Sickle Cell Disease Post - Infusion Data

Registry Use Only

Sequence Number:

Date Received:

CIBMTR Center Number: ___ ___ ___ ___ ___

CIBMTR Research ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___

Event date: ___ ___ ___ ___ — ___ ___ — ___ ___

YYYY MM DD

Visit

☐ 100 day

☐ 6 months

☐ 1 year

☐ 2 years

☐ > 2 years, specify: ___ ___

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CIBMTR Center Number: ___ ___ ___ ___ ___ CIBMTR Research ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___

Report all findings SINCE DATE OF LAST REPORT unless otherwise specified.

Physical Assessments

1. Date of evaluation: ___ ___ ___ ___ — ___ ___ — ___ ___
   YYYY MM DD

2. Abdominal girth
   - ☐ Known – ***Go to question 3***
   - ☐ Unknown – ***Go to question 4***

3. Abdominal girth: ___ ___ ___ cm

4. Blood pressure (BP)
   - ☐ Known – ***Go to question 5***
   - ☐ Unknown – ***Go to question 6***

5. BP: ___ ___ ___ / ___ ___ ___ mmHg

Transfusion Therapy

6. Were red blood cell transfusions administered?
   - ☐ Yes – ***Go to question 7***
   - ☐ No – ***Go to question 9***

7. Date of last transfusion administered: ___ ___ ___ ___ — ___ ___ — ___ ___ *(report last transfusion that was received)*
   YYYY MM DD

8. Was the transfusion for a sickle cell related event?
   - ☐ Yes
   - ☐ No

Therapy for Iron Overload

9. Serum ferritin
   - ☐ Known – ***Go to question 10***
   - ☐ Unknown – ***Go to question 11***

10. Serum ferritin: ___ ___ ___ ___ ___ ng/mL (µg/L)

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11. Was iron chelation therapy given?

- ☐ Yes – ***Go to question 12***
- ☐ No – ***Go to question 17***
- ☐ Unknown – ***Go to question 17***

12. Was iron chelation previously reported?

- ☐ Yes – ***Go to question 15***
- ☐ No - ***Go to question 13***

13. Date started

- ☐ Known ***- Go to question 14***
- ☐ Unknown ***- Go to question 15***

14. Date started: ___ ___ ___ ___ — ___ ___ — ___ ___ ☐ Date estimated

YYYY MM DD

15. Is iron chelation ongoing?

- ☐ Yes – ***Go to question 17***
- ☐ No – ***Go to question 16***

16. Date of last dose: ___ ___ ___ ___ — ___ ___ — ___ ___ ☐ Date estimated

YYYY MM DD

17. Was phlebotomy performed?

- ☐ Yes – ***Go to question 18***
- ☐ No – ***Go to question 23***

18. Was phlebotomy previously reported?

- ☐ Yes – ***Go to question 21***
- ☐ No - ***Go to question 19***

19. Date started

- ☐ Known ***- Go to question 20***
- ☐ Unknown ***- Go to question 21***

20. Date started: ___ ___ ___ ___ — ___ ___ — ___ ___ ☐ Date estimated

YYYY MM DD

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21. Is phlebotomy ongoing?

- ☐ Yes – ***Go to question 23***
- ☐ No – ***Go to question 22***

22. Date completed: ___ ___ ___ ___ — ___ ___ — ___ ___ ☐ Date estimated

YYYY MM DD

Pulmonary Assessments

23. Were pulmonary function tests (PFTs) performed? *(if multiple PFT tests were performed, attach the most recent report)*

- ☐ Yes – ***Go to question 24***
- ☐ No ***– Go to question 25***

24. Indicate if the PFT report is attached

- ☐ Attached
- ☐ Not available

25. For children unable to perform PFTs, was oxygen saturation in room air > 95%? *(only required to answer if children are of 5 years of age or less) (if multiple, report the most recent)*

