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	*APSU Office Use Only*	
	Study ID #:	
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 1.1_04.08.2023*	

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 ☐ Anopthalmia ☐ 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: ____
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4. HORMONE DEFICIENCY

	Yes	**No**	**Don't know**	**Date of diagnosis** (dd/mm/yyyy)
a) Growth hormone deficiency	☐	☐	☐	
b) Central hypothyroidism	☐	☐	☐	
c) Prolactin deficiency	☐	☐	☐	
d) Prolactin excess	☐	☐	☐	
e) Hypogonadotrophic hypogonadism	☐	☐	☐	
f) Central diabetes insipidus	☐	☐	☐	
g) Central adrenal insufficiency	☐	☐	☐	
h) Admissions for adrenal crisis	☐	☐	☐	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	☐	☐	☐	☐
ii. Tobacco	☐	☐	☐	☐
iii. Drugs	☐	☐	☐	☐

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) Best eye measured visual acuity: ☐ ≥ 6/6 ☐ 6/6 - 6/12 ☐ 6/12 – 6/24 ☐ 6/24 – 6/60 ☐ ≤ 6/60 ☐ Don't know

(Age at measurement): ______________

b) Visual acuity assessment: ☐ Snellen ☐ Symbols ☐ Teller acuity cards ☐ Don't know

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

d) Developmental delay: ☐ Yes ☐ No ☐ DK

e) Autism: ☐ Yes ☐ No ☐ DK

f) Seizures: ☐ Yes ☐ No ☐ DK

g) Behavioural issues: ☐ Yes ☐ No ☐ DK *(**If yes**, specify):* ______________

h) 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

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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.