

BULLETIN #19 – June 27, 2007

Summary of Survey Results

Thank you for responding to our survey in Bulletin #14. We were pleased to receive responses from 61 hospitals and 38 midwifery practices, and we appreciate the time you took to provide us with your valuable feedback.

Question 1. How do you ensure that every baby that is born through your institution/practice receives a newborn screen (NBS)?

This question addresses the issue of ensuring that every baby born in Ontario is offered newborn screening. Responses from submitting hospitals indicated that:

- the NBS is recorded on a discharge summary form (24)
- the NBS is routine policy/practice (15)
- an order for the NBS is placed in the Laboratory Information System (LIS) when the baby is born (12)
- the NBS blood dot card is placed in every baby's chart (12)
- the NBS is recorded in a log book (6).

Midwifery practices indicated that:

- the NBS is part of a routine checklist and documented in each chart (26)
- the NBS is the responsibility of the attending midwife (12)
- the NBS is coordinated with the birth hospital (4).

Question 2. How do you ensure that you have received a report for every newborn screening sample taken by your institution/practice?

This question addresses the importance of tracking the results for NBS samples. Most submitting hospitals (37) indicated that pending results are tracked in their LIS, with a list of pending reports sent to the Ontario Newborn Screening Program. Nine hospitals indicated that they perform manual checks for NBS results or note results received in a log book. Of concern, 12 hospitals indicated that they currently have *no* method to track the receipt of these results.

Midwifery practices indicated that receipt of results is either confirmed upon discharge of the baby from midwifery care (22), recorded on a checklist or in the chart (14), or, of concern, is solely the responsibility of the baby's physician and therefore receipt of a result is not confirmed (2).

Additional information about the Ontario Newborn Screening Program can be found at:
http://www.health.gov.on.ca/english/providers/program/child/screening/screen_sum.html

*These bulletins are being circulated to keep you abreast of changes to the Ontario Newborn Screening program. Please share this information with any relevant personnel in your hospital / clinic. If there is someone who would like to be added to this list, contact: Shelley Kennedy or Sari Zelenietz, Genetic Counsellors
(613) 738-3222, option #1; NewbornScreening@cheo.on.ca*

Question 3. When a parent declines the NBS, how is it documented?

This question investigates how you manage the rare situation in which a parent declines newborn screening. Submitting hospitals indicated that:

- the refusal is recorded in the baby's chart (34)
- the baby's physician is informed (10)
- the parents are asked to sign a refusal of treatment form (10)
- the refusal is reported to the Ontario Newborn Screening Program (2)
- the refusal is reported to the Children's Aid Society (1)
- that the parents are not given the option to decline (1).

Midwifery practices indicated that:

- refusal is documented in the chart (23)
- the parents are asked to sign a refusal of treatment form (10)
- the physician is asked to sign a refusal of treatment form (1).

Of note, 10 hospitals and four midwifery practices indicated "Not Applicable."

Recommendations from the Ontario Newborn Screening Program (ONSP)

In order to ensure that no baby is missed, the ONSP suggests that hospitals use their LIS to both request the NBS and track the corresponding results. For hospitals that have a small number of births or no LIS, a manual log book to record the birth of each baby, the collection of the NBS sample, and the receipt of results is an appropriate way to assure that all babies are screened and all results are received. For midwifery practices, depending on volume, a manual log book or recording the sample collection in the chart and ensuring receipt of results prior to discharge is a good strategy.

When a parent declines the NBS, we suggest that institutions/practices have the parent(s) sign a refusal of treatment form and the baby's Health Care Provider be informed. This provides legal protection for the institution and ensures that parents realize they are acting against medical advice. We also ask that the ONSP be notified with the reason the parents declined the NBS.

Again, thank you for your cooperation and assistance in making the Ontario Newborn Screening Program the most effective and efficient that it can be. We welcome any comments that you may have concerning our recommendations.

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