

Newborn Screening Ontario Dried Blood Spot Screening Pathway

This document provides an overview of the Newborn Screening Ontario (NSO) dried blood spot screening pathway. It describes the responsibilities of NSO, submitting hospitals and midwifery practices (submitters), and regional treatment centres (RTCs) at each stage of the pathway.

It should be read in conjunction with the [NSO Submitter Hub](#), where embedded links can be found.

Dried blood spot screening

Dried blood spot screening is considered the standard of care for all newborns in Ontario. A small sample of blood, called a dried blood spot (DBS), is taken from the baby's heel and spotted onto a special newborn screening card. The optimal time for screening is between 24 to 48 hours after birth.

Newborn screening samples are sent to NSO from across the province by courier where they are screened for several rare, treatable diseases. Early detection of these diseases is critical to ensure the baby can receive effective treatment. Results are sent to the health care provider at the birth hospital or midwifery practice group who ordered the test. Primary care providers can access results securely online.

Newborn screening can only tell whether a baby is at high risk or low risk of having one of the diseases screened; diagnostic testing is needed to know for sure. When a baby's blood sample is screen positive for a disease, health care providers at NSO refer the baby to a specialized follow-up clinic in their region called a regional treatment centre (RTC). The treatment centre will arrange more testing to find out whether the baby has the disease.

Find out more about DBS screening at [Dried Blood Spot | Newborn Screening Ontario](#).

Ontario's screening system

Ensuring that every infant born in Ontario is offered screening and that every affected infant receives appropriate treatment and follow-up requires the coordinated efforts of parents/guardians and three main groups of health care providers:

Hospitals, birthing centres, midwifery practices, and primary care providers are responsible for:

- Parent/guardian notification and education about DBS screening
- Answering questions from parents/guardians regarding the screen
- DBS collection as per NSO's collection procedure
- Providing accurate and complete information to NSO for every infant screened
- Promptly following up with the family in the event a baby requires a repeat newborn screen, or a screen is missed.

NSO's responsibilities include, but are not limited to, the following activities:

- Provide education about newborn screening to health care providers and the public through the NSO website resources, webinars, online presentations, professional organization publications, and discussions with NSO team members when required.

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- Performing newborn screening tests and ensuring quality assurance standards are maintained.
- Reporting DBS screening results to submitters, including communication regarding the need for repeat screening (e.g. unsatisfactory samples, missed screens, post transfusion samples).
- Referring DBS screen positive infants to a RTC or specialized health care provider for assessment and obtaining follow-up diagnostic outcome information.

The responsibilities of RTCs and specialist physicians include the following:

- Timely confirmatory testing of DBS screen positive infants referred to them by NSO, including the management and care of affected infants.
- Returning diagnostic outcome information to NSO in response to the medical referral, ensuring quality screening and care.
- Educating health care providers in their region about newborn screening.

DBS screening pathway

1. DBS CARD SUPPLY AND USE

These requirements relate to ensuring that DBS cards are available to submitters, are explained to the parents/caregivers of every baby born in Ontario, and are completed fully and accurately.

Submitters will:

- Maintain a robust supply of DBS cards proportional to the number of births they expect each month.
- Develop a process for ordering DBS cards from NSO's distributor, VWR.
- Notify parents/caregivers about the DBS screen, including reviewing the parent information sheet on the newborn screening card, prior to sample collection. NSO's [sample script](#) can be used to support discussions with parents about the newborn screen.
- Parents may decline screening, and health care providers should discuss this decision with them to ensure they are informed.
 - This should be documented in the infant's medical record, and/or on the DBS card
 - The parents/guardians should sign a decline/deferral form indicating they have refused this testing for their infant. More information about [declining or deferring the screen](#) can be found on our website.
- Ensure the DBS card is not expired prior to use
- Complete the demographic information on the requisition portion of the DBS card. A ballpoint pen should be used; soft-tip pens will not copy through to the other sheets of paper. Hospital stickers or stamps may be used if the patient information is not obscured, and the blood collection area is not compromised; if used, ensure the sticker/stamp is placed on both copies of the card.

