

☐ Unknown 66. Date sample collected: __ __ __ __ / __ __ / __ __ (YYYY / MM / DD)

67. Were platelets transfused ≤ 7 days before date of test? ☐ Yes ☐ No

68. Blasts in blood

☐ Known → 69. ___ ___ ___ %

☐ Unknown 70. Date sample collected: __ __ __ __ / __ __ / __ __ (YYYY / MM / DD)

71. Did the recipient have constitutional symptoms? (> 10% weight loss in 6 months, night sweats, unexplained fever higher than 37.5°C)

☐ Known ☐ Unknown

Laboratory Studies at Last Evaluation Prior to HCT

72. Total serum ferritin

☐ Known → 73. ___ ___ ___ ___ ___ ___ ng/mL (µg/L)

☐ Unknown 74. Date sample collected: __ __ __ __ / __ __ / __ __ (YYYY / MM / DD)

75. CD34+ cells (peripheral blood)

☐ Known → 76. ___ ___ ___ ___ • ___ ___ x 10 ___ ___

☐ Unknown

CIBMTR Center Number: ___ ___ ___ ___ ___ CIBMTR Research ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___

Disease Assessment at the Time of HCT

77. Did the recipient have evidence of pulmonary hypertension at HCT? ☐ Yes ☐ No ☐ Unknown

78. Did the recipient have evidence of portal hypertension at HCT? ☐ Yes ☐ No ☐ Unknown

Specify if the recipient had any of the following at the time of HCT:

79. Hepatomegaly
- ☐ Yes →
- ☐ No

80. Specify the liver size: ___ ___ centimeters below right costal margin

81. Specify the method used to measure liver size:
☐ Physical assessment ☐ Ultrasound ☐ CT

82. Spleen size
- ☐ Known →
- ☐ Unknown
- ☐ Not applicable (splenectomy)

83. Specify the spleen size: ___ ___ centimeters below left lower costal margin

84. Iron overload
- ☐ Yes →
- ☐ No

Indicate how the iron overload diagnosis was made:

85. Serum ferritin ☐ Yes ☐ No

86. Liver MRI ☐ Yes ☐ No

87. Other method
- ☐ Yes →
- ☐ No

88. Specify other method:_____

Specify therapy given for iron overload:

89. Iron chelation therapy ☐ Yes ☐ No

90. Phlebotomy ☐ Yes ☐ No

First Name: _____

Last Name: _____

E-mail address: _____

Date: __ __ __ __ / __ __ / __ __
YYYY MM DD