Survey form B – for patients diagnosed after 6 months age

PAEDIATRICIAN

1. APSU Dr Code/Name: □□□□/…………………………………
2. Report code □□/□□
3. Address:...........................................................................................................................................................
4. Telephone:..................................................5. Fax.......................................................................................................................

PATIENT DETAILS

6. Surname (first two letters only ): □□ 7. First name (first two letters only) : □□
8. Date of birth (day, month, year) : □□/□□/□□ 9. Sex : □ Male □ Female
10. Post code of family : □□□□
11. Ethnic origin of mother : □ Caucasian □ Other (please specify)
12. Ethnic origin of father : □ Caucasian □ Other (please specify)

Features at diagnosis

13. Age at diagnosis □□/□□
14. Features of initial presentation (please indicate which of these were present at initial presentation ,more than 1 may apply):
   □ Genital anomalies / ambiguous genitalia
   □ Virilization without genital ambiguity
   □ Abnormal growth
   □ Asymptomatic , detected during screening of family members
   □ Other (please specify)...........................................................................................................................................

15. Was the child treated for an alternative diagnosis prior to confirmation of CAH □ Yes □ No
   If Yes, please specify ........................................................................................................................................

16. Bone age at presentation □□ Years □□ Months
   Bone age method: □ Greulich and Pyle
                     □ Tanner-Whitehouse
                     □ Other (please specify)...........................................................................................................................

17. Height at presentation □□□□ cm
18. History of CAH in a sibling □ Yes □ No
19. No of affected siblings □□

Laboratory features

20. Biochemical diagnosis in this patient
    □ 21-hydroxylase deficiency
    □ Other adrenal enzyme deficiency (please specify).................................................................................................
Laboratory features (Continued)

*21 – 26. Biochemistry at presentation (if performed)

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<tbody>
<tr>
<td>21.</td>
<td>Plasma renin activity</td>
<td>mmol/L</td>
<td>Lab normal range and units</td>
</tr>
<tr>
<td>22.</td>
<td>ACTH</td>
<td>pmol/L</td>
<td>Lab normal range and units</td>
</tr>
<tr>
<td>23.</td>
<td>Serum testosterone</td>
<td>nmol/L</td>
<td>Lab normal range and units</td>
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<td>24.</td>
<td>Other androgens (if performed, please specify value and units and normal lab ranges)</td>
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<tr>
<td>25.</td>
<td>17-hydroxyprogesterone (17-OHP)</td>
<td>nmol/L</td>
<td>Lab normal range and units</td>
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<td>26.</td>
<td>If a synacthen test was performed, please indicate steroids measured and results:</td>
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Selected management aspects

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<tr>
<td>27.</td>
<td>Age at commencement of treatment</td>
</tr>
<tr>
<td>28.</td>
<td>Continuing therapy</td>
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</tbody>
</table>

If more convenient, a deidentified laboratory printout of results could be provided

Please return the questionnaire in the reply-paid envelope to Dr Geoff Ambler, Institute of Endocrinology, The Children's Hospital, Camperdown, 2050. Phone 02 692 6464, Fax 02 516 4781.

Thank you for your assistance