Parent/Guardian congenital hypothyroidism database information sheet

Dear Parent/Guardian

Background information

All newborn children in Scotland have a small blood test shortly after being born. This test tells us whether the baby's thyroid gland is working properly or not. It is important to do this test because it is the best way to check the thyroid gland is working properly.

If the thyroid is not working properly and not producing enough thyroid hormones then the baby will not grow and develop normally unless the hormones can be replaced. This is called underactive thyroid or hypothyroidism. When a baby is born with this condition it is called congenital hypothyroidism. Fortunately, an underactive thyroid gland is easy to treat with tablets or a syrup that contain the hormones that the body needs. But, because the thyroid hormones are so important for growth and development, it is important that the tablets or syrup are taken every day. If a child has the correct amount of thyroid hormone, even if it is taken as tablets then they should grow and develop as well as any unaffected child.

An underactive thyroid can be a temporary or permanent problem. Temporary means that the gland will eventually start working normally and make enough hormones so that baby can stop taking the tablets or syrup. Permanent underactive thyroid means that the thyroid gland will not get better (or may even be missing completely) and replacement hormones will have to be taken for life.

An adult may need four times as much thyroid hormone or more than a baby does to start with. The amount of hormone will go up as the baby grows. Regular blood tests are necessary to make sure that baby is getting the correct amount of hormone for their body size. Baby will also be weighed and their height measured. From this it is possible to tell whether they are growing properly and what the correct dose of thyroid hormone is.

Why we are writing to you

We would like to keep computer records of all the children in Scotland who have abnormal thyroid gland test results on newborn screening. This will allow us to check that all the children in Scotland who are born with underactive thyroid glands are being treated in the best possible way. It will also allow us to investigate if we can improve the treatment of congenital hypothyroidism in any way. We may publish the results of any investigation using this data but no individual patient would be identifiable from this.

These records will be kept in a secure, computer database. Access to the records will be restricted to children's doctors specialising in medicine to do with the functioning of glands, their research assistants and to hospital computer managers. **All of these people have a duty of confidentiality to patients.** This means that anyone found breaching these rules of confidentiality would face disciplinary procedures. However we need your permission to keep these records and to use these records for medical research. So, we would be very grateful if you could indicate your permission by reading and signing the form "Parental/Guardian Consent for the Congenital Hypothyroidism database". This form will be given to you on the first visit to hospital after you have been notified of an abnormal thyroid screening test result. You should discuss this with other family members and your child's consultant. If you have any questions, please talk things over with your child's paediatrician.

Do I have to give my consent?

No, you do not have to give your consent. If you do not give your consent then we will not keep separate records of your child's progress. Refusing consent will not affect your child's treatment in any way. After you have given consent, you can always withdraw consent at any time. We will cease to record any more data on your child and destroy our existing records up until your withdrawal of consent.

If you give your consent for us to gather information then we will get this information from your child's doctors. All of the information we need is normally gathered anyway and kept in the records that all doctors keep on every patient. The difference here is that we would like to extract information specific to this one condition from the general medical records and keep it all together so that it is easier to investigate.

Can I see a printout of my child's computer record?

Yes. You can request a copy of the record at any time.

What happens next?

We will regularly collect data on all children for whom we have consent and who have an abnormal result on the newborn thyroid screening test. This data will include information on growth, thyroid hormone levels from blood test results, the results of other tests that relate to thyroid gland function, the dose of replacement hormones that you child is getting and the dates of any change to this dose. We will also take general information including who your child's hospital doctor is, who their GP is, your address and any change of address. We will also keep a small amount of information about you, such as how old you were when your baby was born, your heights and whether there is any family history of thyroid disease.

If your child has a temporary form of underactive thyroid then we will stop collecting information when their thyroid gland is proven to be working normally and they are not taking any replacement thyroid hormone. We would like to gather information on children who have a permanent form of underactive thyroid until they are adult. We will seek permission to hold this information from the children themselves, once they have reached an age when they can decide for themselves if they want us to do this. This is usually 12 years of age in Scotland.

We hope that you will allow us to gather and use this information. It may allow us to develop better and more effective treatment for patients born with underactive thyroid.

Yours faithfully,

Dr M G Shaikh
Consultant Paediatric Endocrinologist
Royal Hospital for Children
Glasgow
G51 3TF

0141 201 0000 (switchboard)
0141 451 6548 (Kerri Marshall- secretary)

guftar.shaikh@nhs.scot