

**HAEMOGLOBINOPATHIES (excluding carrier states) QUESTIONNAIRE**  
Australian Paediatric Surveillance Unit

Please ring **Dr Elizabeth Argent** on **02 9382 1729** if you have any difficulty with this questionnaire.

**REPORTING CLINICIAN**

1. APSU Dr Code/Name  /.....  
2. Month/Year of Report ..... /.....

**PATIENT**

3. First 2 letters of first name   
4. First 2 letters of surname   
5. Date of Birth  /  /   
6. Sex  M  F  
7. Post code   
8. Date questionnaire completed  /  /   
9. Is the child of Aboriginal or Torres Strait Islander origin  Yes  No  Don't know

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**If this patient is primarily cared for by another physician whom you believe will report the case, please write the other physician's name and complete questionnaire details above this line and return to the APSU. If no other report is received for this child we will contact you for information requested in the remainder of the questionnaire. Please keep the patient's name and other details on your APSU file.**

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*Instructions: Please answer each question by placing a tick in the appropriate box or writing your response in the space provided.*

**CLINICAL DETAILS**

10. What is the nature of the haemoglobinopathy/ haemoglobin disorder?  
  $\beta$ -thalassaemia major  
 Hb E/  $\beta$ -thalassaemia  
 Hb SS disease (sickle cell anaemia)  
 Hb S/  $\beta$ -thalassaemia  
 Hb SC disease  
 Hb H disease  
 Hb Barts disease  
 Hb CC disease  
 Hb EE disease  
 Other, please specify.....  
 Don't know
11. Date of diagnosis  /  /
12. Is the child currently alive?  Yes  No  Don't know
13. If the child has died,  
a. date of death...../...../.....  Don't know  
b. cause of death.....  Don't know  
c. was the child stillborn?  Yes  No  Don't know  
d. intrauterine foetal death?  Yes  No  Don't know
14. Presentation at diagnosis  
a. Antenatal diagnosis  Yes  No  Don't know  
b. Anaemia/ Pallor  Yes  No  Don't know  
c. Sepsis  Yes  No  Don't know  
d. Haemolysis  Yes  No  Don't know  
e. Aplastic crisis  Yes  No  Don't know  
f. Hepatomegaly &/or splenomegaly  Yes  No  Don't know  
g. Sequestration crisis  Yes  No  Don't know  
h. Vaso-occlusive crisis  Yes  No  Don't know  
i. Other, please specify.....

15. Is the child currently being treated for this condition? Yes No Don't know Not applicable

16. Please indicate treatment(s) the child has received for haemoglobinopathy (tick all that apply)

- a. Medication(s), please specify .....
- b. Regular transfusion program
- c. Intermittent transfusions when symptomatic
- d. Exchange transfusion
- e. Other, please specify .....
- f. Don't know
- g. Not applicable

17. Has the child received a bone marrow transplant? Yes No Don't know Not applicable

18. Is a bone marrow transplant planned? Yes No Don't know Not applicable

**FAMILY HISTORY DETAILS**

19. Are the parents consanguineous? Yes No Don't know

20. If there is consanguinity, please specify relationship (if known).....

21. Are there other family members with the same condition? Yes No Don't know

22. Please list the relationship to the child of any other affected family members.....  
.....

23. Is the Mother's Hb EPG result or other relevant diagnostic information known?  
Yes No (please specify).....

24. Was the mother aware her Hb EPG result prior to this pregnancy?  
Yes No Don't know Not Applicable

25. Is the Father's Hb EPG result or other relevant diagnostic information known?  
Yes No (please specify).....

26. Was the Father aware his Hb EPG result prior to this pregnancy?  
Yes No Don't know Not Applicable

27. What is the mother's ethnic background?..... Don't know

28. What is the father's ethnic background?..... Don't know

29. In which country was the child born? Australia Other (please specify) .....

**ANTENATAL ASSESSMENT OF THIS PREGNANCY**

30. Was the mother screened antenatally for haemoglobinopathy with a Hb EPG?  
Yes No Don't know

31. Was the infant tested antenatally for a haemoglobinopathy?  
Yes No Don't know If YES , what testing was undertaken?.....  
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32. Was information about the risk of haemoglobinopathy discussed with the mother and/or father during the pregnancy? Yes No Don't know

33. Do the parents propose to seek antenatal diagnosis in subsequent pregnancies?  
Yes No Don't know Not planning further pregnancies

34. If no further pregnancies are planned, was this decision influenced by the diagnosis of this affected child? Yes No Don't know Not applicable

**Please return this questionnaire in the addressed reply-paid envelope. Thankyou for your assistance with this study.**