

IDIOPATHIC NEPHROTIC SYNDROME - Initial Questionnaire

Please ring Dr William Wong 09 307 8900 if you have any problems with this questionnaire.

REPORTING CLINICIAN

1. Name
2. NZPSU Dr. Code _ _ _
3. Date of Report/...../.....
4. Date of initial presentation

PATIENT

5. First 2 letters of first name _ _
6. First 2 letters of surname _ _
7. Date of Birth: _ _ / _ _ / _ _
8. Sex M _ F _

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 _____/_____/_____

MOTHER

10. (a) Country of birth: New Zealand ☐ Other ☐ (country) Not known ☐
 (b) Which ethnic group does she identify with? Mark the space/spaces that apply
- | | |
|----------------------|------------------------|
| New Zealand European | () |
| Maori | () |
| Samoan | () |
| Cook Island Maori | () |
| Niuean | () |
| Chinese | () |
| Indian | () |
| Other (eg. Dutch) | () Please state |

FATHER

11. (a) Country of birth: New Zealand ☐ Other ☐ (country) Not known ☐
- (b) Which ethnic group does he identify with? Mark the space/spaces that apply
- | | |
|----------------------|------------------------|
| New Zealand European | () |
| Maori | () |
| Samoan | () |
| Cook Island Maori | () |
| Niuean | () |
| Chinese | () |
| Indian | () |
| Other (e.g. Dutch) | () Please state |

12. Occupation of mother _____
Occupation of father _____

CLINICAL FEATURES

- | | |
|---------------------------------|----------------------|
| Creatinine | (micromoles/L) |
| Blood pressure | (systolic/diastolic) |
| Microscopic haematuria (circle) | Yes No |

Treatment at diagnosis (please circle one)

- 14 Corticosteroid treatment: Prednisone/Prednisolone
Other: please specify:
Total dose:mg/kg/day **or**
.....mg/m²/day
Number of doses/day: _____
Planned duration of daily steroids: _____ weeks **or** until remission
15. Antibiotic prophylaxis: Yes No
If antibiotic prophylaxis was used, specify antibiotic:
16. Aspirin prophylaxis: Yes No
- 17 Albumin infusions Yes No
- 18 Diuretics Yes No
19. Was a 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
20. Are there any relatives who have ever had 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 to the Principal Investigator:
Dr William Wong, Renal Unit, Starship Children's Hospital,
Private Bag 92024, Auckland.**

If you need any help in completing it please contact him on 09 307 8900 or wwong@adhb.hovt.nz

Thank you for your help with this research project.

PLEASE RETAIN A COPY FOR YOUR INFORMATION

New Zealand Paediatric Surveillance Unit
IDIOPATHIC NEPHROTIC SYNDROME - Follow Up Questionnaire

Please contact Dr William Wong on 09 307 8900 if you have any problems with this questionnaire.

REPORTING CLINICIAN

1. Name 2. NZPSU Dr. Code _ _ _
3. Date of Report/...../.....

PATIENT

4. First 2 letters of first name _ _
5. First 2 letters of surname _ _
6. Date of Birth _ _ / _ _ / _ _ _ _
7. Did the child's nephrotic syndrome achieve remission with corticosteroid treatment? (ie. the child became oedema free and his/her urine protein was $\leq 1+$ on dipstick for 3 consecutive days)
Yes No - if no, please go to Q12
8. How long were the daily steroids given for before the child achieved his/her first remission?
_ _ Days
9. What further steroid therapy was given after first remission? (Choose more than one option if applicable)
- | | | |
|---|----------|-------|
| Daily steroids without reducing doses | Duration | weeks |
| Daily steroids with reducing doses | Duration | weeks |
| Alternate day steroids without reducing doses | Duration | weeks |
| Alternate day steroids with reducing doses | Duration | weeks |
10. If the child's nephrotic syndrome responded to steroids, did the child's nephrotic syndrome relapse? (ie. reappearance of urine protein $\geq 3+$ or more on dipstick for 3 consecutive days, having previously been in remission) Yes No
If yes, how long after the initial remission did the child relapse? weeks
11. If the child's nephrotic syndrome relapsed, how would the patient be best described over the twelve month follow up period?
- Infrequent relapser (1 relapse within 6 months following first remission, or less than 4 relapses)
Frequent relapser (2 or more relapses within 6 months following first remission, or 4 or more relapses)
Steroid dependent (2 consecutive relapses occurring during reducing or alternate day steroid treatment, or within 14 days of its cessation)
Total number of relapses in 12 months following the first remission
12. Was a renal biopsy performed? Yes No
13. If a renal biopsy was performed, what was the result?
- Minimal change nephrotic syndrome
Focal segmental glomerulosclerosis
Membranous glomerulonephritis
Other, please specify
14. If not given at diagnosis, was pneumococcal vaccination given to the patient during follow up? Yes No
If given, was the child nephrotic when vaccinated? Yes No

Was the child receiving steroids when vaccinated?

Daily

Alternate days

None

How long after the initial diagnosis was the vaccine given?

Weeks

15. Did the child develop an invasive bacterial infection?

Yes

No

If no, please go to Q17

If yes:

Number of infection(s):

Site of infection(s):

Organism(s) identified:

How many infections occurred: When nephrotic?

When on corticosteroids?

When on antibiotic prophylaxis?

How many infections required intensive care admissions?

Please specify time of first infection from time of diagnosis.

weeks

16. Did the child develop a thrombotic episode?

Yes

No

If no, please go to Q18

If yes:

Number of thrombotic episodes

Time of occurrence after the initial diagnosis

weeks

Site(s) of thrombosis:

17. Status of patient one year after diagnosis:

Alive and well

Alive, with long term sequelae

Please specify (eg: deafness, hemiplegia)

Please specify the cause (eg: infection, thrombosis)

or

Dead, due to nephrotic syndrome complication

Dead, due to other causes, please specify

.....

Please specify the time from diagnosis to death

weeks

19. If alive, please specify status of renal function one year after diagnosis:

Creatinine (if measured)(micromoles/L)

Blood pressure(systolic / diastolic)

Microscopic haematuria

Yes

No

Don't know

Please return this questionnaire to the Principal Investigator

Thank you for your help with this research project.

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