Congenital hypothyroidism (CHT): description in brief

When your baby was around 5 days old, your midwife took some blood from your baby's heel for their newborn blood spot screening test (the 'heel prick test'). The screening test result suggests that your baby may have congenital hypothyroidism (CHT). This result will need to be confirmed by further tests.

This information will help you to understand more about CHT, and what you can expect to happen next.

Public Health England (PHE) created this information on behalf of the NHS. In this information, the word 'we' refers to the NHS service that provides screening.

About CHT

About 1 in 2,000 babies born in the UK has CHT. The word 'congenital' means it is something the baby is born with. There is currently no reliable way to detect CHT before birth and no way to stop babies being born with it. There is nothing the parents of a baby with CHT could have done to prevent it.

Babies with CHT do not make enough of the hormone thyroxine, which is an important natural substance made in the body. Thyroxine is produced by a gland in the neck called the thyroid. Without thyroxine, babies do not grow properly and can develop permanent physical and mental disabilities. CHT cannot be cured but can be treated simply and successfully.

Treatment

The treatment for CHT is to take levothyroxine by mouth once a day. This replaces the thyroxine that the body cannot make. Babies should start their treatment promptly, during the first few weeks after birth. Many children will need to continue it throughout life. Studies of children taking levothyroxine show that this treatment is safe and effective.

Children with CHT are able to live full and active lives, like other children, as long as treatment is taken every day. A few affected children may develop subtle problems with learning and clumsiness, and may need extra help. There may be a slightly increased risk of hearing problems.

Next steps

We understand that this screening result is unsettling for you and your family. You will be given an appointment to see a specialist doctor at the earliest opportunity. The doctor will

be able to discuss the screening test result with you and examine your child. They will arrange further blood tests to find out if your baby does have CHT.

A thyroid scan may also be recommended. Thyroid scans can give information about the type of CHT and can help to determine if it is likely to be a permanent problem. They can also help to find out whether there is a chance of CHT in future children.

The baby's mother may also be asked to have some blood tests to aid the diagnosis.

Information, advice and support

The healthcare team responsible for your baby's care will be happy to discuss any queries you might have.

The 'CHT: further information for families' leaflet is also available, at https://www.gov.uk/government/publications/congenital-hypothyroidism-cht-confirmed-description-in-brief

Other sources of useful information include:

- the British Thyroid Foundation at https://www.btf-thyroid.org/congenital-hypothyroidism
- Medicines for Children at https://www.medicinesforchildren.org.uk/levothyroxine-hypothyroidism
- the Child Growth Foundation at https://childgrowthfoundation.org/
- the British Society for Paediatric Endocrinology and Diabetes (BSPED) at https://www.bsped.org.uk/
- the NHS website, which has general information about NBS screening, at https://www.nhs.uk/conditions/baby/newborn-screening/blood-spot-test/

More information

The NHS Screening Programmes use personal information from your NHS records to invite you for screening at the right time. Public Health England also uses your information to ensure you receive high quality care and to improve the screening programmes. Find out more about how your information is used and protected, and your options at www.gov.uk/phe/screening-data.

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