

The Impact on Families of Receiving a Diagnosis of Congenital Hypothyroidism

Background

- Leeds Paediatric Endocrinology Department approached by the British Thyroid Foundation (BTF)
- Parents requesting information and contact with other parents
- Meeting between BTF and team
- Plan for a 'Family Day'



Family Day

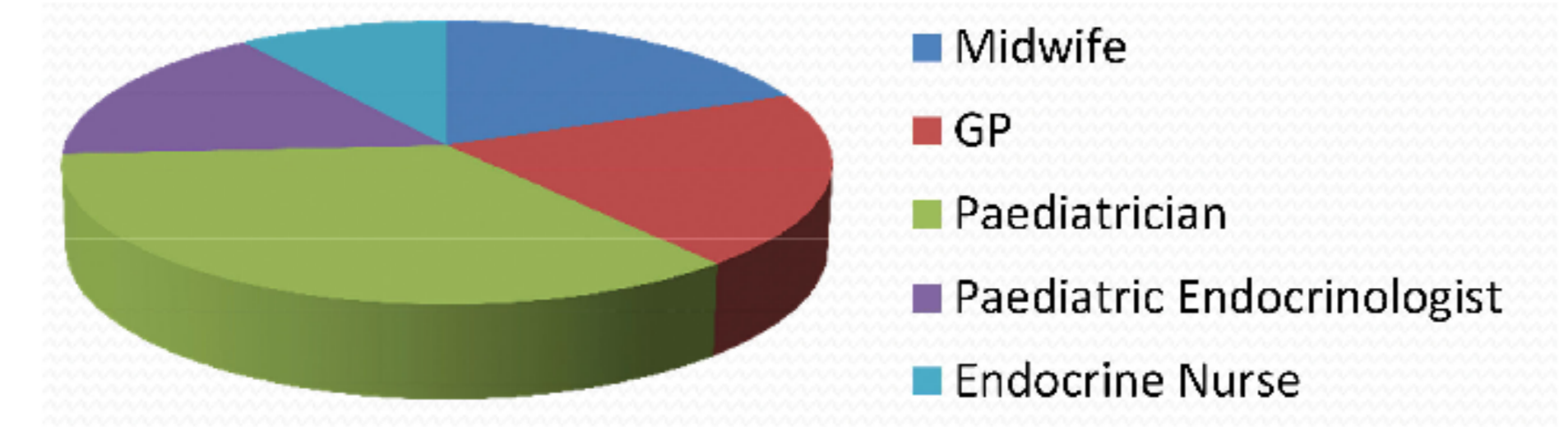
- Attended by parents and children (hypo and hyperthyroidism) from around UK (and Europe!)
- Young children in supervised activity room
- Parents and adolescents in teaching room
 - Formal lectures
 - Parent and patient experiences
 - Interactive sessions

Feedback

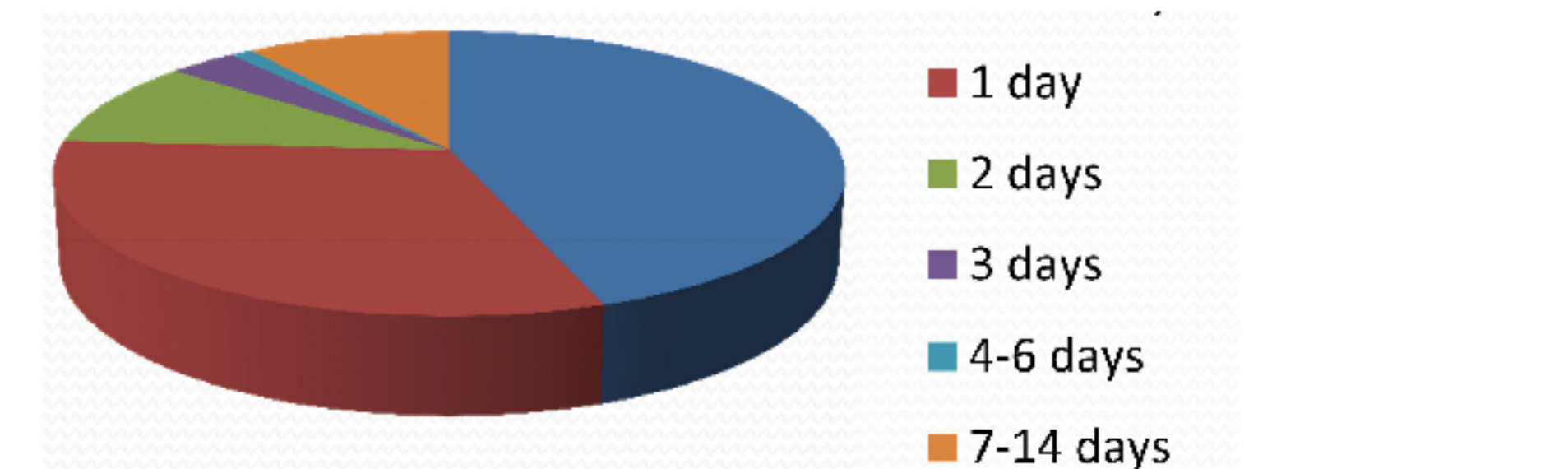
- Family Day very successful
- Discussions for future development
- National online questionnaire solely on CHT distributed by BTF
- Collaboration on questions
- Collation and results fed back to endocrine team

