OMB Number: 0915-0344
Expiration Date: 12/31/2014

Sickle Cell Disease Newborn Screening Program (SCDNBSP)

Minimum Database Project (MDP)

Sickle Cell Disease (SCD) Questionnaire Form

Section A: SITE IDENTIFYING INFORMATION

Today's Date (mm/dd/yyyy): |__|__| - |__|__| - 20|__|__|

Date of Client Visit/Interview (mm/dd/yyyy): |__|__| - |__|__| - 20|__|__|

Data Entry Personnel: _____ Site ID: |__|__|__| State ID: |__|__|

Section B: CLIENT IDENTIFYING INFORMATION

Age of client at time of interview:_____ years _____ months Client ID: |__|__|__|__|__|

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Section C: CLIENT INFORMATION

1. Who referred the client? (Please check one)

☐ State Newborn Screening (NBS) Program ☐ Health Department (not a NBS Program)

☐ Physician ☐ Self-Referral

☐ Hospital ☐ Comprehensive Sickle Cell Center

☐ Community-Based Organization ☐ Other: _____

2. What is the sex of the client? (Please click one) ☐ Male ☐ Female

3. What is the confirmed diagnosis of the client? (Please click one)

☐ Sickle Cell Disease (SS) ☐ Sickle C Disease (SC)

☐ Sickle Beta-Plus Thalassemia ☐ Sickle Beta-Zero Thalassemia ☐ Other_____

4. How old was the client at the time of confirmatory diagnosis? (Enter date of diagnosis)

Date (mm/dd/yyyy): |__|__| - |__|__| - |__|__|__|__|

5. Enter the source of the confirmatory diagnosis: (Please check one)

☐ Caregiver ☐ Physician ☐ Lab ☐ Other:_____

Section D: FAMILY INFORMATION

6. Who is the primary caregiver(s)? (Please click one)

☐ Mother only ☐ Father Only ☐ Both Parents ☐ Foster Parents

☐ Other Family ☐ Grandparent (s) ☐ Other: _____

7. If **mother is the primary caregiver,** does she know about her hemoglobin status (SCD or SCT)? (Please check one) ☐ Yes ☐ No ☐ Not Applicable

8. **If yes**, when did the mother know about her status? (Please check one)

☐ Before pregnancy ☐ During pregnancy ☐ After birth of child ☐ Not Applicable

9. **If no,** has she been asked to be tested? (Please check one) ☐ Yes ☐ No ☐ Not Applicable

10. If **father is the primary caregiver,** does he know about his hemoglobin status (SCD or SCT)? (Please check one) ☐ Yes ☐ No ☐ Not Applicable

11. **If yes**, when did the father know about his status? (Please check one)

☐ Before pregnancy ☐ During pregnancy ☐ After birth of child ☐ Not Applicable

12. **If no,** has he been asked to be tested? (Please check one) ☐ Yes ☐ No ☐ Not Applicable

13. What is the age of the primary caregiver(s)? |__|__| |__|__|

14. Is the client genetically related (mother, father etc) to the primary caregiver(s)? ☐ Yes ☐ No

15. How many more children **(< 18 years old)** are there in the client's home with SCD/SCT? |__|__|

16. What is the diagnosis of other child/children? _____

17. How many people are in the client's household (including the client and caregiver): |__|__|

18. Zip code of primary caregiver(s): |__|__|__|__|__|

19. What is annual household income of the client's family? (Please check one)

☐ Less than $10,000 ☐ $10,000 – $19,999 ☐ $20,000 – $29,999

☐ $30,000 – $39,999 ☐ $40,000 – $49,999 ☐ $50,000 – $59,999

☐ $60,000 – $74,999 ☐ $75,000 and over ☐ Did not answer

☐ Don't Know

20. What type of insurance does the caregiver have for the client? (Please click one)

☐ Medicaid ☐ Medicaid HMO ☐ Private ☐ No Insurance ☐ SCHIP ☐ Medicare

☐ TRICARE ☐ Other: _____

Section E: CLIENTS RECENT MEDICAL HISTORY

21. Where does the client go for primary care? (Please click all that apply)

☐ Private Practitioner's Office ☐ Hospital ER/ED ☐ Urgent Care Center

☐ Community Health Center ☐ Hospital-based Clinic ☐ Public Health Department

☐ Other: _____

22. Whom does the client see for primary care at the above site? (Please click all that apply)

☐ Pediatrician ☐ Hematologist ☐ Internist

☐ Nurse Practitioner ☐ Family Doctor ☐ Other: _____

23. Has the client seen a hematologist in the past year? ☐ Yes ☐ No

24. In the past 12 months, how many times has the client received healthcare services at an ED? |__|

25. What was/were the reasons(s) for the visit? (Please check all that apply)

☐ Fever ☐ Pain ☐ Respiratory Problems

☐ Jaundice ☐ Pallor ☐ Lethargy

☐ Enlarged Spleen ☐ Priapism ☐ Vomiting/Nausea

☐ Swollen Limbs ☐ Other: _____ ☐ Not Applicable

26. In the past 12 months, how many times has the client been admitted to the hospital? |__|

27. What was/were the reasons(s) for the visit? (Please check all that apply)

☐ Fever ☐ Pain ☐ Respiratory Problems

☐ Jaundice ☐ Pallor ☐ Lethargy

☐ Enlarged Spleen ☐ Priapism ☐ Vomiting/Nausea

☐ Swollen Limbs ☐ Other: _____ ☐ Not Applicable

28. Is the client taking prophylactic antibiotics (i.e., penicillin)?

☐ Yes ☐ No (why): _____

29. If yes, at what age was prophylactic penicillin started? (Please check one)

☐ 1 Week ☐ 2 Weeks ☐ 3 Weeks ☐ 4 Weeks ☐ 5 Weeks

☐ 6 Weeks ☐ 7 Weeks ☐ 8 Weeks ☐ 3 Months ☐ 4 Months

☐ Greater than 4 Months – 2 Years ☐ Don't Know ☐ Not Applicable

30. How often is the client taking prophylactic antibiotics? (Please click one)

☐ 2 times per day ☐ 1 time per day ☐ Less than 1 time per day

31. Has the client received the pneumococcal vaccine? ☐ Yes ☐ No
32. If yes, what type? (Please check one)

☐ 7 Valent/13 Valent (i.e. Prevnar as part of childhood immunizations) ☐ 23 Valent (i.e. Pneumovax)

☐ Both 7/13 Valent and 23 Valent Pneumococcal vaccine ☐ Not Applicable ☐ Don't Know

☐ Did Not Answer

33. In the last 12 months, what treatment(s) has the client received? (Please check all that apply)
☐ Nebulizer/Inhaler ☐ Transfusions ☐ Transcranial Doppler (TCD) ☐ Chelation Therapy

☐ Hydroxyurea ☐ None of these services

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Section F: SERVICES CLIENTS FAMILY RECEIVED

34. During the past 3 months, # of genetic counseling sessions attended? |__|__|

35. During the past 3 months, # of referrals has the client or caregiver received? |__|__|

36. During the past 3 months, # of other services (ex: interpreter, transportation etc.) has the client or caregiver received? |__|__|

Section G: CLIENT FAMILY COMMUNICATION

37. For Caregivers of clients under age 18

The following questions pertain to clients under the age of 18 years and their caregivers. ***(Language categories provided below.)***

A. What is the primary spoken language in the client's home? _____

B. If English is not your primary language do you require a translator for medical services/medical information?
☐ Yes ☐ No ☐ Not Applicable

What, if any, is the secondary spoken language?
_____

C. What language is the client/caregiver most comfortable reading?
Client: _____.

☐ Don't Know ☐ Not Applicable

Caregiver: _____.

D. What is highest level of education attained?
Caregiver: _____.

☐ Don't Know ☐ Not Applicable

37. For Clients 18 years or older

The following questions pertain to the client 18 years of age or older. ***(Language categories provided below.)***

A. What is the primary spoken language in the client's home? _____

B. If English is not your primary language do you require a translator for medical services/medical information?
☐ Yes ☐ No ☐ Not Applicable

What, if any, is the secondary spoken language?
_____

C. What language are you most comfortable reading?
_____

D. What is the highest level of education you attained?
_____

Continue to questions 38 and 39

Continue to questions 38 and 39	

*__*Language categories*__: American Sign Language, Arabic, Chinese, Haitian Creole, Igbo, Korean, Somali, Spanish, Vietnamese, Yoruba or please provide any other language not listed.

38.Are you (your child) Hispanic or Latino?

- ☐ No, not Hispanic or Latino
- ☐ Yes, Hispanic or Latino

39.What is your (your child's) race? Mark (X) one or more boxes.

- ☐ White
- ☐ Black or African American
- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Native Hawaiian or Other Pacific Islander

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