

INFORMATION FOR PARENTS/GUARDIANS

My Baby has a Positive Critical Congenital Heart Disease (CCHD) Screening Result

What is Newborn Screening?

These are routine tests offered soon after birth to every baby born in Ontario. Critical congenital heart disease (CCHD) screening involves a quick, painless test measuring the amount of oxygen in your baby's blood. A low amount of oxygen can be a sign of CCHD.

What is CCHD?

CCHD is a condition that occurs when a baby's heart or the heart's major blood vessels have not formed properly. "Critical" congenital heart disease requires surgery or catheter intervention in the first year of life to ensure the best health outcome for the baby. Critical congenital heart disease affects about 3 in every 1000 babies born in Ontario.

Why screen for CCHD?

While some babies with CCHD are diagnosed by ultrasound during pregnancy or during physical examination after birth, others have no symptoms and appear healthy. CCHD screening aims to diagnose babies with CCHD early so that the necessary follow up tests and treatment can begin immediately to prevent health complications or even death.

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

The result does **not** mean that your baby has critical congenital heart disease. Your baby's health care provider will decide what further testing your baby needs. Newborn screening does not diagnose CCHD. Follow-up tests are needed to determine if your baby has CCHD.

What happens after a positive CCHD newborn screening result?

After a positive CCHD screening result, your baby will be examined by a physician to determine the cause for the low oxygen level in your baby's blood. The next steps may involve tests, such as an ultrasound of the heart (also known as an echocardiogram or heart echo) to determine if your baby has CCHD.

How is CCHD treated?

There are several different types of CCHD. Your baby's medical team will discuss with you the particular treatment for your baby's heart problem if your baby is diagnosed with CCHD. Treatment may involve medications and/or surgery. Once identified, babies with CCHD will be seen by heart specialists (cardiologists) and receive specialized care and treatment to help them to grow and develop normally.

Where can I get more information?

For more information on newborn screening, please visit our website at www.newbornscreening.on.ca or talk to your health care provider.

For more information on CCHD, please visit the following sites:

- **Cardiac Kids** website at <http://www.cardiackids.ca> or call 416-850-9055
- **Canadian Congenital Heart Alliance** at <http://www.cchaforlife.org/>

NOTE TO PARENTS/GUARDIANS: This information is for parents about newborn screening for critical congenital heart disease. Please remember that this fact sheet was written for information purposes only. The fact sheet should not replace professional medical advice, diagnosis, or treatment.