National Questionnaire Results

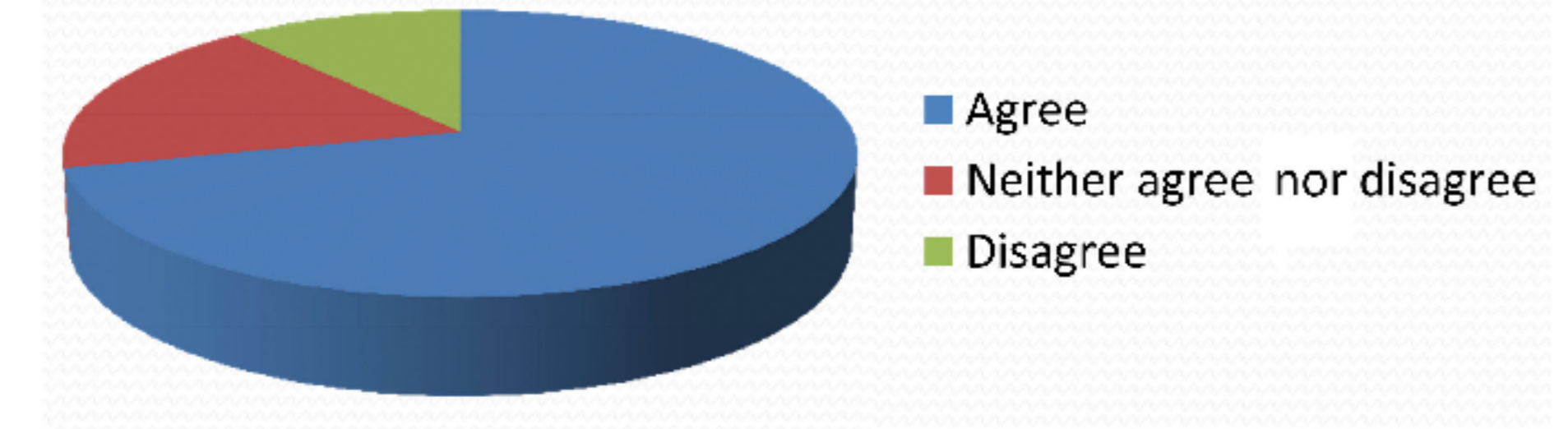
1. What type of health care professional first contacted you with results of the heelprick?



2. How soon after knowing result of heelprick were you referred to hospital?



3. "The specialist doctor I saw clearly explained to me the significance of congenital hypothyroidism (CHT)"



Summary of Results

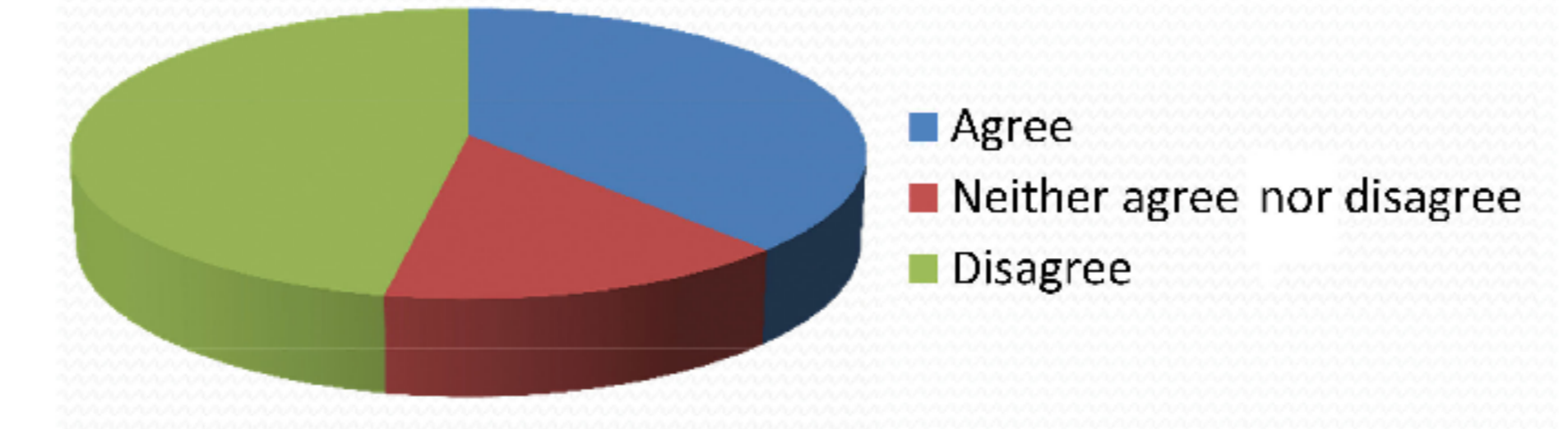
- Nearly 80% referred within 48hrs
- Majority were happy with explanation and significance of condition
- Only 38% given written information
- Fewer than 5% given support group information

