### Congenital Hypothyroidism

**Place Patient Sticker Here**
What is Congenital Hypothyroidism?

The term Congenital hypothyroidism (CH) describes a condition that is present at birth (congenital) and in which the thyroid gland is either not working correctly or is missing.

In New Zealand approximately 1 in 3000 babies are born with this condition. It is usually picked up on Newborn Screening, (the heel prick test your baby had done around 3 days of age)

Different types of Congenital hypothyroidism

- **Athyrosis**— No thyroid gland has developed. Therefore no thyroid hormone can be produced. This is permanent.

- **Ectopic Thyroid**— This means the gland is there but in an abnormal position. Depending on the severity of this condition the gland may produce some thyroid hormone, but not as much as the body needs. This is permanent.

- **Dyshormonogenesis**— This means abnormal production of the thyroid hormone. There is a thyroid gland in the normal position but it is not working properly. This may recover over time.

**ALL REQUIRE TREATMENT WITH THYROID HORMONE**
First 2 years
The first 2 years are the most vital in treatment to protect brain development, and frequent dosage changes are often needed as this is when periods of rapid growth occur.

Contact

Contact details to be provided to Family

Phone _______________________

Email _______________________
Include NHI Number for ease of clinician to look up results

- It may take 1-2 days for you to hear back re the blood results.
- If you do not receive a clinic appointment please also contact the above phone number, or email above address.

If you are unable to contact anyone, then please see your GP.

If you would like further reading then we suggest the following website:

http://www.apeg.org.au
Hormones & me Booklet Series
‘Congenital hypothyroidism’
This can be downloaded for free.

What does Thyroid hormone (Thyroxine) do?
Thyroid hormone (also known as thyroxine) is essential for normal brain development in the first two years of life. It also ensures normal growth and development throughout childhood. It is also important for regulating the body's metabolic rate: Not enough thyroid hormone leads to a slow metabolism, too much thyroid hormone causes the metabolism to speed up.

Why is it so important to treat?
In the first 2 years of life the brain needs Thyroxine to develop normally and without the right amount of thyroxine developmental delay is likely. It is also important for regulating your metabolism and growth.

Symptoms of a slow metabolic rate
- Sluggish physical and mental activity
- Low body temperature
- Slow pulse rate
- Intolerance of cold
- Constipation

Symptoms in your New born Baby
- Persistent Jaundice—improves once treatment starts
- Excessively sleepy
- Poor Feeding and weight gain
- Dry Skin
- Puffy face
Treatment

Medication
As the thyroid gland is unable to make enough thyroid hormone for the body's needs you will be given a prescription for some medication called Thyroxine (this is exactly the same thyroid hormone that is made in the body).

This needs to be given every day at a similar time of day.

Initially we will give this in a liquid form to make it easier to give to baby. The easiest way is to use a syringe to give this medicine orally (via the mouth). It is best given just prior to a feed.

- Pick up weekly from the pharmacy
- Medicine needs to be stored in the fridge
- Shake well before use

The syringes need to be washed with soapy water after every use and sterilised until baby is around 5 months old.

Once your baby is on solids we will discuss changing to thyroxine in tablet form. A detailed explanation of how to do this will be given when we see you in clinic.

If you run out of thyroxine repeat prescriptions can be obtained from your baby's usual Doctor (GP).

Blood Tests

We need frequent blood tests to ensure we are giving the correct amount of medication. Initially these are weekly but as your child gets older the frequency becomes less.

- Weekly bloods (until 4—6 weeks of age or stable)
- Monthly bloods (until 2 years of age)
- 3 monthly bloods (2—5 years of age)
- 6 monthly bloods (5—9 years of age)
- Yearly bloods (for rest of life)

What do the blood tests mean?

FT4 - This is the amount of thyroxine that is available in the bloodstream.

TSH - (Thyroid stimulating hormone) this tells us if the brain is happy with the amount of thyroxine or wants more.

Clinic Follow up

At clinic your child's growth will be monitored, both height and weight will be done at each appointment. We aim to see you within 1—2 weeks of starting the medicine and then every 3 months until your child is 5 years old. You will then be seen every 6 months.

Please note: If your baby has been very sleepy and not feeding well this will improve with treatment. If you have been advised to switch to formula this is not usually necessary unless it is your wish. Your very sleepy baby will become much more alert within a few days.