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**

<table>
<thead>
<tr>
<th>Major Criteria</th>
<th>Y</th>
<th>N</th>
<th>DK</th>
<th>If yes, state: side (R or L), type, severity and method of detection (eg CT scan)</th>
</tr>
</thead>
<tbody>
<tr>
<td>20. Coloboma – iris, retina, choroid, disc</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. Choanal atresia or stenosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22. Ear anomalies external ear (loop or cup shaped), chronic serous otitis, ossicular or cochlear defects, mixed deafness</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23. Cranial nerve defects – Anosmia, facial palsy, sensorineural deafness, vestibular and/or swallowing problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Minor Criteria</th>
<th>Y</th>
<th>N</th>
<th>DK</th>
<th>If yes, state: side (R or L), type, severity and method of detection (eg CT scan)</th>
</tr>
</thead>
<tbody>
<tr>
<td>24. Genital hypoplasia: small penis, labia, undescended testes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25. Developmental delay: delayed motor milestones, hypotonia, mental retardation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26. Cardiovascular malformations - All types: especially conotruncal defects (eg. Tetralogy of Fallot); Atrio-ventricular canal defects and aortic arch anomalies</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>27. Orofacial clefts- cleft lips or palate</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>28. Tracheoesophageal-fistula</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>29. Distinctive face - characteristic face</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
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.