Conclusions

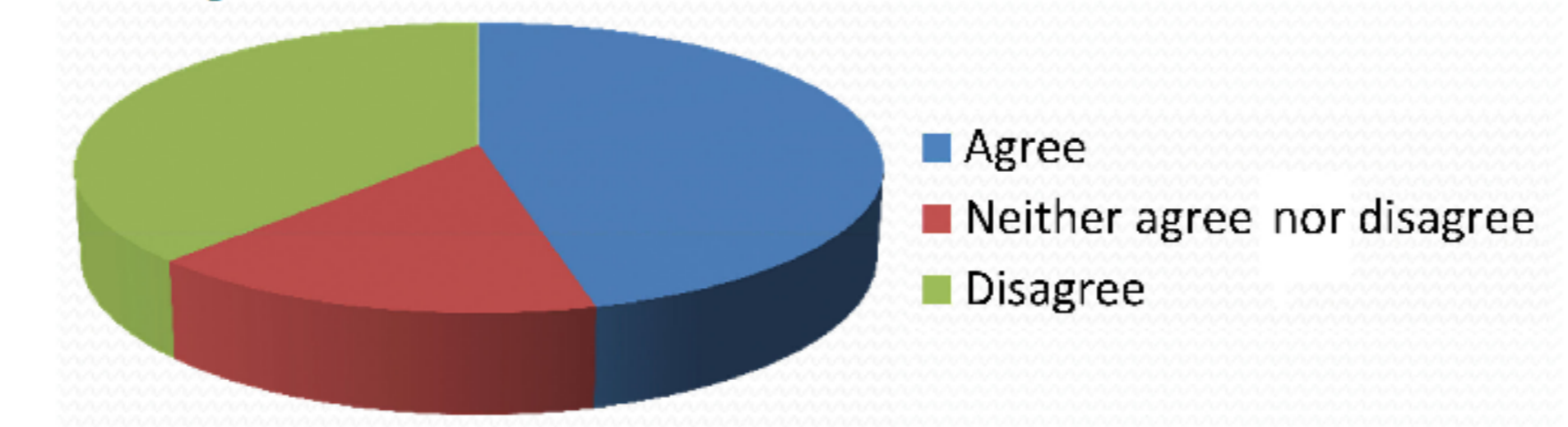
From this pilot study:

- Levels of parental apprehension/experiences variable throughout country
- Parents would like written information/named contact/support groups

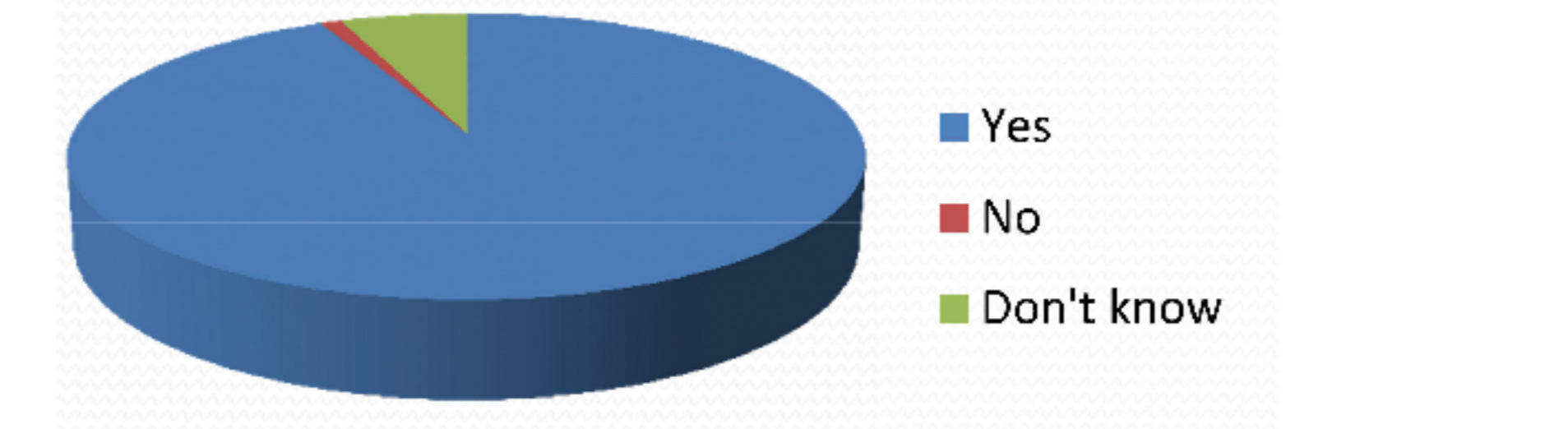
4. "I was given comprehensive information leaflets about CHT to take away and read"



