

SEPTO-OPTIC DYSPLASIA Australian Paediatric Surveillance Unit Please contact the APSU (02) 9845 3005 or SCHN-APSU@health.nsw.gov.au if you have any questions about this form	<i>APSU Office Use Only</i>	
	Study ID #:	
<i>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.</i>		Version 1.0_28.03.2023

1. REPORTING CLINICIAN'S DETAILS:

a) APSU Dr Code/Name: _____ / _____
 b) Date case report form completed: ____ / ____ / ____ (dd/mm/yyyy)

2. PATIENT DETAILS:

a) First 2 letters of first name: ____ ____
 b) First 2 letters of surname: ____ ____
 c) Date of Birth: ____ / ____ / ____ (dd/mm/yyyy)
 d) Sex: Male Female Indeterminate
 e) Postcode of family: _____
 f) Child's ethnicity: Aboriginal Torres-Strait Islander
 Both Aboriginal and Torrest Strait Islander
 Pacific Islander Caucasian
 East Asian South Asian (Indian Subcontinent)
 African Middle Eastern
 Don't Know Other (please specify): _____
 g) Child's country of birth: Australia Other (please specify): _____ DK
 h) Main language spoken at home: _____ DK

If this patient is primarily cared for by another physician who you believe will report the case, please complete the details above this line and return to the APSU. 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 information requested in the remainder of the form.
 The primary clinician caring for this child/young person is: **Name:** _____ **Hospital:** _____

3. SEPTO-OPTIC DYSPLASIA DIAGNOSIS

a) Date of diagnosis: ____ / ____ / ____ (dd/mm/yyyy)
 b) Optic nerve hypoplasia: Yes – Unilateral Yes - Bilateral No DK
 c) Other eye features: Microphthalmia Anophthalmia No DK
 d) Midline defects: Corpus callosum – partial agenesis Corpus callosum – agenesis
 Septum pellucidum – partial agenesis Septum pellucidum – agenesis
 None DK
 e) Anterior pituitary imaging: Normal Abnormal: (please specify): _____
 f) Posterior pituitary imaging: Normal Abnormal: (please specify): _____
 g) Pituitary stalk imaging: Normal Abnormal: (please specify): _____
 h) Was any genetic testing performed Yes No DK
If yes, please list test and results: _____

4. HORMONE DEFICIENCY

	Yes	No	Don't know	Date of diagnosis (dd/mm/yyyy)
a) Growth hormone deficiency	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
b) Central hypothyroidism	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
c) Prolactin deficiency	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
d) Prolactin excess	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
e) Hypogonadotrophic hypogonadism	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
f) Central diabetes insipidus	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
g) Central adrenal insufficiency	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
h) Admissions for adrenal crisis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Please specify number of admissions:

5. FIRST TRIMESTER EXPOSURES/EVENTS

a) Was there first trimester exposure to (please tick all that apply):

	Yes – ceased on discovery of pregnancy	Yes – continued	No	Don't Know
i. Alcohol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ii. Tobacco	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
iii. Drugs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If drugs were consumed, please specify which drugs were used: _____ DK

b) First trimester folate supplementation: Yes – commenced after discovery of pregnancy
 Yes – continued
 No
 DK

c) Other medication used in first trimester: Yes No DK

If other medication was used, please specify below:

Medication	Dose	Frequency

d) First trimester bleeding: Yes No DK

e) Parent declined to answer or unavailable to respond to above questions: Yes No

6. GROWTH

a) Height (current): _____ (cm)

b) Weight (current): _____ (kg)

c) Height at detection of first hormone deficiency: _____ (cm) Unknown

d) Weight at detection of first hormone deficiency: _____ (kg) Unknown

7. CONFIRMED ASSOCIATIONS

a) Vision impairment (parent defined): Yes – mild - moderate Yes – severe No

b) Developmental delay: Yes No DK

c) Autism: Yes No DK

d) Seizures: Yes No DK

e) Behavioural issues: Yes No DK (If yes, specify): _____

f) Family history of hypopituitarism: Yes No DK (If yes, specify): _____

8. DISEASE BURDEN

a) What allied health support is received: Physiotherapy Speech Pathology
 Occupational therapy Dietetics
 Other (please specify): _____

b) Number of different medications: None 1 2 3-4 5-6 >6

c) Medical appointments/month: <1 1 2 3-4 5-6 >6

d) Distance to treating hospital: <5km 5-10km 10-20km
 20-50km 50-100km >100km

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.

The APSU is affiliated with the Royal Australasian College of Physicians (Paediatrics and Child Health Division) and Faculty of Medicine and Health, The University of Sydney.

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