- ☐ Yes
- ☐ No
- ☐ Not done

26. Was a 6-minute walk test performed?

- ☐ Yes ***– Go to question 27***
- ☐ No – ***Go to question 29***
- ☐ Unknown – ***Go to question 29***

27. Distance walked: ___ ___ ___

- ☐ meters
- ☐ feet

28. Indicate if the 6-minute walk test report is attached

- ☐ Attached
- ☐ Not available

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Cardiovascular Assessments

29. Were lipid profiles assessed?
    - ☐ Yes – ***Go to question 30***
    - ☐ No – ***Go to question 35***
    - ☐ Unknown – ***Go to question 35***

30. Specify which lipids were assessed *(check all that apply)*
    - ☐ Cholesterol – ***Go to question 31***
    - ☐ Low-density lipoprotein (LDL) – ***Go to question 32***
    - ☐ Very low-density lipoprotein (VLDL) – ***Go to question 33***
    - ☐ High-density lipoprotein (HDL) – ***Go to question 34***

31. Cholesterol: ___ ___ ___•___ ☐ mg/dL
    ☐ mmol/L

32. LDL: ___ ___ ___•___ ☐ mg/dL
    ☐ mmol/L

33. VLDL: ___ ___ ___•___ ☐ mg/dL
    ☐ mmol/L

34. HDL: ___ ___ ___•___ ☐ mg/dL
    ☐ mmol/L

35. Was an echocardiogram performed?
    - ☐ Yes – ***Go to question 36***
    - ☐ No – ***Go to question 41***
    - ☐ Unknown – ***Go to question 41***

36. Was tricuspid regurgitant jet velocity (TRJV) measured?
    - ☐ Yes – ***Go to question 37***
    - ☐ No – ***Go to question 38***

37. TRJV: ___ ____ ____ • ___ m/sec

38. Was left ventricular ejection fraction (LVEF) or left ventricular shortening fraction reported?
    - ☐ Yes – ***Go to question 39***

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☐ No – ***Go to question 41***

39. LVEF: ___ ___ %

40. Left ventricular shortening fraction: ___ ___ %

41. Is there a new onset of pulmonary hypertension?

☐ Yes – ***Go to question 42***

☐ No – ***Go to question 45***

42. What method was used to diagnose pulmonary hypertension? *(check all that apply)*

☐ Echocardiogram – ***Go to question 43***

☐ Right heart catheterization – ***Go to question 44***

43. Indicate if the echocardiogram report is attached

☐ Attached

☐ Not available

44. Indicate if the right heart catheterization report is attached

☐ Attached

☐ Not available

45. Was cardiac MRI performed?

☐ Yes **– *Go to question 46***

☐ No **– *Go to question 50***

46. Is there evidence of abnormal cardiac iron deposition based on MRI of the heart?

☐ Yes

☐ No

47. Cardiac iron T2 imaging

☐ Known – ***Go to question 48***

☐ Unknown – ***Go to question 49***

48. Cardiac iron T2: ___ ___ msec

49. Indicate if the cardiac MRI report is attached

☐ Attached

☐ Not available

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50. Was brain natriuretic peptide (BNP) assessed?

- ☐ Yes – ***Go to question 51***
- ☐ No – ***Go to question 53***
- ☐ Unknown – ***Go to question 53***

51. BNP: __ __ __ __ __ •__ pg/mL

52. Date BNP collected: ___ ___ ___ ___ — ___ ___ — ___ ___
YYYY MM DD

53. N-terminal pro b-type natriuretic peptide (NT-proBNP)

- ☐ Known – ***Go to question 54***
- ☐ Unknown – ***Go to question 56***

54. NT-proBNP: __ __ __ __ __ •__ pg/mL

55. Date NT-proBNP collected: ___ ___ ___ ___ — ___ ___ — ___ ___
YYYY MM DD

56. Was an electrocardiogram performed?

- ☐ Yes – ***Go to question 57***
- ☐ No – ***Go to question 58***

57. Indicate if the electrocardiogram report is attached

- ☐ Attached
- ☐ Not available

Hepatic Assessments

58. Did the recipient have hepatomegaly? *(≥2 cm below costal margin)*

- ☐ Yes – ***Go to question 59***
- ☐ No – ***Go to question 61***
- ☐ Unknown – ***Go to question 61***

59. Is liver size known?

- ☐ Yes – ***Go to question 60***
- ☐ No – ***Go to question 61***

60. Liver size as measured below the right costal margin at most recent evaluation: ___ ___ cm

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61. Was liver iron content (LIC) tested?

