ERROR CORRECTION FORM

Sequence Number: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐

CIBMTR Recipient ID: ☐☐☐☐☐☐☐☐☐☐

Visit:
☐ 100 day
☐ 6 month
☐ ☐☐ year

Today's Date: ☐☐ Month ☐☐ Day 20☐☐ Year

Infusion Date: ☐☐ Month ☐☐ Day 20☐☐ Year

CIBMTR Center Number: ☐☐☐☐☐

Initials: ☐☐☐

CIBMTR®
CENTER FOR INTERNATIONAL BLOOD & MARROW TRANSPLANT RESEARCH

Sickle Cell Anemia Post-HSCT Data

Registry Use Only

Sequence Number: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Date Received: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐

CIBMTR Center Number: ☐☐☐☐☐

CIBMTR Recipient ID: ☐☐☐☐☐☐☐☐☐☐

Today's Date: ☐☐ Month ☐☐ Day 20☐☐ Year

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: ☐☐ Month ☐☐ Day 20☐☐ Year

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: ☐☐ Month ☐☐ Day 20☐☐ Year ☐ 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: _____

Mail this form to your designated campus (Milwaukee or Minneapolis). Retain the original at the transplant center.

Fax this form to your designated campus (Milwaukee 414-805-0714 or Minneapolis 612-627-5895).

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16. Osteonecrosis
1 ☐ yes → Specify joint(s) affected:
2 ☐ no
3 ☐ unknown

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 → 23. Specify joint: _____

24. Priapism
1 ☐ yes → 25. Number of episodes per year:
2 ☐ no 1 ☐ known → ____
3 ☐ unknown 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 → 30. Specify the number of strokes since the date of the last report:
2 ☐ no 1 ☐ 1
3 ☐ unknown 2 ☐ ≥ 2
3 ☐ unknown

31. Vaso-occlusive pain requiring hospitalization since the date of the last report
1 ☐ yes → 32. Specify the frequency of hospitalization:
2 ☐ no 1 ☐ < 3 instances per year
3 ☐ unknown 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 → 35. Is a copy of the MRI / MRA report attached to this form?
2 ☐ no 1 ☐ yes
3 ☐ unknown 2 ☐ no

36. Was a EKG performed since the date of the last report?
1 ☐ yes → 37. Is a copy of the EKG report attached to this form?
2 ☐ no 1 ☐ yes
3 ☐ unknown 2 ☐ no

CIBMTR Form 2130 (SCA) v1.0 (2–3) July 2007

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CIBMTR Recipient ID: ☐☐☐☐☐☐☐☐☐

Visit:
☐ 100 day
☐ 6 month
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Today's Date: ☐☐ Month ☐☐ Day 2 0 ☐☐ Year

Infusion Date: ☐☐ Month ☐☐ Day 2 0 ☐☐ Year

CIBMTR Center Number: ☐☐☐☐☐

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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 : ☐☐ Month ☐☐ Day ☐☐☐☐ Year ☐ date unknown

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) ≤ 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: _____

CIBMTR Form 2130 (SCA) v1.0 (3–3) July 2007

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