

DOB: / /

Infant ID: <<num>

BPSU ID: / /

Congenital Adrenal Hyperplasia (CAH)

One Year Follow-up Questionnaire

Thank you for filling out our case-notification form.

This questionnaire asks you about this child and the year following initial notification.

We would be grateful if you could complete the following questions on clinical outcomes for this child.

Please provide information for this child for the period from <<date>>, to the most recent clinical appointment/admission. Please try to complete this questionnaire, even if the child has died or if you have not seen them recently. Thank you.

Section 1: Your Details

Your name (please print): _____

Address: _____

Telephone: _____ E-mail: _____

Date: / /

If you have no further information since <<date>>, could you suggest someone else we could contact for more up-to-date information?

Name and contact details: _____

Section 2: Current Status

2.1 When was this child last seen?

/

2.2 Is the child now: At Home In Hospital Dead Not Known

2.3 If the child has died, date of death:

/

Cause of death: _____

Please now complete the following sections about the child's clinical management. If the child is alive, please complete the questions for the period between <<date>> and today.

If the child has died, please go to question 3.2 and complete all remaining questions for the period between <<date>> and death.

Section 3: Treatment

3.1 Is the child is receiving any of the following treatments (please tick):

Glucocorticoids: Hydrocortisone Prednisolone Cortisone acetate Other

Details _____

Mineralocorticoids _____ Fludrocortisone Other

Details _____

Other Treatments _____ Yes No

Details _____

3.2 Has the child ever received any of the following treatments (please tick):

Glucocorticoids: Hydrocortisone Prednisolone Cortisone acetate Other

Details _____

Mineralocorticoids _____ Fludrocortisone Other

Details _____

Other Treatments _____ Yes No

Details _____

Treatment from any other specialists?

Counselling Psychiatrist Psychologist Geneticist Other specialists

3.3 Most recent measured weight (kgs) _____ on / / or Not Known

3.4 Most recent measured height (cms) _____ on / / or Not Known

3.5 Has the child had any episode(s) of adrenal crisis and/or salt wasting? Yes No Not Known

If Yes, how many episode(s)? _____

Dates(s) _____ Admitted to Hospital (circle) _____ Details (eg. Treatment) _____

/ /

Y / N / NK

/ /

Y / N / NK

please continue on overleaf as necessary

3.6 Please indicate which gender the child has been brought up as:

3.7 Has the child had any genital surgery?

Dates(s) _____ Operation type including complications _____

/ /

/ /

3.8 Is the child hypertensive? Yes No Not Known

If yes, treatment details _____

Section 3: Treatment (con't)

3.9 Has the child had any growth problems?

Yes No Not Known

If yes, details _____

Date of child's last bone age x-ray: / /

Result (compared to chronological age):

Advanced Appropriate Retarded Not Known

3.10 Does this child have any confirmed/suspected developmental delay/learning difficulty?

Yes No Not Known

If yes, details _____

3.11 Any other health problem(s) or other relevant information?

If yes, details _____

We are very grateful to you for completing this information. Thank you very much.