- ☐ Yes – ***Go to question 62***
- ☐ No – ***Go to question 65***

62. Liver iron content: ___ ___ ___ • ___
- ☐ mg Fe/g liver dry weight
- ☐ g Fe/kg liver dry weight
- ☐ µmol Fe / g liver dry weight

63. Method used to estimate LIC?

- ☐ T2*MRI *(T2* weighted magnetic resonance imaging)*
- ☐ SQUID MRI
- ☐ FerriScan
- ☐ Liver biopsy
- ☐ Other

64. Indicate if the LIC method report is attached

- ☐ Attached
- ☐ Not available

65. Was a liver biopsy performed?

- ☐ Yes – ***Go to question 66***
- ☐ No – ***Go to question 73***

66. Date assessed

- ☐ Known – ***Go to question 67***
- ☐ Unknown – ***Go to question 68***

67. Date assessed: ___ ___ ___ ___ — ___ ___ — ___ ___
YYYY MM DD

68. Was there evidence of cirrhosis?

- ☐ Yes
- ☐ No
- ☐ Unknown

69. Was there evidence of liver fibrosis?

- ☐ Yes – ***Go to question 70***
- ☐ No – ***Go to question 71***

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☐ Unknown – ***Go to question 71***

70. Type of fibrosis
    - ☐ Bridging
    - ☐ Periportal
    - ☐ Other
    - ☐ Unknown

71. Was there evidence of chronic hepatitis?
    - ☐ Yes
    - ☐ No
    - ☐ Unknown

72. Indicate if the liver biopsy report is attached
    - ☐ Attached
    - ☐ Not available

Laboratory studies

73. Laboratory studies performed *(check all that apply)*

☐ ALT (SGPT) – ***Go to question 74***

☐ AST (SGOT) – ***Go to question 75***

☐ Direct bilirubin – ***Go to question 76***

☐ Lactate dehydrogenase (LDH) – ***Go to question 78***

☐ Total serum bilirubin – ***Go to question 80***

☐ None – ***Go to question 82***

74. ALT (SGPT): ___ ___ ___ ___ • ___ ___ ☐ U/L
    ☐ µkat/L

75. AST (SGOT): ___ ___ ___ ___ • ___ ___ ☐ U/L
    ☐ µkat/L

76. Direct bilirubin: ___ ___ ___ • ___ ☐ mg/dL
    ☐ µmol/L

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77. Upper limit of normal for your institution: ___ ___ ___ • ___

78. LDH: ___ ___ ___ ___ ___ • ___ ___☐ U/L
☐ µkat/L

79. Upper limit of normal for your institution: ___ ___ ___ ___ ___ • ___ ___

80. Total serum bilirubin: ___ ___ ___ • ___ ☐ mg/dL
☐ µmol/L

81. Upper limit of normal for your institution: ___ ___ ___ • ___

Renal Assessments

82. Was proteinuria detected? *(excluding microalbuminuria)*
- ☐ Yes
- ☐ No
- ☐ Not done

83. Urine albumin *(if multiple, report the most recent tested)*
- ☐ Known– ***Go to question 84***
- ☐ Unknown – ***Go to question 85***

84. Urine albumin: ___ ___ ___
- ☐ µg/mL
- ☐ mg/L
- ☐ mg/mmol

85. Urine creatinine *(one time urine)*
- ☐ Known– ***Go to question 86***
- ☐ Unknown – ***Go to question 87***

86. Urine creatinine: ___ ___ ___
- ☐ mg/dL
- ☐ µmol/L

87. Serum creatinine: ___ ___ ___ • ___ ___ *(if multiple, report the most recent tested)*

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☐mg/dL

☐mmol/L

☐µmol/L

88. Glomerular filtration rate (GFR) *(if multiple, report the most recent tested)*

☐ Known – ***Go to question 89***

☐ Unknown – ***Go to question 90***

89. GFR: ___ ___ ___ mL/min/1.73m^2 ☐ Value estimated *(if the actual value cannot be reported use the Cockcroft- Gault equation to report the calculated value) (for pediatric recipients, use the "Bedside Schwartz" or Cystatin C-based equation)*

90. Cystatin-C *(if multiple, report the most recent tested)*

☐ Known – ***Go to question 91***

☐ Unknown – ***Go to question 92***

91. Cystatin-C: __ • __ __ mg/L

Splenic Assessments

92. Did the recipient have a splenectomy?

☐ Yes – ***Go to question 99***

☐ No – ***Go to question 93***

☐ Not applicable *(prior splenectomy previously reported)* – ***Go to question 99***

☐ Unknown – ***Go to question 93***

93. Did the recipient have splenomegaly?

☐ Yes

☐ No

Splenic assessments will only be collected up to two (2) years.

94. Was splenic function assessed?

☐ Yes – ***Go to question 95***

☐ No – ***Go to question 99***

☐ Not applicable **– *Go to question 99***

☐ Unknown – ***Go to question 99***

95. Select which splenic test was completed

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- ☐ Complete red blood cell count – ***Go to question 96***
- ☐ Pitted RBC score – ***Go to question 97***
- ☐ Splenic scan – ***Go to question 98***

96. Complete RBC: ___ ___ ___ ___ • ___ ___ ☐ x 10^3/µL (x 10^9/L) (x 10^3/mm^3)
☐ x 10^6/µL (x 10^{12}/L) – ***Go to question 99***

97. Pitted RBC score: ___ ___ • ___ % – ***Go to question 99***

98. Splenic scan results
- ☐ Normal *(radionuclide uptake)*
- ☐ Abnormal *(no radionuclide uptake)*

Acute Chest Syndrome

99. Has acute chest syndrome (ACS) occurred?
- ☐ Yes – ***Go to question 100***
- ☐ No – ***Go to question 102***
- ☐ Unknown – ***Go to question 102***

Copy and complete questions 100 – 101 to report multiple ACS events.

100. Date of ACS event: ___ ___ ___ ___ — ___ ___ — ___ ___
YYYY MM DD

101. Did this ACS event require hospitalization?
- ☐ Yes
- ☐ No
- ☐ Unknown

Copy and complete questions 100 – 101 to report multiple ACS events.

Pain

102. Has vaso-occlusive pain occurred that required hospitalization or treatment? *(treatment that is in a hospital or clinic setting)*
- ☐ Yes – ***Go to question 103***
- ☐ No – ***Go to question 105***
- ☐ Unknown – ***Go to question 105***

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Copy and complete questions 103 – 104 to report multiple vaso-occlusive pain events.

103. Date of vaso-occlusive pain event: ___ ___ ___ ___ — ___ ___ — ___ ___
YYYY MM DD

104. Did this vaso-occlusive pain event require hospitalization?

- ☐ Yes
- ☐ No
- ☐ Unknown

Copy and complete questions 103 – 104 to report multiple vaso-occlusive pain events.

105. Has there been any new onset of chronic pain? *(chronic pain is defined as pain present a majority of days per month for ≥ 6 months and one or more of the following: without contributory SCD complications or mixed pain types in which chronic pain is occurring at sites, such as arms, back, chest, or abdominal, but unrelated to any sites associated with SCD complications)*

- ☐ Yes
- ☐ No
- ☐ Unknown

106. Were opioids prescribed for the treatment of pain?

- ☐ Yes
- ☐ No

Avascular Necrosis

107. Is there a new area affected by avascular necrosis?

- ☐ Yes – ***Go to question 108***
- ☐ No – ***Go to question 112***
- ☐ Unknown – ***Go to question 112***

108. Specify joint(s) affected *(check all that apply)*

- ☐ Hip – ***Go to question 110***
- ☐ Knee – ***Go to question 110***
- ☐ Shoulder – ***Go to question 110***
- ☐ Other – ***Go to question 109***

109. Specify other: _____

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110. Was a musculoskeletal MRI performed?

