Borderline positive (slightly abnormal) newborn screen for congenital hypothyroidism (CH)

You have just learned that your baby has had a borderline (slightly abnormal) newborn screen. This information will answer some of your questions.

About newborn screening

A short time after your baby was born, some blood was collected from their heel to test for some rare disorders, including congenital hypothyroidism (CH). We screen newborns in this way to find conditions where early treatment can help babies to stay well.

Why your baby needs a second test

Your baby's screening test for CH was **borderline** (slightly abnormal). The laboratory needs to retest your baby using a fresh sample to check the result.

Most babies with abnormal screening results do not have anything wrong.

Common reasons for a borderline CH screening result are:

- the testing card had too much blood on it
- the baby was exposed to iodine around the time that they were born
- the mother had thyroid antibodies.

About CH

A baby with CH is born with a thyroid gland that does not work properly.

Thyroid glands make thyroxine, a hormone which is important for normal growth and development.

CH can be mild or severe. If a baby with a borderline result has CH, they are likely to have a mild form of it.

Babies with CH remain healthy in the first weeks of life and usually have no signs or symptoms. Please discuss any concerns with your midwife.

What happens next

Your midwife will arrange to collect a further blood spot (heel prick) sample from your baby and send the testing card to the laboratory. The laboratory will have the test result one to two days after it gets the sample. It will then call or text your midwife with the result.

In most cases the repeat sample is normal and babies do not need any more testing.

If the result is still not completely normal, your baby will be referred to a paediatrician for a full assessment. That assessment will include a blood test to check thyroid function.

If your baby does have a mild form of CH, the treatment is to give them a medicine to replace the thyroxine hormone (which baby can't make). When babies are treated for CH, they become healthy children and adults.

Where to go for more information

For more information about newborn metabolic screening, go to https://www.nsu.govt.nz/pregnancy-newborn-screening/newborn-metabolic-screening-programme-heel-prick-test

For more about what it is like to live with CH, see Lily and Milton's stories at https://www.nsu.govt.nz/pregnancy-newborn-screening/newborn-metabolic-screening-programme-heel-prick- test/about-newborn/tell

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