

THE CHARGE ASSOCIATION - Questionnaire
Australian Paediatric Surveillance Unit

Please keep a record of the child's unit number in your APSU folder. Please ring Dr. George Williams on (02) 9543 0222 or 0417 241064 if you have any problems with the form. Thank you for your time.

PAEDIATRICIAN

1. APSU Dr Code/Name /..... 2. Month/Year of Report /

PATIENT

3. First 2 letters of first name 4. First 2 letters of surname
 5. Date of Birth: / / 6. Sex M F
 7. Postal code 8. Date of Diagnosis / /

If this patient is primarily cared for by another physician who you believe will report the case there is no need to complete the remainder of this questionnaire. Please keep the patient's name for your records. If no other report is received for this child we will contact you for further information.

MATERNAL HISTORY AND OBSTETRIC AND NEONATAL HISTORY

9. Number of pregnancies stillbirths live births postnatal deaths
 miscarriages T.O.P Don't know

Please indicate whether these occurred before **(B)** or after **(A)** the affected child was born.

10. Child's position in family _____ of _____
 11. Did mother report decreased fetal movements during pregnancy? Yes No Don't Know
 If yes, when.....
 12. Amniotic fluid volume Normal Polyhydramnios Oligohydramnios Don't know
 13. Multiple pregnancy No Twin Triplet or more
 14. Presentation Cephalic Breech Don't know
 15. Delivery LSCS Forceps/Vacuum Normal Vaginal Don't know
 16. Resuscitation at birth None Oxygen Bag & mask Intubation
 17. Apgar score 1 minute 5 minutes Don't know
 18. Birth weight grams Gestational age weeks
 19. Birth length cms Birth head circumference cms

CLINICAL EXAMINATION FINDINGS

Major Criteria	Y	N	DK	If yes, state: side (R or L), type, severity and method of detection (eg CT scan)
20. Coloboma – iris, retina, choroid, disc				
21. Choanal atresia or stenosis				
22. Ear anomalies external ear (loop or cup shaped), chronic serous otitis, ossicular or cochlear defects, mixed deafness				
23. Cranial nerve defects – Anosmia, facial palsy, sensorineural deafness, vestibular and/or swallowing problems				
Minor Criteria	Y	N	DK	If yes, state: side (R or L), type, severity and method of detection (eg CT scan)
24. Genital hypoplasia: small penis, labia, undescended testes				
25. Developmental delay- delayed motor milestones, hypotonia, mental retardation				
26. Cardiovascular malformations- All types: especially conotruncal defects (eg. Tetralogy of Fallot); Atrio-ventricular canal defects and aortic arch anomalies				
27. Orofacial clefts- cleft lips or palate				
28. Tracheoesophageal-fistula				
29. Distinctive face - characteristic face				

POSSIBLE ASSOCIATIONS/RISK FACTORS

30. Paternal age at birth of child Years
31. Does the child have a **parent** with CHARGE Mother Father Don't know
If yes, specify abnormalities.....
32. Does the child have a **sibling** with CHARGE Yes No Don't know
If yes, please specify sex, family rank, twin, abnormalities

RECENT GROWTH

33. Weight kilograms date/age at measurement
34. Height cms date/age at measurement
35. Head circumference . cms date/age at measurement

OTHER FEATURES

36. Seizures Yes No Don't know
If yes, specify types and therapy.....
37. Other clinical features/problems not already mentioned, please specify.....

INVESTIGATIONS

38. Chromosome investigations Yes No Don't know
If yes, were they abnormal? Specify.....
39. Other investigations not yet mentioned (eg. CT scan, MRI, Immunology, Renal Ultrasound).....

MORBIDITY

40. Has the child ever been hospitalised Yes No Don't know
If yes, specify frequency and total duration of hospitalisation up to the time of diagnosis
.....
.....

41. Please list any operations or procedure.....

42. Has a developmental agency been involved Yes No Don't know

MORTALITY

43. At the time of reporting is the child alive Yes No
If no, what was date and cause of death / /

44. How useful did you find the information contained in the CHARGE Association handbook
 Not at all useful A bit useful Useful Very useful Extremely useful

**Please return this questionnaire in the addressed reply-paid envelope.
Thank you for your help with this research project.**