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)?
   1. yes
   2. no
   3. unknown

3. What is the recipient's sickle cell disease genotype?
   1. Hb SS
   2. Hb S beta^0 thalassemia
   3. Hb SC
   4. Hb S beta+ thalassemia
   5. other genotype

4. Specify other genotype:

5. Did the recipient receive red blood cell transfusions at any time prior to the preparative regimen?
   1. yes
   2. no
   3. unknown

6. Date of first transfusion:

7. Specify the total number of transfusions received prior to the preparative regimen:
   1. < 5
   2. 5–10
   3. > 10

8. Did the transfusion(s) induce red cell alloimmunization?
   1. yes
   2. no
   3. unknown

9. Specify the number of alloantibodies detected:
   1. 1
   2. ≥ 2
   3. unknown

If this is a report of a second or subsequent transplant, check here [ ] and continue with question 92.
30. Was iron chelation therapy performed at any time prior to the preparative regimen?

1. yes
2. no
3. unknown

31. Date chelation therapy started: Month Day Year

32. Specify the predominant route of administration:

1. intramuscular
2. intravenous
3. oral
4. subcutaneous
5. other route
6. unknown

33. Specify other route:__________________________

28. Are red cell autoantibodies present?

1. yes
2. no
3. unknown

29. Specify the number of autoantibodies detected:
1. 1
2. ≥2
3. unknown

27. Specify:__________________________

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

10. Duffy –Fy^a
11. Kell –K
12. Kell –k
13. Kidd –Jk^a
14. Kidd –Jk^b
15. Lewis –Le^a
16. Lewis –Le^b
17. MNSs –M
18. MNSs –N
19. MNSs –S
20. MNSs –S
21. MNSs –s
22. Rh –C
23. Rh –D
24. Rh –E
25. Rh –e
26. other

21. 1. yes
2. no
3. unknown

Fax this form to your designated campus (Milwaukee 414-805-0714 or Minneapolis 612-627-5895).
34. Was a liver biopsy performed at any time prior to the preparative regimen?
   - Yes
   - No
   - Unknown

35. Date of most recent liver biopsy:
   - Month
   - Day
   - Year
   - 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
   - Unknown

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: (see definitions on the following page)
   - 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
   1 yes
   2 no
   3 unknown

51. Total number of episodes within 2 years prior to the HSCT:
   1 known
   2 not known

52. Total number of episodes within the recipient's lifetime:
   1 known
   2 not known

53. Did the recipient require exchange transfusion?
   1 yes
   2 no
   3 unknown

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

54. 1 yes 2 no 3 unknown antibiotics
55. 1 yes 2 no 3 unknown intubation / mechanical ventilation
56. 1 yes 2 no 3 unknown oxygen
57. 1 yes 2 no 3 unknown transfusion of red blood cells
58. 1 yes 2 no 3 unknown other

59. Specify: ________________________________
<table>
<thead>
<tr>
<th>Question</th>
<th>Option 1</th>
<th>Option 2</th>
<th>Option 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Osteonecrosis</td>
<td>yes</td>
<td>no</td>
<td>unknown</td>
</tr>
<tr>
<td>Priapism</td>
<td>yes</td>
<td>no</td>
<td>unknown</td>
</tr>
<tr>
<td>Seizures</td>
<td>yes</td>
<td>no</td>
<td>unknown</td>
</tr>
<tr>
<td>Sickle nephropathy</td>
<td>yes</td>
<td>no</td>
<td>unknown</td>
</tr>
<tr>
<td>Stroke</td>
<td>yes</td>
<td>no</td>
<td>unknown</td>
</tr>
<tr>
<td>Vaso-occlusive pain requiring hospitalization within 2 years prior to the HSCT</td>
<td>yes</td>
<td>no</td>
<td>unknown</td>
</tr>
<tr>
<td>Did the recipient receive hydroxyurea at any time prior to the HSCT?</td>
<td>yes</td>
<td>no</td>
<td>unknown</td>
</tr>
<tr>
<td>Date hydroxyurea started</td>
<td></td>
<td></td>
<td>date unknown</td>
</tr>
<tr>
<td>Date hydroxyurea stopped</td>
<td></td>
<td></td>
<td>date unknown</td>
</tr>
<tr>
<td>Hemoglobin electrophoresis performed while the recipient was receiving hydroxyurea?</td>
<td>yes</td>
<td>no</td>
<td>unknown</td>
</tr>
<tr>
<td>Date of electrophoresis</td>
<td></td>
<td></td>
<td>date unknown</td>
</tr>
</tbody>
</table>
91. Did the recipient experience gonadal dysfunction at any time prior to the preparative regimen?
1 □ yes
2 □ no
3 □ unknown

92. Was a brain MRI / MRA performed just prior to the preparative regimen?
1 □ yes
2 □ no
3 □ unknown

Specify the level of each hemoglobin type:
82. Hb A1: % □ not tested while receiving hydroxyurea
83. Hb A2: % □ not tested while receiving hydroxyurea
84. Hb C: % □ not tested while receiving hydroxyurea
85. Hb F: % □ not tested while receiving hydroxyurea
86. Hb S: % □ not tested while receiving hydroxyurea
87. Other hemoglobin
1 □ yes
2 □ no

90. Is a copy of the electrophoresis report attached?
1 □ yes
2 □ no
98. Was an echocardiogram performed prior to the preparative regimen?
   1. yes
   2. no
   3. unknown

99. Specify the echocardiogram results:
   1. normal
   2. abnormal
   3. unknown

100. Is a copy of the echocardiogram report attached to this form?
   1. yes
   2. no

101. Was the recipient’s serum ferritin level tested at any time prior to the preparative regimen?
   1. yes
   2. no
   3. unknown

102. Specify the serum ferritin results:
   1. < 1,000 ng/mL or µg/L
   2. ≥ 1,001 ng/mL or µg/L
   3. unknown

103. Was hemoglobin electrophoresis performed just prior to the preparative regimen (not including any electrophoresis reported in question 80)?
   1. yes
   2. no
   3. unknown

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

104. Date: ____________ Month Day Year

   Specify the level of each hemoglobin type:
   105. Hb A1: ____________ % not tested
   106. Hb A2: ____________ % not tested
   107. Hb C: ____________ % not tested
   108. Hb F: ____________ % not tested
   109. Hb S: ____________ % not tested

110. Other hemoglobin type
   1. yes
   2. no

111. Specify type: ____________________

112. Level: ____________ %

113. Is a copy of the hemoglobin electrophoresis report attached to this form?
   1. yes
   2. no
### 114. What was the primary reason for the HSCT?

1. [ ] acute chest syndrome
2. [ ] excessive transfusion requirements / iron overload
3. [ ] recurrent priapism
4. [ ] recurrent vaso-occlusive pain
5. [ ] stroke
6. [ ] other reason
7. [ ] unknown

115. Specify primary reason for HSCT:

---

### 116. Signed:

Person completing form

Please print name:

Phone: ( )

Fax: ( )

E-mail address: