

BULLETIN 48
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Carrier Results for Sickle Cell Disease from Newborn Screening Ontario

Carrier results for Sickle Cell Disease and some less common hemoglobinopathies can now be requested from NSO by a parent, guardian or primary health care provider.

Newborn screening for Sickle Cell Disease (SCD) began in Ontario on November 24, 2006. The goal of newborn screening for SCD is the early identification of babies with SCD so that treatment begins as soon as possible. Early treatment greatly improves the health of children with SCD. Previously, carrier status for Sickle Cell Disease was not reported. Beginning November 1, 2010 NSO has made this information available by request.

Some important things for you to know:

- Carrier results will **not be included on the newborn screening report**. A parent, guardian or primary Health Care Provider must actively request these results.
- Newborn screening cannot detect carriers of all hemoglobinopathies. The following are detected:
 - Sickle Cell Trait (Hb AS)
 - Hemoglobin C Trait (Hb AC)
 - Hemoglobin D Trait (Hb AD)
 - Hemoglobin E Trait (Hb AE)
 - **Carriers of other hemoglobin variants and thalassemia are not detected.**
- Carrier results will only be released to the child's health care provider, so they can communicate the result to the parents, not to the parents themselves. The result package will include health care provider and parent information pamphlets applicable to the child's result.
- NSO has made changes to the detachable parent information sheet on the front of the blood dot card, to the newborn screening report, and to our website about this new initiative.
- Pamphlets for health care providers and parents about the benefits and disadvantages of learning a child's carrier result in infancy / early childhood are available on our website. French pamphlets are available by request.
- While any child can be a carrier of a hemoglobinopathy, individuals with ancestry from the following regions are at highest risk: Africa, Mediterranean region, Middle East, South East Asia, Western Pacific Region, South America, Central America and Caribbean countries.

More information can be found at www.newbornscreening.on.ca

Again, thank you for your cooperation and assistance in making Newborn Screening Ontario the most effective and efficient that it can be.