### Severe Combined Immunodeficiency (SCID) Questionnaire

**Australian Paediatric Surveillance Unit**

#### PAEDIATRICIAN

1. Dr Code ____________ 2. Report Code ___________ /

3. Name:

4. Address:

5. Telephone: ________________ 6. Fax:

#### PATIENT DATA

7. Surname (1st 2 letters only) __ __ 8. First name (1st 2 letters only)

9. Date of Birth (day,month,year) __ / __ / __

10. Country of birth: Australia Other ________________

11. Sex: M  F

12. Postcode:

13. Mother's ethnic origin: Caucasian ☐ Asian ☐ Aborignal ☐ Other ☐

14. Positive family history Y ☐ N ☐ Unknown ☐ If Yes, describe:

15. Parents 1st cousins Y ☐ N ☐ Unknown ☐

Other consanguinity Y ☐ N ☐

16. Possible undiagnosed male cases Y ☐ N ☐ Unknown ☐

Year, age of death, other information:

#### CLINICAL DETAILS

17. Diagnosis

18. Age at presentation ☐ ☐ months 19. Date of definitive diagnosis: __ / __ / __

Please tick any of the following if noted at presentation (Questions 20-27):

<table>
<thead>
<tr>
<th>Question</th>
<th>Y ☐</th>
<th>N ☐</th>
<th>Unknown ☐</th>
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<tbody>
<tr>
<td>20. Pneumocystis carinii pneumonitis</td>
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<td>☐</td>
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<tr>
<td>21. Failure to thrive</td>
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<tr>
<td>22. Persistent bronchiolitic illness</td>
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<tr>
<td>23. Eczematous rash</td>
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<td>24. Lymphadenopathy</td>
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<td>25. Hepatomegaly/Splenomegaly</td>
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<tr>
<td>26. Persistent thrush</td>
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<td>27. CMV disease</td>
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28. Brief description of presenting illness

__________

Please tick any of the following if noted at any time (Questions 29-36):

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#### INITIAL INVESTIGATIONS

Date: __ / __ / __
37. Haemoglobin __ g/L 38. Platelet count __ x 10⁹/L
39. White cell count __ x 10⁹/L 40. Absolute lymphocyte count __ x 10⁹/L
41. Lymphocyte subsets (x 10⁹/L): CD3 ____ CD4 ____ CD8 ____ CD19 ____ HLA DR ____ NK ____ [CD____]
Other ____ NK function: Absent  Low  Normal  Not done
42. Lymphocyte mitogen response: Absent  Low  Normal [Mitogen: ____] Not done
43. Immunoglobulins: IgG ____ g/L, IgA ____ g/L, IgM ____ g/L
44. Maternal engraftment: Y  N  Comments, method:
45. HLA typing: A ____  B ____  DR ____
If unknown specify: Not done  Unsuccessful
46. Organism Identified: Date: Site: Method (e.g. culture, IF, PCR, histo)

47. Purine nucleoside phosphorylase: ______ 48. Adenosine deaminase: ______ (RBC/WBC)
49. HIV antibody: Negative  Positive  Not done
50. Sweat test: Negative  Positive  Not done

MANAGEMENT
51. Bone marrow transplantation performed: Y  N
52. If Yes, Date ___ / ___ / ___ Engraftment: Y  N
Relationship of donor
Donor Match ____ out of ___ antigens
T cell depleted marrow Y  N
Other tissue (eg cord blood)
Conditioning Y  N

OUTCOME DATA
53. Died Y  N
54. If Yes, Date of death ___ / ___ / ___
Cause of death ____________________________

55. If died and post mortem performed, major findings at post mortem (if available)________________________

SIGNED: ____________________________  DATE: ___ / ___ / ___

Please return in the reply-paid envelope to: A/Professor John B. Ziegler
Sydney Children's Hospital
High Street, Randwick  NSW  2031
Fax: (02) 9382 1515

A brief follow-up questionnaire will be sent in 12 months regarding outcome.