FETAL ALCOHOL SPECTRUM DISORDER (FASD)

Australian Paediatric Surveillance Unit

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

APSU Office Use Only	
Study ID #:	
Month/Year Report:	

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

Version 5: 16-09-2019

REPORTING CLINICIAN'S DETAILS

1. APSU Dr Code/Name: __ __ __ __ /_____ **2**. Date form completed: __ __ /__ __ /__ __ __ __

PATIENT'S 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. Did you make the FASD diagnosis?
☐ Yes ***(please go to Q10)***
☐ 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 the child, we will contact you for further information.
Physician's name: _____
Clinic/Hospital: _____

PATIENT'S FAMILY BACKGROUND

10. Ethnic background for both birth mother and father *(tick all that apply)*:
☐ Caucasian ☐ Asian ☐ Aboriginal ☐ Torres Strait Islander
☐ African ☐ Pacific Islander ☐ DK
☐ Other *(specify)*: _____

11. Who is the child's primary carer?
☐ Biological parent/s ☐ Grandparent/s ☐ Foster carer/s
☐ Adoptive parent/s ☐ Other *(specify)*: _____

12. Have any of the child's siblings been diagnosed with FASD?
☐ Yes ☐ No ☐ NA – no siblings ☐ DK

12a. If yes, *specify* who: _____

13. Have either of the child's birth parents been diagnosed with FASD?
☐ Yes ☐ No ☐ DK

13a. If yes, *specify* who: _____

DIAGNOSTIC CRITERIA – prenatal alcohol exposure

14. Was prenatal alcohol exposure:
☐ Confirmed present ☐ Unknown

15. What was the source of information about prenatal alcohol exposure? *(tick all that apply)*
☐ Birth mother ☐ Direct witness
☐ Offical records (e.g. medical, legal, child protection)
☐ Other *(specify)*: _____

16. In your judgement, what is the reliability of the information about alcohol exposure?
☐ High ☐ Low ☐ Unknown

17. Please complete the following AUDIT-C questions:

(a) How often did the birth mother have a drink containing alcohol during this pregnancy?
☐ Unknown
☐ Never$_0$ ***(please go to Q18)***
☐ Monthly or less$_1$
☐ 2-4 times a month$_2$
☐ 2-3 times a week$_3$
☐ 4 or more times a week$_4$

(b) How many standard drinks did the birth mother have on a typical day when she was drinking during this pregnancy?
☐ Unknown
☐ 1 or 2$_0$
☐ 3 or 4$_1$
☐ 5 or 6$_2$
☐ 7 to 9$_3$
☐ 10 or more$_4$

(c) How often did the birth mother have 5 or more standard drinks on one occasion during this pregnancy?
☐ Unknown
☐ Never$_0$
☐ Less than monthly$_1$
☐ Monthly$_2$
☐ Weekly$_3$
☐ Daily or almost daily$_4$

18. What was the total AUDIT-C score?
(calculate by adding the corresponding subscripts in a, b and c) _____

18a. What was the AUDIT-C category of risk?
(according to the total score range in subscripts)
☐ No exposure$_0$
☐ Confirmed exposure$_{1\text{-}4}$
☐ Confirmed high-risk exposure$_{5+}$

DIAGNOSTIC CRITERIA – neurodevelopmental domains

19. Was there severe impairment in 3 or more neurodevelopmental domains? ☐ Yes ☐ No ☐ DK

20. Which domains were assessed?

Domains *(tick all that apply)*	**Degree of impairment?**		
☐ Brain structure/neurology	☐ None	☐ Severe	
☐ Motor skills	☐ None	☐ Some	☐ Severe
☐ Cognition	☐ None	☐ Some	☐ Severe
☐ Language	☐ None	☐ Some	☐ Severe
☐ Academic achievement	☐ None	☐ Some	☐ Severe
☐ Memory	☐ None	☐ Some	☐ Severe
☐ Attention	☐ None	☐ Some	☐ Severe
☐ Executive function, including impulse control and hyperactivity	☐ None	☐ Some	☐ Severe
☐ Affect regulation	☐ None	☐ Some	☐ Severe
☐ Adaptive behaviour, social skills or social communication	☐ None	☐ Some	☐ Severe

