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

National Questionnaire Results
1. What type of health care professional first contacted you with results of the heelprick?
   - Midwife
   - GP
   - Paediatrician
   - Paediatric Endocrinologist
   - Endocrine Nurse

2. How soon after knowing result of heelprick were you referred to hospital?
   - 1 day
   - 2 days
   - 3 days
   - 4-6 days
   - 7-14 days

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

4. “I was given comprehensive information leaflets about CHT to take away and read”
   - Agree
   - Neither agree nor disagree
   - Disagree

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”
   - Agree
   - Neither agree nor disagree
   - Disagree

6. “It would have helped me to have been put in touch with other parents of children with CHT”
   - Yes
   - No
   - Don’t know

7. “The hospital team told me about patient support groups who might offer further support and information”
   - Yes
   - No

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 vary variable throughout country
- Parents would like written information/named contact/support groups

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 HIV 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

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

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

- 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.

- 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.

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