- ☐ Yes – ***Go to question 111***
- ☐ No – ***Go to question 112***

111. Indicate if the musculoskeletal MRI report is attached

- ☐ Attached
- ☐ Not available

112. Did the recipient undergo joint replacement?

- ☐ Yes – ***Go to question 113***
- ☐ No – ***Go to question 115***

113. Joint replaced *(check all that apply)*

- ☐ Hip – ***Go to question 115***
- ☐ Knee – ***Go to question 115***
- ☐ Shoulder – ***Go to question 115***
- ☐ Other – ***Go to question 114***

114. Specify other joint replaced: _____

Central Nervous System

115. Was transcranial doppler velocity assessed at any time?

- ☐ Yes – ***Go to question 116***
- ☐ No – ***Go to question 119***
- ☐ Unknown – ***Go to question 119***

116. Date of most recent transcranial doppler: ___ ___ ___ ___ — ___ ___ — ___ ___
YYYY MM DD

117. Transcranial doppler velocity: ___ ___ ___ cm/sec

118. Indicate if the transcranial doppler velocity report is attached

- ☐ Attached
- ☐ Not available

119. Have any new sickle cell central nervous system (CNS) complications occurred?

- ☐ Yes – ***Go to question 120***
- ☐ No **– *Go to question 125***

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☐ Unknown **– *Go to question 125***

If there is more than one central nervous event copy questions 120- 124 for each instance.

120. Specify type of CNS complication
- ☐ Cerebral venous thrombosis
- ☐ Hemorrhagic stroke
- ☐ Ischemic stroke
- ☐ Moyamoya
- ☐ Overt stroke
- ☐ Posterior reversible encephalopathy syndrome (PRES)
- ☐ Seizure
- ☐ Silent stroke
- ☐ Transient ischemic stroke

121. Date of onset
- ☐ Known – ***Go to question 122***
- ☐ Unknown – ***Go to question 123***

122. Date of onset: ___ ___ ___ ___ — ___ ___ — ___ ___
YYYY MM DD

123. Was an MRI / MRA of the brain performed for the diagnosis of this reported CNS complication?
- ☐ Yes – ***Go to question 124***
- ☐ No **– *Go to question 125***
- ☐ Unknown **– *Go to question 125***

124. Indicate if the MRI / MRA report is attached
- ☐ Attached
- ☐ Not available

If there is more than one central nervous event copy questions 120 - 124 for each instance.

Other Symptoms

125. Did one or more episodes of priapism occur? *(to be answered for males only)*
- ☐ Yes – ***Go to question 126***
- ☐ No – ***Go to question 127***

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☐ Unknown – ***Go to question 127***

Copy and complete question 126 to report multiple priapism episodes.

126. Date of priapism episode: ___ ___ ___ ___ — ___ ___ — ___ ___
YYYY MM DD

Copy and complete question 126 to report multiple priapism episodes.

127. Has a new onset of sickle cell retinopathy developed?
- ☐ Yes
- ☐ No
- ☐ Unknown

128. Have chronic leg ulcers developed?
- ☐ Yes
- ☐ No
- ☐ Unknown

129. Is there a new diagnosis of asthma or a reactive airway disease?
- ☐ Yes
- ☐ No
- ☐ Unknown

130. Has a venous thromboembolism developed?
- ☐ Yes – ***Go to question 131***
- ☐ No – ***Go to question 132***
- ☐ Unknown – ***Go to question 132***

131. Was it associated with an indwelling catheter?
- ☐ Yes
- ☐ No

Copy and complete question 132 to report multiple splenic sequestration events.

