**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
- **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: ________________

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
Form 2130 R2.0: Sickle Cell Anemia Post-HSCT Data

Center: 
CRID: 

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

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
Form 2130 R2.0: Sickle Cell Anemia Post-HSCT Data

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

44 Specify the level of each hemoglobin type:

- Hb A1: ____________ %
- Hb A2: ____________ %
- Hb C: ____________ %
- Hb F: ____________ %
- Hb S: ____________ %

45 Hb A1 not tested

46 Hb A2 not tested

47 Hb C not tested

48 Hb F not tested

49 Hb S not tested

50 Other hemoglobin type

- [ ] yes
- [ ] no

51 Specify type: ______________________

52 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: __________________