Avoid touching the area within the circles on the filter paper section of the card before, during, and after blood spot collection. Do not allow water, feeding formulas, antiseptic solutions, glove powder, hand lotion, or other materials to contact the card before or after use.

2. DBS SAMPLE COLLECTION

These requirements relate to ensuring that satisfactory DBS samples are collected by submitters, as per NSO's collection guidelines.

Submitters are responsible to:

- Confirm the identity of the infant and ensure accuracy of the demographic data on the card.
- Prepare site and collect DBS sample as per [NSO's collection procedure](#)
- Document completion of the DBS newborn screen in the patient chart/as per institution guidelines

Repeat samples:

Some infants require repeat newborn screening. Please visit our website for [reasons why an infant may require repeat newborn screening](#).

The collection of repeat dried blood spot samples should be **arranged by the birth hospital or midwifery practice that collected the original sample**. Submitters are best equipped to collect and ship samples using the appropriate supplies and procedures. This also ensures timely delivery to NSO and supports accurate sample tracking for quality assurance purposes.

NSO will:

- Inform the submitter of the need for a repeat specimen (e.g. unsatisfactory first sample) by faxing a report on the day of sample receipt
- In cases where a repeat specimen is not received 1 week following initial notification, send a submitter response form to the submitter
- If no repeat or submitter response is received after an additional 7 days, or the submitter indicates they've been unable to reach the infant's family, send a letter to the parents/guardians in the mail. A copy of this letter is cc'd to the submitting institution and the infant's health care provider (if known)

Submitters will:

- Contact the parent/guardian to discuss the requirement for a repeat sample and arrange for repeating the sample collection, OR
- Contact the infant's health care provider to assist in arranging repeat sample collection.
 - This option should be selected if the submitter is unable to reach the family, as this can increase turnaround times to obtaining the repeat sample.
 - In this case, the submitter must communicate the urgency of the repeat request and that the repeat sample must be collected at a birthing hospital. Community labs are **not** able to collect newborn screening samples.
- Complete the repeat request letter from NSO, documenting communication attempts to the family and/or health care provider by the submitter regarding the need for a repeat sample, and fax it back to NSO within one week.
- Document correspondence with parents/guardians and/or primary health care providers surrounding the collection of repeat specimens in the infant's medical record.

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3. DBS SAMPLE RESULTS AND FOLLOW-UP

These requirements relate to ensuring that DBS sample results are communicated to submitters, and screen positive infants are referred to their nearest RTC for follow up.

NSO will:

- Perform laboratory testing of newborn screening samples
- Enter all information provided on the newborn screening requisition into NSO's laboratory information system (LIS)
- Refer babies who screen positive on the dried blood spot screen to a regional treatment centre for diagnostic investigation and treatment as needed
- Send newborn screening dried blood spot results to the submitting location
- Document the referral process in the NSO LIS, including confirmation that the treatment centre has received the referral and the infant has been retrieved

Regional treatment centres will:

- Have systems in place to ensure timely retrieval of infants referred for screen positive results, and communicate retrieval to NSO
- Confirm receipt of the faxed referral form to NSO on the same business day as the referral
- Contact families to discuss the screen positive result(s) and arrange follow up diagnostic investigations within time intervals established in the referral letter

Submitters will:

- Maintain documentation of newborn screening results as per organizational procedures

4. SCREEN POSITIVE DIAGNOSTIC INVESTIGATIONS AND FOLLOW-UP

These requirements relate to the process of following-up babies who have been referred to a regional treatment centre for diagnostic investigation.

Regional treatment centres will:

- Perform diagnostic follow-up for infants who have been referred for screen positive results within the established timeframe appropriate for the referral
- Provide treatment and management for infants who are confirmed positive upon diagnostic investigation
- Provide follow-up information to NSO via Diagnostic Evaluation and Report Form (DERF) completion and submission

NSO will:

- Document any updates from the regional treatment centre regarding the diagnostic work up in the DERF and in the LIS