FOLLOW-UP INSERT XIV
Sickle Cell Anemia

FOR REGISTRY USE ONLY:
I.D. A – _____ – _____
Date received:

TEAM: _____ IUBMID: _____
(Institutional Unique Blood or Marrow Transplant Identification Number)

Registry (circle one): IBMTR ABMTR

Date of transplant for which this form is being completed: ___ ___ Month ___ ___ Day ___ ___ ___ ___ Year

Date of report: ___ ___ Month ___ ___ Day ___ ___ ___ ___ Year

Follow-up Information*

**** Report data for date of last contact as reported in Q.2 of Follow-up Core Form or immediately prior to death***

1. Serum ferritin since last report:
1 ❑ <1000 ng/ml or µg/L
2 ❑ ≥1000 ng/ml or µg/L
8 ❑ Unknown

2. Was chelation therapy given since last report?
1 ❑ Yes
0 ❑ No
8 ❑ Unknown

3. Is patient still receiving chelation therapy or undergoing phlebotomy?
1❑ Yes 0❑ No 8❑ Unknown

4. Date ended: ___ ___ Month ___ ___ Day ___ ___ ___ ___ Year ❑ Date unknown

Disease symptoms since last report *(check all that apply)*:

	Yes	No	Unknown	
5.	1❑	0❑	8❑	Vaso-occlusive pain causing hospitalization
7.	1❑	0❑	8❑	Priapism
10.	1❑	0❑	8❑	Acute chest syndrome

6. Frequency: 1❑ <3/yr 2❑ ≥3/yr 8❑ Unknown

8. Number of episodes/yr: ___ ___ ___ ___

9. Surgery posttransplant? 1❑ Yes 0❑ No 8❑ Unknown

11. Number of episodes since last report: ___ ___ ___

12. Requiring exchange transfusion? 1❑ Yes 0❑ No 8❑ Unknown

Treatment for ACS:

	Yes	No	Unknown	
13.	1❑	0❑	8❑	Transfusion of RBCS
14.	1❑	0❑	8❑	Antibiotics
15.	1❑	0❑	8❑	O_2
16.	1❑	0❑	8❑	Intubation
17.	1❑	0❑	8❑	Other, specify:_____

	Yes	No	Unknown	
18.	1❑	0❑	8❑	Stroke

19. More than one stroke? 1❑ Yes 0❑ No 8❑ Unknown

TEAM: ☐☐☐☐ IUBMID: ☐☐☐☐☐☐

Disease symptoms since last report *(continued)*:

Yes No Unknown

20. 1❑ 0❑ 8❑ Seizures

21. 1❑ 0❑ 8❑ Osteonecrosis

Specify joints:

	Yes	No	Unknown					
22.	1❑	0❑	8❑	Ankle	**25.**	1❑	0❑	8❑ Shoulder
23.	1❑	0❑	8❑	Hip	**26.**	1❑	0❑	8❑ Spine
24.	1❑	0❑	8❑	Knee	**27.**	1❑	0❑	8❑ Other, specify:_____

28. 1❑ 0❑ 8❑ Sickle nephropathy

29. Was a brain MRI/MRA performed since last report?

1 ❑ Yes — ***If MRI/MRA Report is available, check here ❑, attach copy and reference Q.29***

0 ❑ No

8 ❑ Unknown

Cardiac Studies:

Yes No Unknown

30. 1❑ 0❑ 8❑ EKG since last report — ***Attach copy(ies), check here ❑ and reference Qs.30-31***

31. 1❑ 0❑ 8❑ Echocardiogram since last report

32. Was a hemoglobin electrophoresis performed since last report?

1 ❑ Yes — ***If Report is available, check here ❑, attach copy and reference Q.32***

0 ❑ No

8 ❑ Unknown

33. Date: ☐☐ ☐☐ ☐☐☐☐ ❑ Date unknown

Month Day Year

Specify results:

(include all posttransplant electrophoresis results with dates performed)

34. Hb A1 ☐☐ %

35. Hb A2 ☐☐ %

36. Hb S ☐☐ %

37. Hb C ☐☐ %

38. Hb F ☐☐ %

39. Hb Other ☐☐ %

Specify:_____

If more than one posttransplant electrophoresis performed, copy this page.

40. Did patient have gonadal dysfunction since last report?

1 ❑ Yes

0 ❑ No

8 ❑ Unknown

41. Status of disease at time of this report or at time of death *(check only one)*:

1 ❑ Cured: Hb electrophoresis (Hb S ≤50%) and clinical symptoms (see ***Qs.5-28***) absent

2 ❑ Disease recurred: Hb S >50% and absense of clinical symptoms (see ***Qs.5-28***)

3 ❑ Disease recurred: Hb S >50% and presence of clinical symptoms (see ***Qs.5-28***)

8 ❑ Unknown