



Sickle Cell Anemia Post-HSCT Data

Registry Use Only

Sequence Number:

Date Received:

CIBMTR Center Number:

CIBMTR Recipient ID:

Today's Date: / / (20)

Date of HSCT for which this form is being completed: / / (Month Day Year)

HSCT type: autologous allogeneic, unrelated allogeneic, related syngeneic (identical twin)

Product type: marrow PBSC cord blood other product, specify: _____

Visit: 100 day 6 month 1 year 2 years > 2 years, specify:

To be completed in conjunction with a Form 2100 – 100 Days Post-HSCT Data, Form 2200 – Six Months to Two Years Post-HSCT Data, or Form 2300 – Yearly Follow-Up for Greater Than Two Years Post-HSCT Data. Information reported here should reflect the date of last contact as reported in the post-HSCT data collection form, or immediately prior to death.

1. Specify the date the recipient was evaluated for this report: / / (20)

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

- 1 yes
- 2 no
- 3 unknown

3. Specify the serum ferritin results:

- 1 < 1,000 ng/mL or µg/L
- 2 ≥ 1,001 ng/mL or µg/L
- 3 unknown

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

- 1 yes
- 2 no
- 3 unknown

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

- 1 yes
- 2 no
- 3 unknown

6. Date therapy stopped: / / (20) date unknown

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

7. Acute chest syndrome

- 1 yes
- 2 no
- 3 unknown

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

- 1 known
- 2 not known

9. Did the recipient require exchange transfusion?

- 1 yes
- 2 no
- 3 unknown

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

- 10. 1 yes 2 no 3 unknown antibiotics
- 11. 1 yes 2 no 3 unknown intubation / mechanical ventilation
- 12. 1 yes 2 no 3 unknown oxygen
- 13. 1 yes 2 no 3 unknown transfusion of red blood cells
- 14. 1 yes 2 no 3 unknown other treatment

15. Specify treatment: _____

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16. Osteonecrosis

- 1 yes
- 2 no
- 3 unknown

Specify joint(s) affected:

17. 1 yes 2 no 3 unknown ankle

18. 1 yes 2 no 3 unknown hip

19. 1 yes 2 no 3 unknown knee

20. 1 yes 2 no 3 unknown shoulder

21. 1 yes 2 no 3 unknown spine

22. 1 yes 2 no 3 unknown other joint →

24. Priapism

- 1 yes
- 2 no
- 3 unknown

25. Number of episodes per year:

1 known →

2 not known

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

- 1 yes
- 2 no
- 3 unknown

27. Seizures

- 1 yes
- 2 no
- 3 unknown

28. Sickle nephropathy

- 1 yes
- 2 no
- 3 unknown

29. Stroke

- 1 yes
- 2 no
- 3 unknown

30. Specify the number of strokes since the date of the last report:

- 1 1
- 2 ≥ 2
- 3 unknown

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

- 1 yes
- 2 no
- 3 unknown

32. Specify the frequency of hospitalization:

- 1 < 3 instances per year
- 2 ≥ 3 instances per year
- 3 unknown

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

- 1 yes
- 2 no
- 3 unknown

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

- 1 yes
- 2 no
- 3 unknown

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

- 1 yes
- 2 no

36. Was a EKG performed since the date of the last report?

- 1 yes
- 2 no
- 3 unknown

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

- 1 yes
- 2 no

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38. Was an echocardiogram performed since the date of the last report?

- 1 yes
2 no
3 unknown

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

- 1 yes
2 no

40. Was hemoglobin electrophoresis performed since the date of the last report?

- 1 yes
2 no
3 unknown

If the recipient received more than one hemoglobin electrophoresis test since the date of the last report, copy this page and complete for each instance.

41. Date : date unknown
Month Day Year

Specify the level of each hemoglobin type:

42. Hb A1: % not tested

43. Hb A2: % not tested

44. Hb C: % not tested

45. Hb F: % not tested

46. Hb S: % not tested

47. Other hemoglobin type

- 1 yes
2 no

48. Specify type: _____

49. Level: %

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

- 1 yes
2 no

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

- 1 disease cured: Hb electrophoresis (Hb S) \leq 50% and clinical symptoms described in questions 7–32 are absent
2 disease recurred: Hb S > 50% and clinical symptoms described in questions 7–32 are **absent**
3 disease recurred: Hb S > 50% and clinical symptoms described in questions 7–32 are **present**
4 unknown

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

- 1 yes
2 no

53. Signed: _____

Person completing form

Please print name: _____

Phone: (_____) _____

Fax: (_____) _____

E-mail address: _____