Childhood Interstitial Lung Disease (ChILD)
Australian Paediatric Surveillance Unit
Please contact the APSU (02) 9845 3005; apsu@chw.edu.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

REPORTING CLINICIAN'S DETAILS **1**. APSU Dr Code/Name: ☐☐☐☐/_____ **2.** Month/Year of Report: ☐☐/☐☐

3. Date questionnaire completed: ☐☐/☐☐/☐☐☐☐

PATIENT DETAILS **4**. First 2 letters of first name: ☐☐ **5**. First 2 letters of surname: ☐☐ **6**. Date of Birth: ☐☐/☐☐/☐☐

7. Sex: ☐ M ☐ F **8.** Child's ethnicity: ☐Aboriginal and/or Torres Strait Islander ☐Caucasian ☐Asian ☐African ☐ Other *(specify):*_____

9. Postcode of family: ☐☐☐☐ **9a.** Length of time at this postcode: ☐ <1 year ☐ >1 year ☐ DK

9b. If <1 year, previous postcode *(if known)*: ☐☐☐☐

If this patient is primarily cared for by another physician who you believe will report the case, please complete the questionnaire details above this line and return to 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 questionnaire.

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

DIAGNOSIS **10.** A specific diagnosis has been made: ☐ Yes ☐ No (unspecified/idiopathic ChILD)

If Yes, diagnosis: _____ Date diagnosis made: ☐☐/☐☐/☐☐

INVESTIGATIONS CONDUCTED TO REACH DIAGNOSIS

11. Investigations	**Tick if done**	**Normal**	**If abnormal, specify anomalies**
a) Chest X-ray			
b) Diagnostic lung CT			
c) Pulmonary Lung Function			
d) Arterial gases in room air			
e) Sleep Study			
f) Echocardiogram			
g) Bronchoalveolar lavage			
h) Respiratory screening (from serum, saliva or nasopharyngeal aspirate)			
i) Immunology			
j) Haematology			
k) Lung biopsy			
l) Gastro-oesophageal reflux investigations			
m) Genetic studies			Which genetic anomalies were identified? ☐ SP-B ☐ SP-C ☐ ABCA3 ☐ TTF-1/Nkx2.1 ☐ other (specify below)

CLINICAL PRESENTATION **12.** Date patient first presented to you: ☐☐/☐☐/☐☐

13. Patient presented via:

☐ referred at birth **or** referral by ☐ GP ☐ paediatrician ☐ other specialist *(specify)*_____

☐ emergency department ☐ direct transfer *(specify hospital transferred from)* _____

☐ other (specify) _____

14. Symptoms/signs at presentation (tick all that apply):

☐ respiratory failure ☐ digital clubbing ☐ cough ☐ cyanosis ☐ wheeze ☐ fever

☐ crackles ☐ failure to thrive ☐ retractions ☐ tachypnoea ☐ gastrooesophageal reflux

☐ exertional dyspnoea ☐ other *(specify)* _____

15. When did symptoms begin: ☐ at birth ☐ < 1 week before presentation ☐ 1-4 weeks before presentation ☐ > 4 weeks before presentation

16a. Weight Percentile *(at presentation)* : _____ **16b.** Height Percentile *(at presentation)*: _____

BIRTH HISTORY

17. Gestation: ☐Term ☐ Premature _____ *(weeks of gestation)* ☐ DK

18. Delivery: ☐ Spontaneous ☐ Labour induced ☐ Assisted (instrument) ☐ Caesarean ☐ DK

19. Birth weight: _____ *(grams)* ☐ DK

20. Did respiratory symptoms at birth necessitate hospitalisation? ☐ Yes ☐ No ☐ DK (***If No or DK, please go to Q21***)

20a. Was oxygen required? ☐ Yes ☐ No ☐ DK **20b.** Was mechanical ventilation required? ☐ Yes ☐ No ☐ DK

20c. If Yes, date of discharge after birth: ☐☐/☐☐/☐☐ ☐ Still in hospital since birth ☐ DK

21. Has this child ever had any of the following?

☐ lower respiratory tract infection with identified pathogen (specify pathogen)_____

☐ pneumonia ☐ asthma ☐ bronchitis

☐ other respiratory disease/condition *(specify):* _____

22. Vaccinations up to date: ☐ Yes ☐ No ☐ DK

FAMILY HISTORY

23. Has any other family members ever been diagnosed with ChILD: ☐ Yes ☐ No ☐ DK

If Yes, specify who and diagnosis: _____

24. Parental consanguinity: ☐ Yes ☐ No ☐ DK

25a. Did the mother smoke during this child's pregnancy? ☐ Y ☐ N ☐ DK **25b.** If yes, mother still smoking? ☐ Y ☐ N ☐ DK

26a. Did the father smoke during this child's pregnancy? ☐ Y ☐ N ☐ DK **25b.** If yes, father still smoking? ☐ Y ☐ N ☐ DK

MANAGMENT

27. Has this patient been admitted to hospital for their ChILD disorder? ☐ Yes ☐ No

If yes, how many times has the patient been admitted _____ ☐ DK

has the patient ever required oxygen therapy? ☐ Yes ☐ No *(If yes specify)*_____

has the patient ever required mechanical ventilation? ☐ Yes ☐ No *(If yes specify)*_____

is the patient on home oxygen therapy? ☐ Yes ☐ No *(If yes specify)*_____

28. Has this child been prescribed any specific medications to treat their ChILD disorder (e.g. hydroxyquine, inhaled steroids etc.)?

☐ Yes ☐ No **If yes,** list drugs prescribed:_____

LATEST PATIENT REVIEW

29. Is the patient currently alive? ☐ Yes ☐ No **If No**, date patient died: ☐☐/☐☐/☐☐

30. What was the date of last review of this patient? ☐☐/☐☐/☐☐

31. Since initial presentation respiratory symptoms/signs have: ☐ improved ☐ stayed the same ☐ worsened

REGISTRY

32. Has this patient been enrolled into into a a registry either in Australia or overseas? ☐ Yes ☐ No ☐ DK

If yes, which one(s)? _____

Thank you for your help with this research project. Please return this questionnaire to the APSU in the reply-paid envelope or fax to 02 9845 3082. Australian Paediatric Surveillance Unit, Kid's Research Institute, Locked Bag 4001, Westmead NSW 2145. The APSU is affiliated with the Royal Australasian College of Physicians (Paediatrics and Child Health Division) and Sydney Medical School, The University of Sydney. APSU is funded by the Australian Government Department of Health and Ageing. This study has been approved by a Human Research Ethics Committee properly constituted under NHMRC guidelines.