

NEWBORN SCREENING BC

Blood spot card screening | Parent information sheet

Congenital Hypothyroidism (CH)

Your baby had a newborn screen. This test was done on a blood sample collected by heel prick shortly after birth. This is done to identify a number of rare but treatable conditions which usually do not have any symptoms early on. Knowing if your child has one of these conditions early in life is important, because early diagnosis allows for early treatment and better health outcomes.

Your baby had a positive newborn screen result for Congenital Hypothyroidism (CH). **This result does not mean that your baby has CH but means the chance is increased and more testing is needed.**

What is CH?

CH is a condition in which a baby does not make enough thyroid hormone. Thyroid hormone is extremely important for the normal function of all the body's organs and for brain development.

The newborn screen test measures the level of **thyroid stimulating hormone (TSH)**, which is increased in babies with CH. Your baby's screen showed a higher-than-expected level.

What are the signs and symptoms of CH?

Most babies with CH appear normal at birth. Some may have jaundice, constipation and / or have feeding problems. However, if they are not identified and treated quickly, they are at risk for intellectual disability and failure to thrive (poor growth).

What causes CH?

The thyroid hormone is made by the thyroid gland. Most babies with CH are born with a missing or underdeveloped thyroid gland. Other babies have a thyroid gland, but it is unable to make the thyroid hormone. CH has many different causes, both genetic and non-genetic.

How is the diagnosis confirmed?

The diagnosis is confirmed with a repeat measurement of TSH and the thyroid hormone (free thyroxine, T4) using a blood sample. The doctor may recommend imaging of the thyroid gland using an ultrasound or thyroid scan.

How is CH treated?

Daily medication (thyroid hormone replacement) is given to the baby by mouth. Regular follow up tests are used to monitor and adjust the dose.

Treatment is coordinated by a specialist doctor in endocrinology.

What is the outcome of treatment?

Infants with CH who are identified early and treated appropriately can be as healthy and intelligent as other children their age.

What is the incidence of CH?

CH is relatively common condition that affects about 1 in every 1,700 babies born in BC.

How do you feel?

For most parents, this is an unexpected result. You may feel scared and upset which are normal feelings. If you are feeling overwhelmed or have questions, you can talk with your health care provider to discuss supports available.



Where can I get more information?

Talk to your primary care provider.

Information about the BC Newborn Screening Program can be found at

www.newbornscreeningbc.ca

Information about CH can be found at:

- <http://www.nlm.nih.gov/medlineplus/ency/article/001193.htm>

This fact sheet provides basic information only. It does not take the place of medical advice, diagnosis or treatment. Always talk to your health care provider about specific health concerns.



Provincial Health
Services Authority

Newborn Screening BC is a collaboration of Provincial Lab Medicine Services, BC Children's Hospital and BC Women's Hospital and Health Centre, and Perinatal Services BC, all part of the Provincial Health Services Authority.