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):

20. *Pneumocystis carinii* pneumonitis ☐
21. Failure to thrive ☐
22. Persistent bronchiolitic illness ☐
23. Eczematous rash ☐
24. Lymphadenopathy ☐
25. Hepatomegaly/Splenomegaly ☐
26. Persistent thrush ☐
27. CMV disease ☐
Site:

28. Brief description of presenting illness

_____

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

29. *Pneumocystis carinii* pneumonitis ☐
30. Failure to thrive ☐
31. Persistent bronchiolitic illness ☐
32. Eczematous rash ☐
33. Lymphadenopathy ☐
34. Hepatomegaly/Splenomegaly ☐
35. Persistent thrush ☐
36. CMV disease ☐
Site:

INITIAL INVESTIGATIONS Date: __ __ / __ __ /

37. Haemoglobin ___ g/L 38. Platelet count ___ x 10^9/L

39. White cell count ___ x 10^9/L 40. Absolute lymphocyte count ___ x 10^9/L

41. Lymphocyte subsets (x 10^9/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 phophorylase: _____ 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

COMMENTS

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.