

FETAL ALCOHOL SPECTRUM DISORDER (FASD)

APSU Office Use Only

Australian Paediatric Surveillance Unit

If you have any questions about this form please contact the APSU (02) 9845 3005; SCHN-APSU@health.nsw.gov.au

Study ID #:

Month/Year Report:

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Instructions: Please answer each question by ticking the appropriate box or writing your response in the space provided. DK=Don't Know; NA = Not Applicable**REPORTING CLINICIAN'S DETAILS** 1. APSU Dr Code/Name: _____ / _____ 2. Date questionnaire completed: ___/___/_____**PATIENT DETAILS**

3. First 2 letters of first name: ___ 4. First 2 letters of surname: ___ 5. Date of Birth: ___ / ___ / _____

6. Sex: Male Female 7. Postcode of family: _____ 8. Date of diagnosis: ___ / ___ / _____9. Racial Background (*select all that apply*): Aboriginal Caucasian Pacific Islander Torres Strait Islander African
 Asian DK Other (*specify*): _____10. Did you make the FASD diagnosis? Yes (*please go to Q11*) No – if this patient is primarily cared for by another physician who you believe could provide additional details, please write their name below and return this form to the APSU. If no other report is received for this child we will contact you for further information. Physician's Name: _____ Clinic/hospital: _____**BIOLOGICAL MOTHER'S DETAILS**11. Mother's age at the time of child's birth: ___ (years) or DK12. Mother's country of birth: Australia Other (*specify*): _____ 13. Mother's racial background: Caucasian Aboriginal
 Pacific Islander Torres Strait Islander African Asian DK Other (*specify*): _____**PATIENT'S FAMILY CHARACTERISTICS**14. Who is the child's primary carer? biological parents grandparent/s foster carer/s adoptive parent/s Other (*specify*): _____15. Has the child ever been or previously been under the care of community or child protection services? Yes No DK

15a. If yes, specify: _____

16. Have any of the child's siblings been diagnosed with FASD? No No siblings Yes (*specify*): _____**FASD DIAGNOSIS**17. Who first suspected this child may have a FASD? I did parent/caregiver teacher GP Other (*specify*): _____18. What is the child's FASD diagnosis? FASD with 3 Sentinel Facial Features FASD with *less than* 3 Sentinel Facial Features
 Other (*specify*): _____19. Was the diagnosis made by: paediatrician or other medical practitioner in a multidisciplinary or interdisciplinary team
 paediatrician or other medical practitioner, based on reports from one or more health professionals
 paediatrician or other medical practitioner, on their own
 Other (*specify*): _____

20. Did the diagnostic process include assessments by any of the following health professionals?

 clinical geneticist psychologist/neuropsychologist occupational therapist speech pathologist physiotherapist child/adolescent psychiatrist Other (*specify*): _____**GROWTH**21. Please specify birth measurements: (i) Gestational age: ___ (Wks) DK (ii) Head Circumference: ___ (cm) ___ (%ile) DK(iii) Birth Weight: ___ (kg) ___ (%ile) DK (iv) Birth Length: _____ (cm) ___ (%ile) DK22. Has the child had unexplained deficit in height or weight ($\leq 10^{\text{th}}$ percentile) at any time after birth? Yes No DK*If Yes, please specify:* Age ___ (years) ___ (months) Weight: ___ (kg) ___ (%ile) DK Height: ___ (kg) ___ (%ile) DK23. Which growth charts were used? CDC Growth Charts WHO Child Growth Standards None DK Other: _____**DIAGNOSTIC CRITERIA – FASD facial features**

24. Were any of the following characteristic FASD facial features identified?

(i) short palpebral fissures (2 SD or more below the mean) Yes No DK not assessed(ii) smooth philtrum (philtrum rank 4 or 5 on Lip-Philtrum Guide UW guidelines) Yes No DK not assessed(iii) thin upper lip (lip rank 4 or 5 on Lip-Philtrum Guide UW guidelines) Yes No DK not assessed25. How were the characteristic FASD facial features assessed (*tick all that apply*)? visual examination for facial phenotype (gestalt method) direct measurement palpebral fissure (ruler) ranking lip-philtrum guide facial photographic analysis not assessed26. Which University of Washington Lip-Philtrum Guide was used? Caucasian African American None

26a. Which palpebral fissure normative values used? _____

DIAGNOSTIC CRITERIA27. Was the child's head circumference $\leq 3^{\text{rd}}$ percentile at any time? i) No DK Yes ii) Age when first noted? _____28. Was CNS imaging performed? No Yes; *If yes, which tests* (eg. CT, MRI, PET) _____29. Was a clinically significant structural CNS abnormality detected? No Yes (*specify*): _____30. If child is < 6 years of age was there global developmental delay? Yes No DK30a. If yes, what age was this diagnosed? _____ (years) _____ (months) DK

31. Was there evidence of clinically significant neurological CNS abnormality otherwise unexplained? No Yes DK

If yes: seizure disorder cerebral palsy visual impairment sensorineural hearing loss other (specify): _____

32. Was CNS function assessed? Yes (Complete table below) No (please go to Q33)

Which domains were assessed (please tick all that apply)	Severe Impairment Yes/No/DK	How were impairments assessed? (please tick all that apply)			
		Caregiver report	Clinical evaluation /observation	Standardised, validated or psychometric testing	Specify other test used
<input type="checkbox"/> Motor skills		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Cognition		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Language		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Academic achievement		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Memory		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Attention		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Executive functioning, including impulse control and hyperactivity		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Affect regulation		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Adaptive behaviour, social skills or social communication		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

