



## INFORMATION FOR PARENTS/GUARDIANS: My Baby Has a Positive Congenital Hypothyroidism Newborn Screening Result

### What is newborn screening?

These are routine tests done soon after birth on every baby born in Ontario. A small sample of blood is taken from your baby and is tested for rare, treatable diseases, including congenital hypothyroidism (CH).

### What does it mean if my baby has a positive CH newborn screening result?

This result does **not** mean that your baby has CH. It means that more testing is needed because your baby **might** have CH. Babies with CH grow and develop normally if treatment begins early, so it is important to have follow-up testing done quickly to find out if your baby has CH.

You may feel worried about your baby's screen positive result. Many parents in this situation feel this way. Remember, we do not know for sure that your baby has CH until follow up testing has been done.

### What is the thyroid gland?

The thyroid is a small butterfly shaped gland located at the base of the neck. It makes hormones that are important for normal growth of the body and normal development of the brain.

### What is congenital hypothyroidism (CH)?

CH is a condition that occurs when a baby does not make enough thyroid hormone (thyroxine). Normal amounts of thyroid hormone are important for normal growth and development of the body and the brain.

Congenital hypothyroidism affects about 1 in every 3 000 – 1 in every 4 000 babies born in Ontario.

### How do I find out if my baby has CH?

Blood tests are done to determine if a baby who is screen positive actually has CH. Thyroid scans or ultrasounds are often done as well.

### When can my baby have these tests?

Your baby's doctor or a health care professional at a Newborn Screening Treatment Centre will call you to talk about the results of your baby's positive newborn screen and arrange follow up testing as soon as possible.

### Why screen for CH?

Babies who have CH but do not receive thyroid replacement hormone develop mental retardation, physical handicaps and do not grow well. Screening means that babies with CH can be treated early with thyroid hormone replacement. Babies diagnosed with CH in the first few weeks of life who have early treatment grow normally and have normal brain development.





### **How is CH treated?**

Babies with CH are treated or followed by a specialist called an endocrinologist. Lifelong thyroid hormone replacement therapy is started, usually in the form of a pill. Babies with CH have regular blood tests to make sure they are getting the right amount of thyroid hormone. Babies with CH who begin treatment early grow up to be like any other child the same age.

### **How does a baby get CH?**

CH can happen when the thyroid gland is missing, the thyroid gland is in the wrong location, the thyroid gland is smaller than usual or the thyroid gland is not working properly. A few babies with CH will have it due to a genetic condition but most of the time, it happens just by chance.

### **Where can I get more information?**

For more information on newborn screening, please talk to your local health care provider or visit the Parents section of our website at [www.newbornscreening.on.ca](http://www.newbornscreening.on.ca).

For more information on CH, please visit the Thyroid Foundation of Canada website at <http://www.thyroid.ca> or call 1-800-267-8822.

**NOTE TO PARENTS/GUARDIANS: This information is only for parents whose baby has had a positive newborn screening result for congenital hypothyroidism (CH). Please remember that this fact sheet was written for information purposes only. The fact sheet should not replace professional medical advice, diagnosis or treatment.**

