



Bulletin #79
April 2, 2014

1) Clarification of "Ordering health care provider" for newborn screens:

As mentioned in bulletins #72 and #78, the 'ordering health care provider' field on the NSO requisition form is mandatory. To clarify, NSO asks for the names of 2 health care providers on the requisition form (see image below).

1. Ordering health care provider: this is the physician or midwife who is legally ordering the newborn screen. For hospitals, this is the individual listed in your Lab Information System (LIS) as ordering the test. For midwifery practices, this is typically the midwife.
2. Healthcare provider following discharge: this is the primary health care provider in the community after the baby has been discharged from the hospital (i.e. family doctor, pediatrician, nurse practitioner, or midwife). In the event that there is a screen positive result, this individual will be notified.

Many hospitals have not previously provided the ordering health care provider on the newborn screening requisition. Please alert your team that you will be contacted by NSO for the name of the ordering health care provider, if it is not indicated on the requisition form.

Ordering health care provider (mandatory): this is the physician or midwife who is legally ordering the newborn screen.

Healthcare provider following discharge (important for screen positive, unsat & transfusion): this is the individual in the community who provides care for the baby (i.e. family doctor, pediatrician, nurse practitioner, or midwife).

2) Info sheet for parents of a significantly premature (<33^o WGA) or very low birth weight (<1500g) baby

NSO has developed an information sheet that can be given to parents of a significantly premature or very low birth weight baby to explain the need for multiple newborn screening samples for babies in this situation. This information sheet is attached to this bulletin. Please consider incorporating this into your practice.

3) Reports indicating sample unsatisfactory for 1 disease

On occasion, NSO is able to complete screening a sample for all but 1 disease on our panel. In this situation, the newborn screening results will state "UNSAT" for that disease. On rare occasions the sample may be "unsat" for several diseases. If you receive a report with this type of result, please proceed as you would usually do to bring the baby back for a repeat newborn screen. If a satisfactory sample has previously been received & screened for that disease, NSO will indicate that no repeat sample is required.

4) Ordering blood spot collection cards from VWR

Just a reminder that blood spot collection cards come in packages of 25; therefore when you are ordering, please be sure to divide the number of cards you need by 25 and order accordingly. For example, if you want to order 200 cards, this corresponds to 8 PKGS Cat# CATX89013-658 CHEO 903 BLOOD COLLECT FORM. If ordering by phone you do not need to specify that these are at no charge as this is all taken care of internally at VWR. Please also note that the VWR account numbers you're using to order these cards cannot be used to order other items from VWR.



**INFORMATION FOR PARENTS/GUARDIANS:
My Baby was Born at Less Than 33 weeks Gestation and/or Weighing Less Than 1500 grams and
Needs a Repeat Newborn Screen**

What is Newborn Screening?

These are routine tests done shortly after birth on every baby born in Ontario. A small sample of blood is taken from your baby and is tested for 29 rare treatable diseases.

Why do significantly premature and very low birth weight babies need repeat newborn screening?

Babies born before 33 weeks gestational age and/or who have a very low birth weight (less than 1500 grams) may have inaccurate newborn screening results on their first sample and require a repeat newborn screening sample at 3 weeks of age.

What does it mean if my baby already had a normal newborn screening result?

Testing for most diseases is accurate even if your baby is premature and/or very low birth weight. However, significant prematurity and/or very low birth weight can affect newborn screening results for Congenital Hypothyroidism (CH) and Severe Combined Immune Deficiencies (SCID). **To accurately screen your baby for these diseases, he or she needs a repeat newborn screen.**

What is Congenital Hypothyroidism (CH)?

CH is a condition that occurs when a baby does not make enough thyroid hormone. Normal amounts of thyroid hormone are important for normal growth and development of the body and the brain.

What is Severe Combined Immune Deficiency (SCID)?

Severe Combined Immune Deficiency is a disease that causes the immune system to not work well. The role of the immune system is to fight off infections. Children with SCID are at risk of getting serious infections.

When should my baby have a repeat newborn screen performed?

Three weeks of age is the best time for the repeat newborn screen. If your baby is discharged from hospital prior to three weeks of age a repeat sample may be taken at the time of discharge, or you may be asked to return to the hospital for a repeat newborn screen.

Who should arrange the repeat newborn screen for my baby?

The hospital where your baby is admitted or your baby's primary health care provider (e.g. doctor, midwife) should organize a repeat newborn screen for your baby.

Where can I get more information?

For more information on newborn screening, please visit the Parents section of the Newborn Screening Ontario website at www.newbornscreening.on.ca or talk to your health care provider.

NOTE TO PARENTS/GUARDIANS: This information is only for parents whose baby is less than 33 weeks gestational age and/or less than 1500 grams. This fact sheet is for information purposes only and should not replace professional medical advice, diagnosis or treatment.