Juvenile onset Recurrent Respiratory Papillomatosis (JoRRP)

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

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; NK = Not Known

APSU Office Use Only	
Study ID #:	
Version	

REPORTING CLINICIAN'S DETAILS

1. APSU Dr Code/Name: ☐☐☐☐/_____

2. Month/Year of Report: __ __ / __ __

3. Date questionnaire completed: __ __ / __ __ / __ __ __ __ *(dd/mm/yyyy)*

PATIENT DETAILS

4. First 2 letters of first name: ☐☐

5. First 2 letters of surname: ☐☐

6. Date of Birth: __ __ / __ __ / __ __ __ __

7. Sex: ☐ Male ☐ Female

8. Postcode of family: ☐☐☐☐

9. Date of diagnosis: ☐☐ month / ☐☐ year

10. Child's Country of Birth: ☐ Australia ☐ Other *(please specify):* _____

11. Child's Ethnicity:
☐ Aboriginal ☐ Torres Strait Islander ☐ Caucasian
☐ Pacific Islander ☐ Maori ☐ Asian
☐ Middle Eastern ☐ African
☐ Other *(please specify):* _____

12. Biological mother's country of birth: _____ ☐ DK

Ethnicity: _____ ☐ DK

Age: _____ yrs ☐ DK

13. Biological father's country of birth: _____ ☐ DK

Ethnicity: _____ ☐ DK

Age: _____ yrs ☐ DK

If this patient is primarily cared for by another physician whom you believe will report the case, please write the other physician's name below, complete the questionnaire details above this line and return. If no other report is received for this child we will contact you for information requested in the remainder of the questionnaire.
Please keep the patient's name and other details on your APSU file.

The primary clinician caring for this child is: **Name:** **Hospital:**

PATIENT Section 1: Diagnosis

14. Age when child first developed symptoms of JoRRP:
Years: _____ and **months:** _____

15. Which of the following were the initial symptoms or signs of JoRRP?
☐ Stridor ☐ Hoarseness ☐ Dyspnoea
☐ Chronic Cough ☐ Pneumonia ☐ Dysphagia
☐ Failure to thrive ☐ Acute respiratory distress
If other, please specify: _____

16. Age of child when diagnosis of JoRRP was made by direct visualisation:
Years: _____ and **months:** _____

17. What additional procedures were done at initial microlaryngoscopy and biopsy?
Bronchoscopy ☐ YES ☐ NO ☐ DK
Debulking ☐ YES ☐ NO ☐ DK

If YES, please indicate which method(s) were used?	☐ Microdebrider ☐ Cold steel resection ☐ CO_2 laser ☐ Other: _____

18. Please attach a de-identified copy of the diagnostic histology report for this child or provide result:

19. Is the child immunocompromised?	☐ YES ☐ NO ☐ DK
If YES, please indicate whether this is a condition of:	☐ Primary immunocompromise ☐ Secondary immunocompromise ***If known*** please report underlying condition: _____

Section 2: HPV vaccination

20. Has the child received the HPV vaccine?	☐ YES ☐ NO ☐ DK
If YES, which Vaccine?	☐ Gardasil® ☐ Cervarix® ☐ Gardasil 9®
Number of doses given:	_____
Please provide dates for each dose:	Date of 1st Dose: _____ Date of 2nd Dose: _____ Date of 3rd Dose: _____ *(if applicable)*

*If you do not know the vaccination status of the child or mother, please contact **The Australian Immunisation Register on 1800 653 809** or access your patient's history through the AIR online system.*
The register can provide you and your patient with details of any HPV vaccine doses registered for that patient, as long as you have consent from the patient (either written or by putting the patient on the phone) or if you were the immunisation provider

21. Has HPV genotyping of papillomata been conducted?	☐ YES ☐ NO ☐ DK Comments: _____
If YES and results available, please tick which of the following HPV genotypes have been identified:	☐ HPV6 ☐ HPV11 ☐ Other genotype
Please provide genotypes:	_____

HPV genotyping of specimens from patients in this study will be provided at no cost to patient or doctor.
Specimens must be collected in a special container, transported on ice and transported overnight.
Please see attached protocol sheet for detailed information about this process.

MATERNAL AND BIRTH HISTORY

Section 1: Birth details

22. Gestation of child:	_____		
23. Birth order of child:	☐ First	☐ Second	☐ Third
	☐ Fourth	☐ Fifth	☐ Other: _____
24. Mode of delivery of child:	☐ Vaginal	☐ Caesarean section	

25. Length of labour: ☐ Less than 2 hours ☐ 2 - 6 hours ☐ 7 - 12 hours ☐ 13 - 24 hours ☐ Longer than 24 hours

26. Was there premature rupture of membranes (>24 hours prior birth) for this child's birth? ☐ YES ☐ NO ☐ DK

If YES, number of hours ruptured before birth: _____

Section 2: Mother's details

27. Gravida: _____

Para: _____

Date of Birth: ☐☐ / ☐☐ / ☐☐

OR Age at birth of affected child: _____

28. History of maternal genital condylomata (warts)? ☐ YES ☐ NO ☐ DK

29. Has the mother received HPV vaccination? ☐ YES ☐ NO ☐ DK

If YES, which Vaccine? ☐ Gardasil® ☐ Cervarix® ☐ Gardasil 9®

Number of doses given: _____

Please provide dates for each dose:

Date of 1st Dose: _____

Date of 2nd Dose: _____

Date of 3rd Dose: _____

If you do not have information on maternal vaccination you may contact The Australian Immunisation Register as described above.

FAMILY HISTORY

30. Does the child have siblings? ☐ YES ☐ NO ☐ DK

If YES, does any sibling have JoRRP? ☐ YES ☐ NO ☐ DK

If YES, please give details: _____

OUTCOME

31. Have the symptoms resolved? ☐ YES ☐ NO ☐ DK

32. Did the child require tracheostomy? ☐ 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 post to Australian Paediatric Surveillance Unit, Kids Research, Locked Bag 4001, Westmead NSW 2145 - even if you don't complete all items. If you have any questions about this form, please contact the APSU on (02) 9845 3005 or Dr Daniel Novakovic on 0418 500 067

APSU is affiliated with the Royal Australasian College of Physicians (Paediatrics and Child Health Division) and Sydney Medical School, The University of Sydney.
The APSU is funded by the Australian Government Department of Health.
This study has been approved by a Human Research Ethics Committee properly constituted under NHMRC guidelines.