Brain structure/neurology domain

21. Was the child's head circumference ≤ 3rd percentile at any time? ☐ Yes ☐ No ☐ DK

21a. If yes, *specify* age when recorded: _____

22. Which of the following tests have been performed? ☐ None ☐ Brain MRI ☐ Brain CT ☐ EEG ☐ DK

23. Was a structural brain or EEG abnormality detected? ☐ Yes ☐ No ☐ DK

23a. If yes, *specify* abnormality: _____

24. Was there evidence of a neurological condition otherwise unexplained? ☐ Yes ☐ No ☐ DK

24a. If yes, *specify* condition: ☐ Seizure disorder ☐ Cerebral palsy ☐ Hearing impairment ☐ Visual impairment ☐ Other *(specify)*: _____

25. If the child is < 6 years of age, was there global developmental delay? ☐ Yes ☐ No ☐ DK

25a. If yes, *specify* age of this diagnosis: _____ years _____ months ☐ DK

DIAGNOSTIC CRITERIA – sentinel facial features

26. What was the total number of sentinel FASD facial features? ☐ None ☐ 1 ☐ 2 ☐ 3 ☐ DK

27. Which sentinel facial features were abnormal? *(tick all that apply)*
☐ Short palpebral fissure length *(2 SD or more below the mean)*
☐ Smooth philtrum *(philtrum rank 4 or 5 on Lip-Philtrum Guide)*
☐ Thin upper lip *(lip rank 4 or 5 on Lip-Philtrum Guide)*

28. How were the sentinel facial features assessed? *(tick all that apply)*
☐ Direct measurment ☐ Lip-Philtrum Guide (Caucasian)
☐ 2D photographic analysis ☐ Lip-Philtrum Guide (African American)
☐ 3D photographic analysis ☐ Not assessed ***(please go to Q32)***

29. What was the palpebral fissure length Z-score? _____ ☐ DK

29a. Which palpebral fissure charts were used? ☐ Stromland ☐ Clarren ☐ Iosub ☐ Hall
☐ Other *(specify)*: _____

30. What was the philtrum rank (1-5)? _____ ☐ DK

31. What was the lip rank (1-5)? _____ ☐ DK

FASD DIAGNOSIS

32. What is the child's FASD diagnosis?
☐ FASD with 3 sentinel facial features
☐ FASD with *less than* 3 sentinel facial features
☐ At risk of FASD ☐ Incomplete assessment
☐ Other *(specify)*: _____

PRENATAL FACTORS

33. Was there prenatal exposure to the following substances?

(a) Nicotine ☐ Yes ☐ No ☐ DK

(b) Cannabis ☐ Yes ☐ No ☐ DK
(c) Opioids ☐ Yes ☐ No ☐ DK
(d) Amphetamines ☐ Yes ☐ No ☐ DK
(e) Cocaine ☐ Yes ☐ No ☐ DK
(f) Phenytoin or valproate ☐ Yes ☐ No ☐ DK
(g) Prescription medication: ☐ Yes ☐ No ☐ DK
If yes, *specify* medication/s: _____
(h) Other *(specify)*: _____

34. Was there prenatal exposure to pregnancy complications (e.g. infection, diabetes, hypertension)? ☐ Yes ☐ No ☐ DK

34a. If yes, *specify* exposure: _____

35. Was there prenatal growth impairment with:
(a) weight ≤ 3rd percentile for gestation ☐ Yes ☐ No ☐ DK
(b) length ≤ 3rd percentile for gestation ☐ Yes ☐ No ☐ DK

