

# Early Detection Saves Lives

To help your baby get the best start in life, newborn screening is offered shortly after birth to look for rare but treatable diseases. Finding diseases through screening allows for early treatment, which can prevent serious health problems and save lives. Newborn screening is important for all babies, even those that appear healthy or have no history of the disease in their family.

Results from the newborn screening blood test are sent to the hospital or midwifery practice that ordered the screen. A baby's parent, guardian or health care provider can also request that results be sent to the baby's health care provider.

**A screen negative result** means that the chance of your baby having one of the diseases is very low and no follow up is needed. More than 99% of babies will have a screen negative result.

**A screen positive result** means that your baby has a higher chance of having one of the diseases and needs further testing. It does not mean your baby has a disease. Newborn Screening Ontario will refer your baby to specialists for follow-up testing. You will be contacted by your health care provider or a specialist if your baby has a positive result. For Critical Congenital Heart Disease screen positive results, your health care provider will arrange for more tests at the time of the screen.



NEWBORN SCREENING  
**ONTARIO**  
DÉPISTAGE NÉONATAL  
**ONTARIO**

For more information about newborn screening, please talk to your health care provider or contact **Newborn Screening Ontario** directly.

## NEWBORN SCREENING AND YOUR BABY

A healthy start leads to a healthier life



### PHONE:

Toll Free: 1-877-627-8330

Local: 613-738-3222

Fax: 613-738-0583



### GENERAL INQUIRIES:

NSO@cheo.on.ca



### Newborn Screening is located at CHEO:

415 Smyth Road

Ottawa, Ontario K1H 8M8



### WEBSITE:

[www.newbornscreening.on.ca](http://www.newbornscreening.on.ca)

Funded by the Government of Ontario





## Dried Blood Spot (DBS)

The DBS sample is obtained using a heel prick, where a small amount of blood is collected from all babies shortly after birth. In Ontario, this blood is sent to Newborn Screening Ontario (NSO) where it is screened for serious diseases. With these rare diseases, early detection is the key to effective treatment. NSO screens newborn blood spot samples for >25 diseases; a full list of diseases is available on the NSO website. Some babies may need to have a repeat DBS sample collected. The baby's midwifery practice or hospital where the original sample was collected will be notified. They will ensure that you are contacted to organize the repeat DBS collection.

This will happen if:

- your baby's first sample was taken before 24 hours of age
- not enough blood was taken
- the sample was of poor quality

Screening for some diseases may also detect if your baby is a carrier (also known as trait). Babies who are carriers are healthy and do not need any special medical treatment. Carrier results are available by request. Information on how to obtain your baby's carrier results is on the NSO website – or, ask your baby's health care provider.

# Types of Screening



## Critical Congenital Heart Disease (CCHD)

Screening for CCHD is offered to babies in Ontario. CCHD refers to conditions where a baby's heart or major blood vessels around the heart have not formed properly. This is a quick and painless test using pulse oximetry to measure the level of oxygen in your baby's blood. This test is done at the bedside and results are available right away so further steps for assessment and intervention can occur immediately.



## Biliary Atresia (BA)

Pale-coloured stool is often an early sign of a liver disease called biliary atresia (BA). You can screen for BA by monitoring your baby's stool colour during the first month of life using an Infant Stool Colour Card (ISCC). If you notice pale stool, you can contact NSO using one of the methods on the ISCC. If follow up is required, NSO will refer your baby to a specialist for more testing.



## Permanent Hearing Loss (PHL)

The Infant Hearing Program provides hearing screening in Ontario. This is done by measuring the response to soft sounds played in your baby's ear and may use small stickers on the baby's head. NSO screens for risk factors for PHL using the dried blood spot sample collected for newborn screening. The risk factors screened are congenital cytomegalovirus (CMV) and common variants in some hearing loss genes. You can request that your baby's results are sent to their health care provider through the NSO website.

NSO is committed to keeping your information and your baby's blood sample safe and confidential. We follow the rules set out in law about their collection and use. More information on the storage and use of dried blood spot samples can be found on the NSO website.