

Form 2130 R2.0: Sickle Cell Anemia Post-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 apply):

Autologous

Allogeneic, unrelated

Allogeneic, related

Syngeneic (identical twin)

Product type (check all that apply):

Marrow

PBSC

Cord blood

Other product

Specify: _____

Visit:

100 day 6 months 1 year 2 years > 2 years,

Specify: _____

Post - HSCT Sickle Cell

Questions: 1 - 54

1 Specify the date the recipient was evaluated for this report: ____-____-____

2 Was the recipient's serum ferritin level tested at any time since the date of the last report?

yes no Unknown

3 Specify the serum ferritin results:

<1,000 ng/mL or µg/L

≥1,001 ng/mL or µg/L

Unknown

4 Was chelation therapy given since the date of the last report?

yes no Unknown

5 Is the recipient still receiving chelation therapy or undergoing phlebotomy at the time of the evaluation for this report?

yes no Unknown

6 Date therapy stopped: ____-____-____ Date unknown

Specify the sickle cell disease symptoms experienced since the date of the last report:

7 Acute chest syndrome

yes no Unknown

8 Total number of episodes since the date of the last report:

Known Not known

9 Total number of episodes: _____

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10 Did the recipient require exchange transfusion?

yes no Unknown

Specify any treatment(s) given for acute chest syndrome since the date of the last report:

11 antibiotics

yes no Unknown

12 intubation / mechanical ventilation

yes no Unknown

13 oxygen

yes no Unknown

14 transfusion of red blood cells

yes no Unknown

15 other treatment

yes no Unknown

16 Specify treatment: _____

17 Osteonecrosis

yes no Unknown

Specify joint(s) affected:

18 ankle

yes no Unknown

19 hip

yes no Unknown

20 knee

yes no Unknown

21 shoulder

yes no Unknown

22 spine

yes no Unknown

23 other joint

yes no Unknown

24 Specify joint: _____

25 Priapism

yes no Unknown

26 Number of episodes per year:

Known Not known

27 Number of episodes: _____

28 Was surgery performed to correct blood flow since the date of the last report?

yes no Unknown

29 Seizures

yes no Unknown

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Center:

CRID:

30 Sickle nephropathy

yes no Unknown

31 Stroke

yes no Unknown

32 Specify the number of strokes since the date of the last report:

1 >=2 Unknown

33 Vaso-occlusive pain requiring hospitalization since the date of the last report

yes no Unknown

34 Specify the frequency of hospitalization:

<3 instances per year

>=3 instances per year

Unknown

35 Did the recipient experience gonadal dysfunction since the date of the last report?

yes no Unknown

36 Was a brain MRI / MRA performed since the date of the last report?

yes no Unknown

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

yes no

38 Was a EKG performed since the date of the last report?

yes no Unknown

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

yes no

40 Was an echocardiogram performed since the date of the last report?

yes no Unknown

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

yes no

42 Was hemoglobin electrophoresis performed since the date of the last report?

yes no Unknown

Hemoglobin Electrophoresis Test (1)

Questions: 43 - 52

43 Date: _____ - ____ - ____ Date of hemoglobin electrophoresis unknown

Specify the level of each hemoglobin type:

44 Hb A1: _____ % Hb A1 not tested

45 Hb A2: _____ % Hb A2 not tested

46 Hb C: _____ % Hb C not tested

47 Hb F: _____ % Hb F not tested

48 Hb S: _____ % Hb S not tested

49 Other hemoglobin type

yes no

50 Specify type: _____

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51 Level: _____ %

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

yes no

53 What is the status of sickle cell anemia at the time of this report, or at the time of death?

- disease cured: Hb electrophoresis (Hb S) ≤ 50% and clinical symptoms described in questions 7-32 are absent
- disease recurred: Hb S > 50% and clinical symptoms described in questions 7-32 are absent
- disease recurred: Hb S > 50% and clinical symptoms described in questions 7-32 are present
- Unknown

54 Has the recipient received red blood cell transfusions since the date of the last report?

yes no

First Name: _____ Last Name: _____

Phone number: _____ Fax number: _____

E-mail address: _____