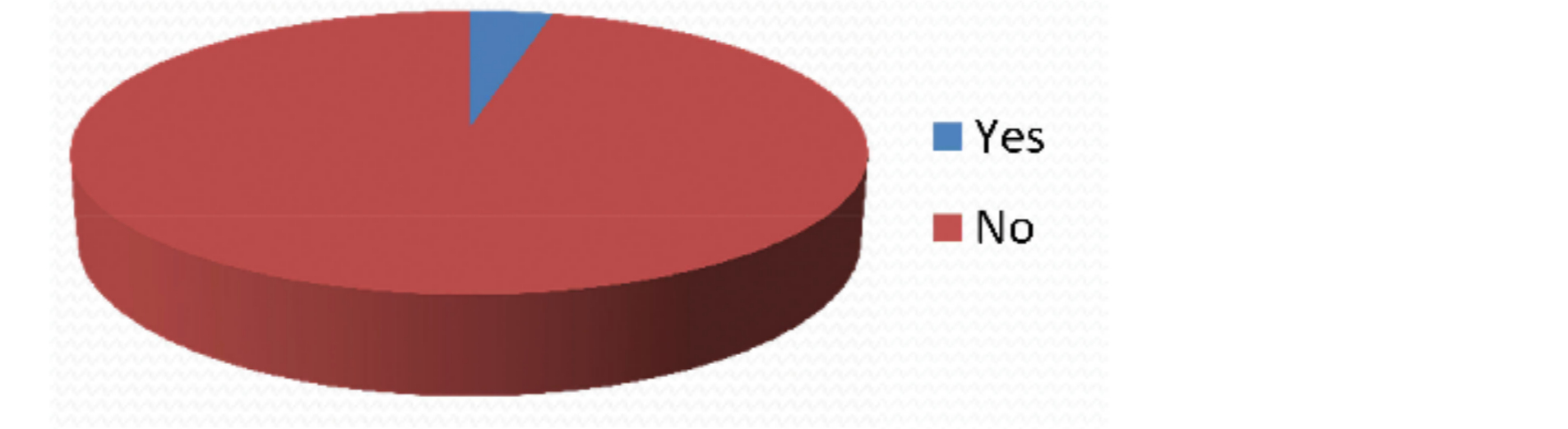
5. "I was given a named contact within the paediatric team and felt that if I had questions I could have contacted them at any time"



6. "It would have helped me to have been put in touch with other parents of children with CHT"



7. "The hospital team told me about patient support groups who might offer further support and information"



Outcome

- In our department (Leeds only):
- Consultant contacts family directly
 - Hospital appointment within 48-72h
 - First dose supervised in department (tablets)
 - Information leaflet for family; links (BTF etc)
 - Specialist Nurse support immediately after diagnosis
 - Liaison with HV etc
 - Plan to re-audit

Recommendations

- Recognition of impact of "minor" diagnosis on new parents
- Provision of written information on condition and contact with support groups and other families
- Named contacts in endocrinology/paediatric department

8. Free text response
Please let us know ways in which your baby's diagnosis was managed well

Prompt communication initially. Lovely, caring staff

Once diagnosed we got treatment that same day. It was good to have a scan of the thyroid too so we knew what we were dealing with. Neonatal nurses were wonderful.

Once we found a paediatric endocrinologist we felt a lot better. She explained things to us and we felt more confident that our son was going to be just fine.

Very quick action as soon as diagnosed we were called straight to the hospital & started on medicine there and then

Treatment was started immediately following diagnosis, scans and bloodwork were done same day as phone call

Please let us know ways in which you feel your baby's diagnosis could have been managed better

More information could have been provided at diagnosis.

The midwife gave me a leaflet stating that he may be mentally & physically handicapped, or words to that effect. She didn't know what it was all about, read the results the wrong way so thought he had the opposite problem.

The urgency to see a specialist was terrifying.

We were sent home from the hospital with some info about the heel-prick and it listed CH as something that caused severe mental retardation. We got a call from a nurse just saying our son had CH and we had an appt with an endo in 2 hours. It was a very scary, long 2 hours with only that one piece of info from the hospital pamphlet.

Acknowledgements

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