POSTNATAL FACTORS

36. Was there postnatal exposure to the following?
(a) Early-life trauma ☐ Yes ☐ No ☐ DK
(b) CNS infections (e.g. meningitis) ☐ Yes ☐ No ☐ DK
(c) Significant head injury ☐ Yes ☐ No ☐ DK
(d) Other *(specify)*: _____

37. Was there postnatal growth impairment with:
(a) weight ≤ 3rd percentile for gestation ☐ Yes ☐ No ☐ DK
(b) length/height ≤ 3rd percentile for gestation ☐ Yes ☐ No ☐ DK

38. Has the child ever been in out-of-home care? ☐ Yes ☐ No ☐ DK

38a. If yes, *specify* time the child has been in out-of-home care: _____ months ☐ DK

CONCURRENT DIAGNOSES

39. Does the child have any of the following conditions?
(a) Attention-deficit hyperactivity disorder ☐ Yes ☐ No ☐ DK Type/Details: _____
(b) Trauma/stress-related/attachment disorders ☐ Yes ☐ No ☐ DK Type/Details: _____
(c) Autism spectrum disorder ☐ Yes ☐ No ☐ DK Type/Details: _____
(d) Intellectual disabilites ☐ Yes ☐ No ☐ DK Type/Details: _____
(e) Communication disorders ☐ Yes ☐ No ☐ DK Type/Details: _____
(f) Specific learning disorders ☐ Yes ☐ No ☐ DK Type/Details: _____
(g) Motor disorders ☐ Yes ☐ No ☐ DK Type/Details: _____
(h) Anxiety disorders ☐ Yes ☐ No ☐ DK Type/Details: _____
(i) Mood disorders ☐ Yes ☐ No ☐ DK Type/Details: _____
(j) Disruptive/impulse control/conduct disorders ☐ Yes ☐ No ☐ DK Type/Details: _____
(k) Sleep disorders ☐ Yes ☐ No ☐ DK Type/Details: _____
(l) Other *(specify)*: _____

40. Does the child have any *major* congenital anomalies (e.g. heart, lung, kidney)? ☐ Yes ☐ No ☐ DK

40a. If yes, *specify* anomalies: _____

41. Does the child have any *minor* congenital anomalies (e.g. clinodactyly, epicanthic folds, midface hypoplasia)? ☐ Yes ☐ No ☐ DK

41a. If yes, *specify* anomalies: _____

OTHER INVESTIGATIONS

42. Has the child had a chromosomal microarray analysis? ☐ Yes ☐ No ☐ DK

42a. If yes, *specify* results: ☐ Normal ☐ DK
☐ CNV of known significance ☐ CNV of unknown significance
Deletion details: _____ Duplication details: _____

43. Has the child had Fragile X testing? ☐ Yes ☐ No ☐ DK

43a. If yes, *specify* results: ☐ Normal ☐ Abnormal ☐ DK
Details: _____

44. Has the child had whole exome sequencing? ☐ Yes ☐ No ☐ DK

44a. If yes, *specify* results: _____

45. Has the child had any other relevant abnormal results (e.g. ferritin, CK, urine metabolic screen, lead)? ☐ Yes ☐ No ☐ DK

45a. If yes, *specify* tests and results: _____

MANAGEMENT

46. Which services have been or are currently being accessed by the child?

☐ General or developmental paediatrics
☐ Occupational therapy
☐ Psychology
☐ Speech pathology
☐ Physiotherapy
☐ Social work
☐ Early childhood intervention
☐ Educational support
☐ Child protection services
☐ NGOs
☐ Other *(specify)*: _____

47. Does the child receive NDIS funding? ☐ Yes ☐ No ☐ DK

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

Thank you for your help with this research project.

Please return this questionnaire to the APSU via email to SCHN-APSU@health.nsw.gov.au or fax to 02 9845 3082

or mail to Australian Paediatric Surveillance Unit, Kids Research, Locked Bag 4001, Westmead NSW 2145 – even if you don't complete all items

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This study has been approved by a Human Research Ethics Committee properly constituted under NHMRC guidelines.