Juvenile onset Recurrent Respiratory Papillomatosis (JoRRP) Questionnaire
Australian Paediatric Surveillance Unit

Please call the APSU on (02) 9845 3005 or Dr Daniel Novakovic on 0418500067
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

REPORTING CLINICIAN

1. APSU Dr Code/Name ☐☐☐☐ …….…….. 2. Month/Year of Report …..… /……
3. Date questionnaire completed ☐☐ / ☐☐ / ☐☐

PATIENT

4. First 2 letters of first name ☐☐ 5. First 2 letters of surname ☐☐
6. Date of Birth ☐☐ / ☐☐ / ☐☐ 7. Sex ☐ M ☐ F
8. Postcode ☐☐☐☐ 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 ☐ $C0_2$ 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®
    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 know the vaccination status of child or mother, please contact The National HPV Vaccination Program Register on ***1800 478 734 (1800 HPV REG) or email*** *provider_support@hpvregister.org.au 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 _____

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®

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 National HPV Vaccination Program Register as described above.

FAMILY HISTORY

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

If YES, does any sibling have JoRRP or other HPV-related illness? ☐ 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 PARTICIPATING IN THIS STUDY

Please return this questionnaire to the APSU in the reply-paid envelope or Fax to 02 98453082. If you have any questions about this form, please contact the APSU on (02) 9845 3005 or Dr Daniel Novakovic on 0418500067.

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