

## **Your Newborn Baby's Blood Test: Te Whakamātau Toto O To Peepi Hōu**

A nurse at the hospital, or a midwife or doctor at home, may ask to take a few drops of your newborn baby's blood. The blood is for tests that could save your baby's life or prevent serious physical or mental problems. This leaflet outlines why the tests are done and what the process will be.

Without a blood test these problems are hard to find – and it only takes a few drops of blood from a prick on the heel and a few minutes time.

The tests have to be done as soon after 48 hours of age as possible so that fast action can be taken if any is needed.

### **Few Babies Have Problems: Ruarua Noa Iho Ngā Peepi Ka Raruraru**

Most babies born in New Zealand are normal. Only a very few\* have rare, serious problems (disorders) that can be helped with a special diet or other treatment.

If your baby does have a problem, she or he will still probably look and act normally to start with. Sometimes the problem won't show up for quite some time.

Even if you and your family have never had any of the problems, your baby might still have one. But the chances are very small; only testing can tell.

### **No News Is Good News: Ki Te Kore He Kōrero He Tohu Pai Tēnā**

If you haven't heard anything after a month you can be sure your baby is free from any of the problems – no news is good news.

But no news about these tests won't stop your baby getting a cold or some other illness! You still need to get your baby immunised against infectious diseases such as measles and hepatitis B. Ask your child health worker for details.

### **Note**

If you think your baby hasn't been tested yet, for your baby's sake, tell your child health worker, nurse, midwife or doctor now.

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### **A Second Blood Test: He Whakamātau Toto Tuarua**

A second blood test is needed for about 1 in every 100 babies, and it is usually done because the blood wasn't taken right the first time.

The second test usually happens in the first 3 weeks after the baby is born. If you are asked for a second test, please get it done straight away - it is important to get a result while your baby is still very young. The second test usually takes another 2 weeks – find out the results through your lead maternity caregiver.

If this second test also shows up a problem you and your lead maternity caregiver and your doctor will need to start treatment for the baby.

### **Treatment: Te Haumanu**

The worst effects of these problems can often be reduced – either by a special diet or medicine – but treatment must be started early.

Most of these problems are inborn chemical problems. They cannot be “cured” but they can be treated, each in their own special way.

### **Future Children: Ngā Tamarika O Ngā Wā E Heke Mai Nei**

If your baby has a problem, your doctor or a specialist doctor can tell you if your future children might also have the same problem.

### **The disorders tested**

Tests of your baby’s blood are carried out at the National Testing Centre in Auckland.

At the moment the blood tests look for the disorders listed below, but this may change as more is learnt. Tests for other disorders may be added to those listed.

If your baby does have one of these problems, then much more information about the disorder and its treatment will be given to you.

#### **Biotinidase Deficiency**

- Caused by: Lack of an enzyme (leading to a deficiency of biotin).
- Can lead to: Life-threatening complications
- Treated by: Taking vitamin H (biotin)
- Chances: Happens to 1 in 50,000 newborn babies.

#### **Congenital Adrenal Hyperplasia (CAH)**

- Caused by: There is a lack of an enzyme in the adrenal gland
- Can lead to: Life-threatening complications
- Treated by: Steroid medication
- Chances: Happens to 1 in 20,000 newborn babies.

#### **Cystic Fibrosis (CF)**

- Caused by: Abnormal secretions in lung, pancreas, and other parts of the body.
- Can lead to: Poor growth, chest infections and shortened life.
- Treated by: Medicine and physiotherapy to keep the lungs healthy.
- Chances: Happens to 1 in 3,000 newborn babies.

#### **Galactosaemia**

- Caused by: An enzyme defect prevents normal use of milk sugar.
- Can lead to: Jaundice, cataracts and life-threatening illness.
- Treated by: Special diet: replacement of milk-containing foods.
- Chances: Happens to 1 in 120,000 newborn babies.

## Hypothyroidism

- Caused by: Not enough normal thyroid gland.
- Can lead to: Slowed growth and mental development.
- Treated by: Taking thyroid hormone.
- Chances: Happens to 1 in 4,500 newborn babies.

## Maple Syrup Urine Disease (MSUD)

- Caused by: An enzyme is missing.
- Can lead to: Life-threatening complications
- Treated by: Special diet.
- Chances: Happens to 1 in 250,000 newborn babies.

## Phenylketonuria (PKU)

- Caused by: An enzyme is missing from the liver. Without this enzyme an aminoacid (called phenylalanine), which is found in all protein, rises to harmful levels.
- Can lead to: Brain damage.
- Treated by: Special diet.
- Chances: Happens to 1 in 15,000 newborn babies.

From 1 December 2006, new technology has made it possible for the programme to now include 21 other metabolic disorders. No extra blood is needed to do these additional tests. The groups of new disorders are:

### Disorders of Amino Acid breakdown (12 disorders)

- Caused by: Each disorder is caused by a missing enzyme. Without the enzymes, waste products such as ammonia rise to harmful levels.
- Can lead to: Life threatening complications.
- Treated by: Special diet
- Chances: Happens to 1 in 12,000 babies

### Disorders of Fatty Acid oxidation (9 disorders)

- Caused by: Each disorder is caused by a missing enzyme. Without these enzymes energy cannot be used from fats. Without energy from fats the body can run out of energy.
- Can lead to: Brain damage and life-threatening complications
- Treated by: Regular feeding
- Chances: Happens to 1 in 12,000 babies

**Notes**

The information collected about your baby on the newborn screening card is used to:

- Correctly interpret the test results
- Ensure any abnormal results are given to your lead maternity caregiver.

It may also be used in comparison with hospital birth data to check that all babies receive a screening test.

When the testing of your baby's blood is completed, the sample card is stored so that if a baby has one of the disorders tested for, but does not have a positive test result we can find out why the mistake occurred again. Some of the blood might be used to set up new screening tests; if a leftover scrap of your baby's blood is used for this all the information about your baby will be disconnected from the blood so any results cannot be traced back to you and your baby. If you would like your baby's card returned to you after testing please fill in the form which is available from your LMC or the National Testing Centre.

If you would like to discuss this, or would like more information about newborn baby blood tests, you can contact us on phone 09-3074949, ext 6759; fax 09-3074936; email [ntc@adhb.govt.nz](mailto:ntc@adhb.govt.nz) or mail PO Box 872, Auckland.

National Testing Centre, Auckland, New Zealand.