132. Date of splenic sequestration event: ___ ___ ___ ___ — ___ ___ — ___ ___
YYYY MM DD

Copy and complete question 132 to report multiple splenic sequestration events.

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Existing Organ Impairments

Copy and complete 133 - 145 to report multiple impairments.

133. Specify organ impairments or disorders developed

- ☐ Amenorrhea – ***Go to question 134***
- ☐ Cardiomyopathy – ***Go to question 134***
- ☐ Cholelithiasis – ***Go to question 134***
- ☐ Growth hormone deficiency / short stature – ***Go to question 134***
- ☐ Hypersplenism – ***Go to question 134***
- ☐ Hypogonadism / gonadal dysfunction- ***Go to question 134***
- ☐ Hypothyroidism requiring replacement therapy – ***Go to question 134***
- ☐ Osteonecrosis – ***Go to question 134***
- ☐ Osteopathies (porosis, penia) – ***Go to question 134***
- ☐ Retinal changes ***– Go to question 134***
- ☐ Thrombosis – ***Go to question 134***
- ☐ None – ***Go to question 146***

134. Was this organ impairment previously reported?

- ☐ Yes – ***Go to question 136***
- ☐ No – ***Go to question 135***

135. Date of diagnosis: ___ ___ ___ ___ — ___ ___ — ___ ___ ☐ Date estimated
YYYY MM DD

136. Method used to assess osteopathies *(report the most recent Z or T-score available; Z-scores are used in patients younger than or equal to 20 and T-score in patients older than 20) (check all that apply)*

- ☐ Dual-energy X-ray absorptiometry (DEXA) scan – ***Go to question 137***
- ☐ Quantitative CT– ***Go to question 141***
- ☐ Unknown - ***Go to question 146***

137. DEXA scan vertebral

- ☐ Known ***– Go to question 138***
- ☐ Unknown ***– Go to question 139***

138. Z or T– score: __ __. __ __ ☐ Negative value

139. DEXA scan hip

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☐ Known **– *Go to question 140***

☐ Unknown **– *Go to question 141***

140. Z or T – score: __ __. __ __ ☐ Negative value

141. Quantitative CT vertebral

☐ Known **– *Go to question 142***

☐ Unknown **– *Go to question 143***

142. Z or T– score: __ __. __ __ ☐ Negative value

143. Quantitative CT hip

☐ Known **– *Go to question 144***

☐ Unknown **– *Go to question 145***

144. Z or T – score: __ __. __ __ ☐ Negative value

145. Indicate if the DEXA scan report is attached

☐ Attached

☐ Not available

Copy and complete 133 - 145 to report multiple impairments.

Disease Modifying Therapies

146. Were disease modifying therapies given or stopped? *(excludes blood transfusions)*

☐ Yes – ***Go to question 147***

☐ No – ***Go to question 153***

☐ Unknown – ***Go to question 153***

☐ Not applicable *(therapy previously reported and is still ongoing)* – ***Go to question 153***

If there is more than one therapy given copy questions 147 - 152 for each therapy.

147. Specify the disease modifying therapy

☐ Crizanlizumab (Adakveo) – ***Go to question 149***

☐ Hydroxyurea – ***Go to question 149***

☐ L-Glutamine (Endari) – ***Go to question 149***

☐ Voxelotor (Oxbryta) – ***Go to question 149***

☐ Other **– *Go to question 148***

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148. Specify other: _____

149. Date therapy started

- ☐ Known - ***Go to question 150***
- ☐ Unknown **–** Go to question ***151***
- ☐ Previously reported – ***Go to question 151***

150. Date therapy started: ___ ___ ___ ___ — ___ ___ — ___ ___
YYYY MM DD

151. Date therapy stopped

- ☐ Known – ***Go to question 152***
- ☐ Unknown – ***Go to question 153***
- ☐ Not applicable *(still receiving therapy)* – ***Go to question 153***

152. Date therapy stopped: ___ ___ ___ ___ —___ ___ —___ ___
YYYY MM DD

If there is more than one therapy given copy questions 147 - 152 for each therapy.

