Please File For Your Information

Australian Paediatric Surveillance Unit

IDIOPATHIC & CONGENITAL NEPHROTIC SYNDROME - Initial Questionnaire

Please ring Dr Elisabeth Hodson on 02 9845 3430 if you have any problems with this questionnaire.

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

PATIENT
4. First 2 letters of first name
5. First 2 letters of surname
6. Date of Birth: day  month  year
7. Sex  M  F
8. Postcode

If this patient is primarily cared for by another physician who you believe will report the case, then there is no need to complete the remainder of this questionnaire at this stage. Please keep the patient's name and other details in your records. If no other report is received for this child we will contact you for further information.

9. Date of diagnosis  day  month  year

MOTHER
10. Country of birth:  Australia  New Zealand  Other
    If other please specify: ..........................................................
    If born in Australia is she an  Aboriginal  Torres Strait Islander
    If born in New Zealand is she a  Maori  Pacific Islander
    Country of origin: (eg. if she was born in Fiji but the ancestral line originated from India, then the country of origin is India) ..........................................................

FATHER
11. Country of birth:  Australia  New Zealand  Other
    If other please specify: ..........................................................
    If born in Australia is he an  Aboriginal  Torres Strait Islander
    If born in New Zealand is he a  Maori  Pacific Islander
    Country of origin: (as above) ..........................................................

12. Language spoken at home:- ..........................................................

13. Occupation of mother: ..........................................................
    Occupation of father: ..........................................................

14. Status at presentation: (Please record the first measurement)
    Creatinine ............................................... (micromoles/L)
    Blood pressure ............................................... (systolic/diastolic)
    Microscopic haematuria  Yes  No

15. Case definition at presentation: (tick appropriate box)
    Idiopathic nephrotic syndrome  Congenital nephrotic syndrome
ONLY COMPLETE THIS SECTION (Q 16 - 22) IF YOU HAVE NOTIFIED A CASE OF
IDIOPATHIC NEPHROTIC SYNDROME

IF YOU HAVE NOTIFIED A CASE OF CONGENITAL NEPHROTIC SYNDROME
ONLY COMPLETE THE QUESTIONS (Q 23 - 26) ON THE REVERSE SIDE OF THIS
PAGE

**Treatment at diagnosis**

16. Corticosteroid treatment: Prednisone  Prednisolone
Other: please specify: .............................

Total dose: .......... mg/day  or
.......... mg/kg/day  or
.......... mg/m^2^/day

Number of doses/day:

Planned duration of daily steroids: weeks  or  until remission

17. Antibiotic prophylaxis: Yes  No
If antibiotic prophylaxis was used, specify antibiotic:  ..............................................

18. Aspirin prophylaxis  Yes  No

19. Albumin infusions  Yes  No

20. Diuretics  Yes  No

21. Was pneumococcal vaccination given to patient? Yes  No
If yes, was the child nephrotic when vaccinated? Yes  No
Was the child receiving steroids when vaccinated?
Daily  Alternate days  None

22. Are there any relatives with idiopathic nephrotic syndrome? Yes  No
If yes:
Was it responsive to steroids? Yes  No  Not known
Was renal pathology available? Yes  No  Not known
If yes, please specify..............................................................................................
Relationship of affected relative to child....................................................................

Please return this questionnaire in the addressed reply-paid envelope.

*Thank you for your help with this research project.*
23. Family history:-
   Are the parents consanguineous?  Yes  No  Not known
   Have any relatives been affected with the same condition?  Yes  No  Not known
   If yes, please specify: ..............................................................

24. Suggestive diagnostic indicators in the antenatal period:-
   Ultrasound  Yes  No  Not known
   High $\alpha$- feto protein levels  Yes  No  Not known
   Presence of polyhydramnios  Yes  No  Not known

25. Condition of the child at birth:-
   Gestational age  weeks
   Birth weight  grams
   Placental weight  grams  Not known
   Congenital infection  Yes  No  Not known
   If yes, please specify: ..........................................................................................
   Other congenital abnormalities  Yes  No  Not known
   If yes, please specify: ..........................................................................................

26. Treatment following diagnosis:-
   Antibiotic prophylaxis  Yes  No
   Aspirin prophylaxis  Yes  No
   Albumin infusions  Yes  No
   Immunoglobulin infusions  Yes  No
   Diuretics  Yes  No
   Thyroxine  Yes  No
   ACE inhibitors  Yes  No
   NSAIDS  Yes  No
   Anticoagulants (eg:-warfarin)  Yes  No
   Corticosteroids  Yes  No
   Pneumococcal vaccine  Yes  No
   Other  Yes  No
   If yes, please specify ..........................................................

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