

## CHT Carer Feedback Questionnaire

We would like to ask your experience of when your child was diagnosed with an underactive thyroid at birth. This is so that we can better understand what it was like for you and your family when you were given the diagnosis.

1. Who contacted you to tell you that the screening test for CHT was positive?

- a. Midwife
- b. Health visitor
- c. GP
- d. Hospital doctor
- e. Paediatric consultant (senior doctor)
- f. Paediatric registrar (junior doctor)
- g. Other (please specify)

2. Do you think that the information were you given over the phone was?

- a. Too little
- b. Just right
- c. Too much

3. How soon after you were contacted were you seen at the hospital?

- a. Same day
- b. Following day
- c. Two days later
- d. Three days later
- e. Four days later
- f. Other (please specify)

4. Who did you see at the hospital? (please tick all that apply)

- a. Paediatric consultant
- b. Paediatric registrar
- c. Endocrine nurse
- d. Neonatologist
- e. Other (please specify)

5. How well did you feel the staff at the hospital explained about what they were going to do? with 1 being the lowest and 10 being the highest. (Please circle appropriate rating)

1      2      3      4      5      6      7      8      9      10

6. When did treatment with thyroxine start?

- a. Before being seen by a paediatrician
- b. Immediately after being seen by a paediatrician
- c. After blood tests and scans
- d. Some time after the initial tests

7. If your child did not start treatment after being seen by the paediatrician, how long after you were first seen did your child start treatment?

- a. One day later
- b. Two days later
- c. Three days later
- d. Four days later
- e. Five days later
- f. Other (Please Specify)

8. Do you know if your child had any other tests? (tick all that apply)

- a. More blood tests
- b. Genetic tests
- c. Ultrasound scan of thyroid
- d. Isotope scan of the thyroid
- e. Do not know

9. How well was it explained to you about your child's condition 1 being the lowest and 10 being the highest. (Please circle appropriate rating)

1      2      3      4      5      6      7      8      9      10

10. Was your child diagnosed with any of the following? (please tick applicable)

- a. Thyroid agenesis (absent thyroid)
- b. Ectopic thyroid gland (gland in the wrong place)
- c. Dyshormonogenesis (gland not working properly)
- d. Small thyroid gland
- e. Do not know
- f. Other (please specify)

11. Were you given any written information?

- a. Yes
- b. No

12. How would you rate your overall experience of your child being diagnosed with congenital hypothyroidism? 1 being the lowest and 10 being the highest. (Please circle appropriate rating)

1    2    3    4    5    6    7    8    9    10

13. How would you rate the amount of information you received about the diagnosis at the time? 1 being the lowest (nothing was explained) and 10 being the highest (had as much information as I needed). (Please circle appropriate rating)

1    2    3    4    5    6    7    8    9    10

14. If not enough information, what other information would have been helpful?

15. If too much information, what could have been left out?



16. Was there anything else that could have been done that would have helped you at the time?

17. Is there anything else you would like to tell us that would have helped you or that might help other families who will go through the same experience as you did?