Other Laboratory Studies

153. Was hemoglobin electrophoresis performed? *(do not include results if an RBC transfusion occurred within 4 weeks of the electrophoresis study)*

- ☐ Yes – ***Go to question 154***
- ☐ No – ***Go to question 168***
- ☐ Not applicable *(transfused within the last month)* – ***Go to question 168***
- ☐ Unknown – ***Go to question 168***

154. Date of most recent electrophoresis: ___ ___ ___ ___ — ___ ___— ___ ___
YYYY MM DD *(if multiple, report the most recent)*

Specify the hemoglobin allele types based on the sample tested in question 154.

155. Hb A1

- ☐ Yes – ***Go to question 156***
- ☐ No – ***Go to question 157***

156. Hb A1: ___ ___ %

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157. Hb A2

- ☐ Yes – ***Go to question 158***
- ☐ No – ***Go to question 159***

158. Hb A2: ___ ___ %

159. Hb C

- ☐ Yes – ***Go to question 160***
- ☐ No – ***Go to question 161***

160. Hb C: ___ ___ %

161. Hb F

- ☐ Yes – ***Go to question 162***
- ☐ No – ***Go to question 163***

162. Hb F: ___ ___ %

163. Hb S

- ☐ Yes – ***Go to question 164***
- ☐ No – ***Go to question 165***

164. Hb S: ___ ___ %

165. Other sickle related hemoglobin allele type

- ☐ Yes- ***go to question 166***
- ☐ No – ***Go to question 168***

166. Specify: _____

167. Level: ___ ___ %

168. Were absolute reticulocyte counts tested?

- ☐ Yes – ***Go to question 169***
- ☐ No – ***Go to question 171***
- ☐ Unknown – ***Go to question 171***

169. Absolute reticulocyte count: ___ ___ ___ ___ • ___ ___ ___ ___ ☐ x 10^3/ µL (x 10^9/L) (x 10^3/mm^3)
☐ x 10^6/ µL (x 10^{12}/L)

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170. Date sample drawn: ___ ___ ___ ___ — ___ ___ — ___ ___
YYYY MM DD

171. Were soluble transferrin receptors (sTfR) tested?

- ☐ Yes – ***Go to question 172***
- ☐ No – ***Go to question 174***
- ☐ Unknown – ***Go to question 174***

172. sTfR : ___ ___ • ___ mg/L

173. Date sample drawn: ___ ___ ___ ___ — ___ ___ — ___ ___
YYYY MM DD

174. Was an erythropoietin (EPO) level tested?

- ☐ Yes – ***Go to question 175***
- ☐ No – ***Go to question 177***
- ☐ Unknown – ***Go to question 177***

175. EPO level: ___ ___ ___ IU/L

176. Date sample drawn: ___ ___ ___ ___ — ___ ___ — ___ ___
YYYY MM DD

177. Was a D-dimer level tested?

- ☐ Yes – ***Go to question 178***
- ☐ No – ***Go to question 179***
- ☐ Unknown – ***Go to question 179***

178. D-dimer level: __ __ __ .__ __
- ☐ ng/mL
- ☐ µg/mL
- ☐ mg/mL

Disease Status

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

- ☐ Hb S ≤ 50% and clinical symptoms described are absent
- ☐ Hb S ≤ 50% and clinical symptoms described are present

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- ☐ Hb S > 50% and clinical symptoms described are absent
- ☐ Hb S > 50% and clinical symptoms described are present
- ☐ Recipient is receiving disease modifying therapy

Marrow Evaluation

Complete question 180 for gene therapy infusions only

180. Was a marrow aspirate and / or biopsy performed?

- ☐ Yes - **Also complete Laboratory Studies Form 3502 and Marrow Surveillance Form 3506**
- ☐ No
- ☐ Unknown

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