

Please File For Your Information

PRADER-WILLI SYNDROME (PWS) QUESTIONNAIRE
Australian Paediatric Surveillance Unit

Please keep a record of the child's unit number in your APSU folder. Please ring Dr Arabella Smith on 02 9845 3222, fax 02 9845 3238 if you have any problems with the form. Thank you for your time.

PAEDIATRICIAN

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 : day month year
6. Sex M F
7. Postcode

If this patient is primarily cared for by another physician who you believe will report the case then there is no need at this stage to complete the remainder of this questionnaire. 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

8. Date of diagnosis day month year

PERINATAL/NEONATAL HISTORY

9. Delivery LSCS Forceps Normal
10. Fetal movements Normal Decreased Don't know
11. Presentation Cephalic Breech DK
12. Amniotic fluid Normal Polyhydramnios
 Oligohydramnios DK
13. Birth weight grams
14. Gestational age weeks
15. Birth length cms
16. Birth head circumference . cms
17. Apgars 1 minute 5 minutes
18. Jaundice Yes No DK
19. Multiple pregnancy No Twin Triplet or more
20. Resuscitation at birth None Oxygen +/- or suction
 Bag & mask Intubation DK
21. Ventilation required subsequently? Yes No DK
 If yes, for how long days / weeks
22. Neonatal tone Severe hypotonia Mild hypotonia
 No hypotonia Hypertonia
23. Breast or bottle feeding Fully breast fed Partially breast fed
 Never breast fed DK

CLINICAL EXAMINATION

24. Hypogonadal Undescended testes Small genitalia
 Normal genitalia DK
25. Unusual facies? Yes No DK
26. Hypopigmented compared to family Yes No Don't know

27. Kyphosis/scoliosis Yes No DK
28. Osteoporosis Yes No
- Don't know
29. Eye abnormality Yes No DK
If yes, please describe (eg squint)
30. Thick saliva Yes No
- Don't know
31. Temperature instability Yes No DK
32. Excessive sleep Yes No DK
33. High pain threshold Yes No
- Don't know

BEHAVIOUR AND DEVELOPMENT (Please complete if the child is older than 1 year)

34. Skin picking Yes No
- Don't know
35. Age of onset walking
36. Age of onset talking
37. Behaviour problems Yes No DK
If yes, please describe
38. Unusual behaviour related to food Yes No DK
If yes, please describe (eg over-eating, food foraging, food stealing, eating unusual objects)
39. Unusual skills in jigsaws Yes No DK
40. Has this child ever vomited? Yes No DK

CURRENT MEASUREMENTS

41. Does this child have small hands? Yes No Don't know
Total hand length
42. Does this child have small feet? Yes No
- Don't know
- Shoe size
43. Weight kilograms
44. Height cms
45. Current head circumference cms
46. Narrow hand/ulna border Yes No DK

INVESTIGATIONS

47. Muscle biopsy Normal Abnormal Not done
48. Chromosomes Translocation Deletion Normal Not done
49. FISH test Normal Deletion Not done
50. Methylation test Normal Abnormal Not done
51. Other investigations, such as IQ tests, Griffith developmental assessment, other diagnostic molecular tests (please specify date performed, type of test and results)
52. Please list any other feature or diagnosis known for this child not already reported in the questionnaire

**Please return this questionnaire in the addressed reply-paid envelope.
Thank you for your help with this research project.**