



INFORMATION FOR PARENTS/GUARDIANS: My Baby Needs a Repeat Newborn Screen

What is Newborn Screening?

Newborn screening is done shortly after birth on every baby born in Ontario. A small sample of blood is taken from your baby and is screened for rare but treatable diseases. Every baby is at risk. About 1 out of every 350 babies born in Ontario have a disease that screening looks for. These babies usually seem healthy and have no history of the disease in their family.

Why does my baby need a repeat newborn screen?

Some babies need to have repeat newborn screening. The baby's midwife or the hospital where the baby was born will help organize the repeat newborn screen. There are a few reasons why a baby may require a repeat newborn screen.

- 1. The first newborn screening sample was “unsatisfactory”.** This means that the sample could not be tested properly. A sample could be unsatisfactory for various reasons:
 - The newborn screen was taken too soon, before the baby was 24 hours old,
 - The newborn screening card was not filled out properly or was mislabeled,
 - The sample was received at NSO more than 2 weeks after it was taken,
 - There was not enough blood to test,
 - The quality of the blood sample was not sufficient for testing,
 - The sample was damaged in transit.

- When the first newborn screening sample is unsatisfactory, a repeat is needed as soon as possible to perform newborn screening.
- 2. The baby had a packed red blood cell (PRBC) transfusion** before their initial newborn screening sample was collected. In these cases, a repeat sample is required 4-6 months after the baby's last PRBC transfusion.
- 3. The baby was premature** (born before 33 weeks gestational age) or had a **very low birth weight** (below 1500g). In these cases, their initial newborn screen may have inaccurate results for some of the diseases screened, and a repeat is required when the baby is 3 weeks old.

When a repeat sample is needed, NSO will notify the hospital or midwifery practice who collected the original newborn screening sample. The hospital or midwifery practice will communicate the need for a repeat sample directly to you or your baby's health care provider and will provide direction on how to have it completed.