33. Has the child been diagnosed with ADHD? Yes No DK

34. Does the child have a hearing impairment? No DK Not tested Yes (specify): _____

35. Does the child have a vision impairment? No DK Not tested Yes (specify): _____

DIAGNOSTIC CRITERIA – prenatal alcohol exposure and exposure to other substances

36. Was prenatal alcohol exposure: confirmed present unknown (please go to Q39) confirmed absent

37. Was a standard tool used to assess prenatal alcohol exposure: No Yes; specify which tool (e.g. AUDIT-C): _____

37a. If the AUDIT-C was used, what was the score? _____

38. What was the main source of information about prenatal alcohol exposure? biological mother direct witness

official records (e.g. medical, legal) Other (specify): _____

39. At any time during pregnancy, was alcohol consumption reported at the following levels:

(i) 7 or more standard drinks per week: Yes No DK (ii) 5 or more standard drinks on any occasion: Yes No DK

40. Does the biological mother have a history of: (i) alcohol use disorder (including dependency): Yes No DK

(ii) alcohol-related health problems/injury: Yes No DK

41. Was there prenatal exposure to other substances? (i) Cigarettes: Yes No DK (ii) Marijuana: Yes No DK

(iii) Heroin: Yes No DK (iv) Amphetamines: Yes No DK (v) Cocaine: Yes No DK

(vi) Phenytoin or Valproate: Yes (specify): _____ No DK (vii) Other(specify): _____

OTHER CONDITIONS

42. Does the child have any other congenital anomalies? No DK Yes (specify): _____

43. Does the child have any behavioural/psychiatric conditions?

(i) Conduct disorder: Yes No DK (ii) Anxiety: Yes No DK (iii) Oppositional defiant disorder Yes No DK

(iv) Intermittent Explosive Disorder: yes no DK (v) Depression: Yes No DK (vi) Sleeping disorder: Yes No DK

(vii) Other (specify): _____

44. Does the child have any of the following dysmorphisms?

(i) clinodactyly Yes No DK (ii) camptodactyly Yes No DK

(iii) 'railroad-track' ear (helix crus horizontal) Yes No DK (iv) epicanthic folds Yes No DK

(v) 'hockey stick' palmar creases Yes No DK (vi) Other(specify): _____

45. Has the child had: Chromosomal microarray analysis; No DK Yes; Results: _____

Karyotype testing: No DK Yes; Results: _____

46. Have the following conditions been excluded: (i) fragile X syndrome Yes No DK (ii) fetal anticonvulsant syndromes (Dilantin/Valproate)

Yes No DK (iii) chromosome microdeletions syndromes (e.g. Williams syndrome) Yes No DK

MANAGEMENT

47. Which services are currently being accessed by this child?

general or developmental paediatrics occupational therapy psychology speech pathology

physiotherapy early childhood intervention educational support social work

child protection services Other (specify): _____

48. Are these services adequate to manage this child's needs? Yes DK No

If No, (specify): _____

49. Has information on this child's FASD diagnosis been provided to any third parties (e.g. other health professionals, teacher, lawyer, community services)? No DK Yes (specify): _____

50. Has the family been told about the National Organisation for Fetal Alcohol Spectrum Disorders (NOFASD)? Yes No DK

Evaluation Questions regarding the Australian Guide to the Diagnosis of FASD and FASD Education Modules

Please answer all questions and click on SUBMIT when completed.

1. Are you aware of the Australian Guide to the Diagnosis of FASD? Yes No
If yes, please answer the questions below, If No go to Q 6
2. Did you read the Guide? Yes No
3. Have you used the Guide in your clinical practice? Yes No
4. If you have read or have used the Guide please indicate your level of agreement with the following statements by placing an **X** under the most appropriate option on the scale Strongly Agree – Strongly Disagree:

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Suggestions for improvement?
4a. I found the Guide useful						
4b. The content of the Guide was easy to understand						

5. How did you hear about the Australian Guide to the Diagnosis of FASD?

- APSU website
- APSU newsletter or mail-out
- Telethon Kids Institute Website
- A colleague
- Other, *Please Specify:* _____

FASD Education Modules

6. Are you aware of the FASD educational modules that accompany the Australian Guide to the Diagnosis of FASD? Yes No

If yes, please answer the questions below; *If No* there are no more questions

		I found this module useful (place an x under the most appropriate option below for each module)					Suggestions for improvement?
	Did you complete this module?	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	
Module 1: What is Fetal Alcohol Spectrum Disorder?	<input type="checkbox"/> Yes <input type="checkbox"/> No						
Module 2: Alcohol use in pregnancy	<input type="checkbox"/> Yes <input type="checkbox"/> No						
Module 3: Conducting a diagnostic assessment (includes 3 sub modules)	<input type="checkbox"/> Yes <input type="checkbox"/> No						
Module 4: Referral and screening guidelines for FASD	<input type="checkbox"/> Yes <input type="checkbox"/> No						
Module 5: Support and intervention after diagnosis	<input type="checkbox"/> Yes <input type="checkbox"/> No						

**Thank you for taking the time to complete this survey.
Your answers are important and will inform the future development of FASD Guidelines and educational modules.**