Congenital hypothyroidism and your baby

You have just learned that your baby has congenital hypothyroidism. The information in this leaflet will help you understand more about this condition and answer some of your questions.

Congenital hypothyroidism

Congenital hypothyroidism is a condition where a baby is born with a thyroid gland that does not work properly. The thyroid gland is a butterfly-shaped organ at the base of the neck. Its job is to make thyroxine hormone that helps the cells of the body function correctly. A normally working thyroid gland is critical for normal growth and brain development.

A small, under-developed (not fully grown) thyroid gland or one that is missing altogether are the commonest causes of congenital hypothyroidism. The reasons why the thyroid gland does not develop properly in the fetus are not known.

Sometimes congenital hypothyroidism is caused by the absence of an enzyme in the thyroid gland, preventing it from making thyroxine.

One case of congenital hypothyroidism occurs in about every 2,300 babies born in New Zealand so there are about 30 babies born with this condition each year.

Treatment

As soon as you know your baby has congenital hypothyroidism, baby will be given thyroxine suspension. Enough thyroxine is given to your baby to increase levels to those of unaffected babies.

During the first two years of your baby's life your paediatrician (doctor for children) will arrange frequent blood tests (usually weekly for six weeks then monthly until one year of age) to make sure that the thyroxine levels are normal. The thyroxine suspension will be given in different amounts for the first few months of life depending on the thyroid blood results.

The thyroxine suspension has to be made up by a pharmacist each week as it won't work reliably for longer than this. As it is a suspension it needs to be shaken well before using. The suspension should always be kept in the fridge.

Your baby will also have regular checkups to make sure they are growing and developing normally. As your child becomes older, blood tests and hospital checkups are needed less often.

Some Answers

What does the thyroid gland do?

The thyroid gland is responsible for making thyroxine which has 3 main functions:

- Thyroxine helps develop your baby's brain in the first two years of life. A lack of thyroid hormone during this time will lead to intellectually disability.
- Thyroxine is needed for normal growth, so not having enough can lead to poor growth and short height as an adult.
- Thyroxine is the 'get-up-and-go' hormone – a child without it may feel cold, tired, and be constipated (not able to move their bowels).

Will my child be normal when they grow up?

There can never be a guarantee. With careful monitoring and treatment with thyroxine every day your baby has the best chance of achieving their full potential in growth and development.

Where does congenital hypothyroidism come from? Is it inherited?

The more common forms of congenital hypothyroidism such as an under-developed or absent thyroid gland are not inherited. Only conditions where the thyroid gland enzyme is absent are inherited. Your paediatrician can talk to you about this.

Could congenital hypothyroidism have been prevented during pregnancy?

No. The reasons for underdevelopment of the thyroid gland are not known, so we do not know if there is any way of preventing it.

What are the symptoms of congenital hypothyroidism?

In the first weeks after birth, a baby with congenital hypothyroidism may have no obvious symptoms and be difficult to distinguish from an unaffected baby. However, babies born with congenital hypothyroidism may be very sleepy and feed slowly. They may have a tendency to be constipated and suffer from yellowing of the skin that lasts a long time.

Congenital hypothyroidism can be diagnosed by a blood test before the baby develops any symptoms and signs of the condition. The blood test (heel prick test) is done as part of the Newborn Metabolic Screening Programme.

Why are babies screened for congenital hypothyroidism?

The aim of screening is to identify as soon as possible which babies are more likely to have congenital hypothyroidism so that treatment can be started. Most babies with congenital hypothyroidism are not obviously different from unaffected babies. Without a screening test your child may be months or years old before you find out. This delay in diagnosis and treatment will lead to intellectually disability.

Where can I go for further information?

- Talk to your paediatrician
- View www.newbornscreening.info/Parents/otherdisorders/CH.html
- View www.nsu.govt.nz for information on the Newborn Metabolic Screening Programme

MINISTRY OF HEALTH
MANATŪ HAUORA
National Screening Unit
New Zealand Government
www.nsu.govt.nz