

## Congenital Hypothyroidism Answers to frequently asked questions

### What is Congenital Hypothyroidism (CH)?

"Congenital" means present at birth and "hypothyroidism" is a condition where the thyroid gland does not produce enough thyroid hormone to meet the needs of the body. It occurs in 1 in 3000 children born in Ontario. CH results from an abnormality that occurs before birth and is most often picked up on the newborn screening test done at the birth hospital.

### Why is Thyroid Hormone Necessary?

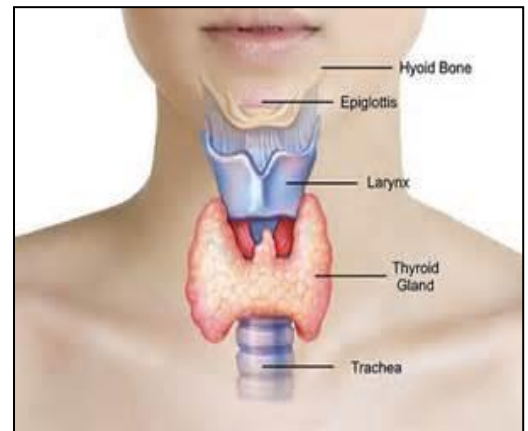
Thyroid hormones are responsible for metabolism and are essential for growth and brain development. The most critical period of the effect of thyroid hormone on brain development is the first few years of life as this is when connections in the brain are formed. These connections are formed at a faster rate during these years than any other time. By age 3 a child's brain has reached 80% of its adult volume. Experience around the world has shown that babies born with congenital hypothyroidism grow up to be healthy adults when correctly treated.

### What is the Thyroid Gland?

The thyroid gland is located at the front of the neck just below the Larynx (voicebox). As a baby grows in the uterus, thyroid cells start developing near the tongue and then move to their final position at the base of the neck. These cells then grow and develop into the thyroid gland which is in the shape of a butterfly.

There are 2 different reasons for congenital hypothyroidism:

- 1) Dysgenesis: The thyroid gland is missing, in the wrong place or severely underdeveloped (in about 80-85% of cases)
- 2) Dyshormonogenesis: The thyroid gland is present but has decreased or absent hormone production



### How does the Thyroid Gland Function?

The thyroid gland is part of a complicated messaging system to regulate body metabolism. The brain has an inbuilt "thermometer" that senses the level of thyroid hormone. When the body has enough thyroid hormone, the brain sends a message to the thyroid to stop or slow thyroid hormone production which keeps the hormones in balance. When there isn't enough thyroid hormone, the thyroid gland is stimulated to produce more and this can be assessed by measuring thyroid stimulating hormone (TSH) levels. A high TSH could mean there isn't enough thyroid hormone and a low TSH means there may be too much thyroid hormone.

## What is the Treatment for Congenital Hypothyroidism?

The treatment for CH is a pill, levothyroxine (thyroid hormone) that is taken by mouth every day. Levothyroxine must be given at the same time each day. If you forget, give it as soon as possible and return to your regular schedule the next day. If you do not remember until the next day, give only that day's dose and do not double up. A missed dose is not an emergency and is generally well tolerated however to maintain stable thyroid levels and well-being it is important to minimize missed doses. Levothyroxine does not interfere with immunizations and can be taken with most other medications. Avoid giving soy products, iron or calcium supplements, Simethicone (Ovol) or antacids within 4 hours of giving L-thyroxine as this can decrease rate of absorption. Changes are made to the dose based on periodic blood tests.

## How Long will my Child Need to Take the Thyroid Hormone?

Most children will need to continue taking levothyroxine for the remainder of their life because their thyroid problem is permanent. In some children, the physician may stop the hormone for a brief period as a trial around the age of 3 or older to see if the hypothyroidism was temporary (measured by blood tests). The medication may need to be restarted, depending on the results of the blood tests.

## Signs and Symptoms of Under or Over Treatment

As your child grows it is possible for your child to require a higher dose of medication. Most often it is hard to tell when your child needs a higher dose, and they won't show any signs or symptoms. That's why it's important to do the blood tests as recommended by your doctor.

As thyroid levels fluctuate it is also possible for your child to receive more thyroid hormone medication than needed. Some of the things you may see if your child is getting too much thyroid hormone include: **irritability, sweating, diarrhea, trouble sleeping and an increase in feedings**. You may notice this 1-2 months after starting the medication or after a dose change. If you see the signs listed above, please contact Lori Brnjac (endocrine nurse) at 416-813-7332, Irena Hozjan 416-813-7654 ext. 204321 or the endocrine fellow on call at 416-813-7500.

## How Often Does my Child Need To Be Seen?

Visits	Blood Work	Clinic Visit
1 <sup>st</sup> Visit	X	X
2-3 weeks after starting meds	X	X
Age 2 mos	X	
Age 3 mos	X	X
Age 6 mos	X	X
Age 9 mos	X	
Age 12 mos	X	X
Age 15 mos	X	
Age 18 mos	X	X
Age 2 yrs	X	X
Age 2.5 yrs	X	
Age 3 yrs	X	X
Age 4 yrs	X	X
Age 5 yrs	X	X

- Further blood work/additional visits may be needed in between

- Transfer to a fellow pediatric endocrinologist closer to your home may be arranged after 3 years of age

# Congenital Hypothyroidism: My bloodwork result log

Newborn screen results (TSH): \_\_\_\_\_

Repeat TSH level \_\_\_\_\_

<u>Date</u>	<u>TSH</u>	<u>Free T4</u>	<u>Dosage Change?</u>	<u>Comments</u>

TSH ranges by age (mIU/L)

- < 5 days 3.2 - 19
- 6 - 31 days 1.7 - 9.1
- 1 - 2 months 0.5 - 6.3
- 3 - < 6 months 0.5 - 4.77
- 6 months - < 1 year 0.61 - 4.58
- 1 year - < 14 years 0.73 - 4.09
- 14 years - < 19 years 0.47 - 4.00

FreeT4 ranges by age (pmol/L)

- 3 d - < 15 d 13.0 - 52.2
- 15 d - < 30 d 10.5 - 30.0
- 30 d - < 4 mo 10.5 - 22.7
- 4 mo - < 1 y 10.0 - 22.0
- 1 y - < 19 y 10.0 - 17