Form 2030 R2.0: Sickle Cell Anemia Pre-HSCT Data

Center: CRID:

Key Fields

Sequence Number: _____

Date Received: __ __ __ __ - __ __- __ __

CIBMTR Center Number: _____

CIBMTR Recipient ID: _____

Today's Date: __ __ __ __ - __ __- __ __

Date of HSCT for which this form is being completed: __ __ __ __ - __ __- __ __

HSCT type (check all that appy):

- Autologous
- Allogeneic, unrelated
- Allogeneic, related
- Syngeneic (identical twin)

Product type (check all that apply):

- Marrow
- PBSC
- Cord blood
- Other product

Specify: _____

- If this is a report of a second or subsequent transplant, check here and continue with question 95.

Sickle Cell Anemia Pre-HSCT Data

Questions: 1 - 118

1 What was the date of diagnosis of Sickle Cell Anemia? __ __ __ __ - __ __- __ __

2 Was the recipient diagnosed with sickle cell disease at birth (i.e., newborn screening)?

yes no Unknown

3 What is the recipient's sickle cell disease genotype?

- Hb SS
- Hb S beta^0 thalassemia
- Hb SC
- Hb S beta$^+$ thalassemia
- other genotype

4 Specify other genotype: _____

5 Did the recipient receive red blood cell transfusions at any time prior to the preparative regimen?

yes no Unknown

6 Date of first transfusion: __ __ __ __ - __ __- __ __ Date of first transfusion unknown

7 Specify the total number of transfusions received prior to the preparative regimen:

< 5 5-10 >10

8 Did the transfusion(s) induce red cell alloimmunization?

yes no Unknown

9 Specify the number of alloantibodies detected:

1 >=2 Unknown

Specify the blood group(s) the recipient has developed alloantibodies to:

10 Duffy - Fy^a

yes no Unknown

11 Kell - K

yes no Unknown

12 Kell - k

yes no Unknown

13 Kidd - Jk^a

yes no Unknown

14 Kidd - Jk^b

yes no Unknown

15 Lewis - Le^a

yes no Unknown

16 Lewis - Le^b

yes no Unknown

17 MNSs - M

yes no Unknown

18 MNSs - N

yes no Unknown

19 MNSs - S

yes no Unknown

20 MNSs - s

yes no Unknown

21 Rh - C

yes no Unknown

22 Rh - D

yes no Unknown

23 Rh - E

yes no Unknown

24 Rh - e

yes no Unknown

25 Rh - hr^a

yes no Unknown

26 Other

yes no Unknown

27 Specify: _____

28 Are red cell autoantibodies present?

yes no Unknown

29 Specify the number of autoantibodies detected:

1 >=2 Unknown

30 Was iron chelation therapy performed at any time prior to the preparative regimen?

yes no Unknown

31 Date chelation therapy started: __ __ __ __ - __ __- __ __ Date unknown

32 Specify the predominant route of administration:

intramuscular intravenous oral subcutaneous other route Unknown

33 Specify other route: _____

34 Was a liver biopsy performed at any time prior to the preparative regimen?

yes no Unknown

35 Date of most recent liver biopsy: __ __ __ __ - __ __- __ __ Date unknown

36 Was hepatitis present?

yes no Unknown

37 Specify the severity of hepatitis:

mild moderate severe Unknown

38 Was siderosis present?

yes no Unknown

39 Specify the severity of siderosis:

mild moderate severe Unknown

40 Was fibrosis present?

yes no Unknown

41 Specify the severity of fibrosis:

mild moderate severe Unknown

42 Were serial liver biopsies performed?

yes no

43 Did the liver biopsies show progressive disease?

yes no Unknown

44 What was the hepatic iron concentration (HIC)?

Known Unknown

45 Specify HIC: _____ **mg/g**

46 Is a copy of the biopsy report attached?

yes no

47 Were pulmonary function tests (PFTs) performed at any time prior to the preparative regimen?

yes no Unknown

48 Specify PFT results:

Normal Stage 1 disease Stage 2 disease Stage 3 disease Stage 4 disease Unknown

49 Is a copy of the PFT report attached?

yes no

Specify the sickle cell disease symptoms experienced at any time prior to the preparative regimen:

50 Acute chest syndrome

yes no Unknown

51 Total number of episodes within 2 years prior to the HSCT:

Known Not known

52 Number of episodes: _____

53 Total number of episodes within the recipient's lifetime:

Known Not known

54 Number of episodes: _____

55 Did the recipient require exchange transfusion?

yes no Unknown

Specify any treatment(s) the recipient required for acute chest syndrome:

56 antibiotics

yes no Unknown

57 intubation / mechanical ventilation

yes no Unknown

58 oxygen

yes no Unknown

59 transfusion of red blood cells

yes no Unknown

60 other treatment

yes no Unknown

61 Specify: _____

62 Osteonecrosis

yes no Unknown

Specify joint(s) affected:

63 ankle

yes no Unknown

64 hip

yes no Unknown

65 knee

yes no Unknown

66 shoulder

yes no Unknown

67 spine

yes no Unknown

68 Other

yes no Unknown

69 Specify: _____

70 Priapism

yes no Unknown

71 Number of episodes experienced in the last 2 years:

Known Not known

72 Number of episodes: _____

73 Was surgery performed to correct blood flow?

yes no Unknown

74 Seizures

yes no Unknown

75 Sickle nephropathy

yes no Unknown

76 Stroke

yes no Unknown

77 Specify the total number of strokes:

1 >=2 Unknown

78 Vaso-occlusive pain requiring hospitalization within 2 years prior to the HSCT

yes no Unknown

79 Specify the frequency of hospitalization:

<3 instances per year

>=3 instances per year

Unknown

80 Did the recipient receive hydroxyurea at any time prior to the HSCT?

yes no Unknown

81 Date hydroxyurea started: __ __ __ __ - __ __- __ __ Date hydroxyurea started unknown

82 Date hydroxyurea stopped: __ __ __ __ - __ __- __ __ Date hydroxyurea stopped unknown

83 Was hemoglobin electrophoresis performed while the recipient was receiving hydroxyurea?

yes no Unknown

If the recipient received chronic transfusions prior to HSCT, provide pre-transfusion electrophoresis data.

84 Date of electrophoresis: __ __ __ __ - __ __- __ __ Date of electrophoresis unknown

Specify the level of each hemoglobin type:

85 Hb A1: _____ % Hb A1 not tested while receiving hydroxyurea

86 Hb A2: _____ % Hb A2 not tested while receiving hydroxyurea

87 Hb C: _____ % Hb C not tested while receiving hydroxyurea

88 Hb F: _____ % Hb F not tested while receiving hydroxyurea

89 Hb S: _____ % Hb S not tested while receiving hydroxyurea

90 Other hemoglobin

yes no

91 Specify type: _____

92 Level: _____ %

93 Is a copy of the electrophoresis report attached?

yes no

94 Did the recipient experience gonadal dysfunction at any time prior to the preparative regimen?

yes no Unknown

95 Was a brain MRI / MRA performed just prior to the preparative regimen?

yes no Unknown

96 Specify the MRI / MRA results:

Normal Abnormal Unknown

97 Is a copy of the MRI / MRA report attached to this form?

yes no

98 Was a EKG performed prior to the preparative regimen?

yes no Unknown

99 Specify the EKG results:

Normal Abnormal Unknown

100 Is a copy of the EKG report attached to this form?

yes no

101 Was an echocardiogram performed prior to the preparative regimen?

yes no Unknown

102 Specify the echocardiogram results:

Normal Abnormal Unknown

103 Is a copy of the echocardiogram report attached to this form?

yes no

104 Was the recipient's serum ferritin level tested at any time prior to the preparative regimen?

yes no Unknown

105 Specify the serum ferritin results:

<1,000 ng/mL or µg/L

>=1,001 ng/mL or µg/L

Unknown

106 Was hemoglobin electrophoresis performed just prior to the preparative regimen (not including any electrophoresis reported in question 83)?

yes no Unknown

If the recipient received chronic transfusions prior to HSCT, provide pre-transfusion electrophoresis data.

107 Date: __ __ __ __ - __ __- __ __ Date unknown

Specify the level of each hemoglobin type:

108 Hb A1: _____ % Hb A1 not tested

109 Hb A2: _____ % Hb A2 not tested

110 Hb C: _____ % Hb C not tested

111 Hb F: _____ % Hb F not tested

112 Hb S: _____ % Hb S not tested

113 Other hemoglobin type

yes no

114 Specify type: _____

115 Level: _____ %

116 Is a copy of the hemoglobin electrophoresis report attached to this form?

yes no

117 What was the primary reason for the HSCT?

- acute chest syndrome
- excessive transfusion requirements / iron overload
- recurrent priapism
- recurrent vaso-occlusive pain
- stroke
- other reason
- Unknown

118 Specify primary reason for HSCT: _____

First Name: _____ Last Name: _____

Phone number: _____ Fax number: _____

E-mail address: _____